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USING FOCUS GROUPS OF OLDER AFRICAN AMERICANS AND LATINOS WITH DIABETES TO MODIFY A SELF-CARE EMPOWERMENT INTERVENTION

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Objective: To make cultural and age-specific modifications to a self-care empowerment intervention.

Design: Focus groups with self-administered surveys.

Setting: Two public health diabetes and geriatrics clinic and two senior centers in and around South Los Angeles.

Participants: African Americans and Latinos aged ≥55 years with diabetes (*N*=79), and two groups of health educators (*N*=16).

Main Outcome Measures: After describing the proposed intervention, the focus group facilitators asked participants: 1) whether the community of interest would be interested in the proposed empowerment intervention; 2) why or why not; and 3) how the intervention could be modified to better address the concerns of the study community of interest. All groups were audiotaped, transcribed, and (when appropriate) translated into English. Three independent investigators read all transcripts and completed standardized coding forms for each transcript. In addition, at the end of each focus group, all participants completed a self-administered written survey asking them to rate aspects of the proposed intervention.

Results: Older African Americans and Latinos endorsed the intervention but desired an expanded dietary educational component and identified disability as an important missing content area. Participants rejected the use of an audio learning tool and did not believe that matching group-facilitator sociodemographic characteristics was important as long as facilitators demonstrated cultural competency.

Conclusions: These findings illustrate a model of participatory research in which researchers and community members work together to develop an empowerment intervention that will meet community needs and will have greater cultural appropriateness. Modifying the intervention in accordance with these findings should enhance the relevance and impact of the self-care intervention. (*Ethn Dis*. 2005;15: 283–291)

Key Words: Diabetes Mellitus, Focus Groups, Self Care, Aged, Blacks, Hispanic Americans, African American, Latino

INTRODUCTION

Diabetes mellitus (diabetes), and especially type 2 diabetes, is a chronic disease disproportionately affecting older African Americans and Latinos. Among those aged ≥75 years, 22% of African Americans and 30% of Latinos have diabetes.[1] Clinical trials in the United Kingdom and the United States have demonstrated that reducing hyperglycemia, controlling blood pressure, and lowering lipids can decrease rates of microvascular and macrovascular disease,[2–5] but despite this clinical trial evidence, achieving this level of control remains a great challenge. Fewer than half of African Americans and Latinos with diabetes achieve optimal glycemic control[6]; older adults in particular appear to be at increased risk for undertreatment.[7] Self-management education interventions can succeed in improving glycemic control,[8] but few studies have been conducted among non-White seniors.[9] Developing and testing interventions to optimize glycemic, blood pressure, and lipid control among minority elders is therefore crucial to the United States' public health priority of eliminating ethnic disparities in health.[10]

We describe the first phase of an ongoing project aimed at improving self-care of older African Americans and Latinos with diabetes. Our goal for this phase of the study was to modify an existing self-care empowerment curriculum that has been effective in improving self-care and glycemic control among younger, mostly-Caucasian patients.[11] Like others in the self-care community,[11–13] we espouse a model of community-based participatory research, whereby community members work as partners with researchers on the development, implementation, and evaluation of interventions designed to improve community health.[14] Accordingly, we presented the existing curriculum to focus groups of older African Americans and Latinos with diabetes and to groups of their health educators, without assuming that they would welcome this program. The specific aims of this study were to: 1) assess the level of community interest in participating in a self-care empowerment intervention; 2) identify barriers to implementing

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Among those aged ≥75 years, 22% of African Americans and 30% of Latinos have diabetes.[1]

the intervention in the target communities; and 3) modify the intervention to better address the issues valued by older African Americans and Latinos with diabetes in these communities.

METHODS

Study Population—Older Persons with Diabetes

Participants were recruited by using purposive sampling methods. In collaboration with community leaders, we recruited participants from two public health diabetes and geriatric clinics and two senior centers in and around South Los Angeles. Recruitment flyers were posted, and bilingual study personnel gave brief presentations describing the project at each site. Inclusion criteria were: 1) age ≥55 years; 2) self-identifies as having diabetes and being either African American or Latino; and 3) verbal fluency in Spanish or English. We chose the cutpoint of 55 years for inclusion in this study after consulting with our community advisors, who felt that this was an age at which persons in general begin to be perceived as "older."

Study Population—Health Educators

We used flyers and telephone calls to recruit nurses, nutritionists, and diabetes educators from eight diabetes and geriatric clinics in the greater Los Angeles region that serve a large number of older African-American and/or Latino patients. Community leaders, including leaders from nursing circles, supported the project, provided some of the names and telephone numbers of health educators, and encouraged us to use their names to increase participation. We chose not to invite physicians to the health educator focus groups because the proposed intervention would be administered by non-physician health educators, and we were also concerned that non-physician health educators might not feel able to speak freely in front of physicians, who in some cases had a supervisory relationship with the health educators. All of the health educators who participated in this project had experience in both group and one-on-one education of older African-American and/or Latino persons with diabetes.

Focus Group Implementation

Our objective, to modify an existing self-care empowerment curriculum, was exploratory by nature, and thus was best pursued with qualitative research methods. A focus group is a planned discussion designed to obtain perceptions on a defined area of interest in a permissive, nonthreatening environment.[15] Unlike in qualitative interviews, in focus groups participants influence each other by responding to ideas and comments in the discussion. This format has proven successful for identifying perceptions among older adults on many unexplored topics[16–20] and was well suited to our objectives. We conducted 11 focus groups: 2 with health educators (N=16), 3 with African-American patients (N=32), 5 with Latino patients (N=34), and 1 with both African-American and Latino patients (N=13). Data were collected between September 2001 and January 2002. Health educator groups were held in the early evening, but all the others were held in the mornings or afternoons, because based on our previous experience and the advice of our community advisors, older adults are less likely to want to attend groups in the evening. The five Latino-only groups were conducted in Spanish. A trained non-physician facilitator skilled at eliciting input from all participants led each group by using a standardized script describing different aspects of the proposed empowerment intervention. For the health educator groups, none of the facilitators were African Americans or Latinos. For the Latino groups, one co-facilitator was Latino. For all but one of the African-American groups, the facilitator was not African-American. One research team member was present at each focus group. None of the participants knew the facilitators.

The proposed self-care empowerment intervention, described in detail elsewhere,[11] consists of a series of facilitated group sessions in which participants are taught to take control of their own diabetes in the ways that work best for them personally. The empowerment intervention is based on the reality that in caring for their diabetes, patients make choices each day that affect, and are affected by, their emotions, thoughts, values, goals, and other psychosocial aspects of living with this chronic disease.[21] The curriculum teaches persons with diabetes to: 1) identify and set realistic goals; 2) apply a systematic problem-solving process to eliminate barriers to achieving those goals; 3) cope with circumstances that cannot be changed; 4) manage the stress caused by living with diabetes as well as the general stress of daily life; 5) identify and obtain appropriate social support; and 6) improve their ability to be self-motivated. Group facilitators implementing the existing intervention have the option of using a series of discussion-generating 10-minute video vignettes illustrating an African American with diabetes confronting a personal barrier to participation in diabetes self-care (such as insufficient time for exercise) and engaging in a group problem-solving process around that specific issue.[22] One option for the proposed intervention is to create new videos that could be culturally and age-tailored for older Latinos and African Americans. To obtain input

on whether this option might be desirable, we showed focus group participants a sample video vignette. We also described other potential mechanisms for generating group discussions, including using "telenovellas" (soap operas) and using slide-show (rather than video) vignettes, audio-only vignettes, and distributing personalized clinical data sheets (including glycosylated hemoglobin, cholesterol, blood pressure, and other health measures important to those with diabetes) to each participant. After describing the proposed intervention, showing the video vignette, discussing the other possible pieces of the intervention, and encouraging the group to creatively brainstorm about other ways to improve the intervention, the focus group facilitator asked participants: 1) whether persons with diabetes such as themselves would be interested in the proposed empowerment intervention; 2) why or why not; and 3) how the intervention could be modified to better address the concerns of minority elders with diabetes. Each focus group lasted approximately 2 hours, with a 15-minute break. At the end of the session, all participants completed a self-administered written survey asking them to rate aspects of the proposed intervention. The written survey was formatted in a large font to increase readability for our older participants. All groups were audiotaped and transcribed. English and Spanish audiotapes were transcribed by research staff. The transcripts were reviewed for accuracy by an investigator who had been present at the focus groups. The Spanish translations were done by a certified translator who did not know the identity of focus group participants. All relevant institutional review boards approved the project; all participants provided written documentation of informed consent. Participants were paid a small cash honorarium for their time.

Coding of Transcripts

We chose to have 3 investigators code the transcripts because, based on our previous experience conducting focus group research,[19] we have found that having three reviewers code transcripts is the best way to obtain a rich range of perspectives without unnecessary redundancy. Each coder was instructed to read the transcripts independently, prior to reaching consensus, to eliminate the risk that a coder's interpretation might be influenced by hearing the interpretation of one of the other coders. Three coders therefore (RB, CM, CS) independently read all 11 transcripts and completed a standardized coding form for each one. The coding form contained a series of closed-ended items with Likert-type response sets asking the coder to assess the extent to which: 1) focus group participants support the self-care empowerment intervention; and 2) 12 potential barriers (including transportation, poor health, and other factors culled from the geriatric and diabetes self-care literature)[12,16–18,23] would hinder participation. Each coding form also contained a series of open-ended items asking the coders to describe: 1) content areas of the existing curriculum most valued by focus group participants; 2) any content areas identified by participants that should be added to the curriculum; and 3) preferences regarding logistical issues, eg, timing of the group sessions, and characteristics of the facilitator.

Analysis

We analyzed three different types of data: 1) survey data; 2) responses to closed-ended items on the transcript coding forms; and 3) responses to open-ended items on the transcript coding forms. Survey responses were summarized by using simple descriptive statistics. We assessed the extent of intercoder agreement for each of the closed-ended barrier items in order to help us determine which barriers to participation were the strongest. When at least two of the three coders agreed (ie, gave the exact same Likert-type response to an item), we counted that as one occurrence of intercoder agreement. If all three coders gave a different rating to an item, no intercoder agreements occurred, and this item was not counted. The number of intercoder agreements was counted for each item across focus groups. Those barriers which coders most frequently agreed were "strong" were included as planned modifications to the interventions. All independent coder responses to open-ended items on the coding forms were compiled verbatim.

Results from the survey, the closed-ended coding form analysis, and the open-ended coding form responses were distributed to the coders. Coders then met in person, examined each survey and coding form result, analyzed responses to the open-ended items for common themes, and decided how the intervention could be modified to address each finding.

RESULTS

The mean age of the 79 patient focus group participants was 64 years (standard deviation 11 years). Seventy-one percent of participants were women; 49% self-identified as African American, and 51% as Latino. Participants reported having diabetes for a mean of 8.3 years (standard deviation 6.5 years); 77% took oral medications for diabetes, and 20% used insulin. The mean age of the 16 health educators was 45 (standard deviation 10) years. All health educators were women; 81% were nurses; 19% were nutritionists, and 44% of the nurses and nutritionists were certified diabetes educators.

Table 1 shows the percentages of survey responses in which the highest ratings were given to the questions about the value of the intervention. At least 80% of health educators and patients felt the proposed empowerment intervention would generate a high level of participation and would increase participation in self-management of diabetes. Nearly 100% of Latinos rated the

Table 1. Survey responses of focus group participants

Survey Item	Health Educators *N*=16 % Responding "Extremely" or "Quite a Bit" (Other Choices were "Moderately," "A Little Bit," or "Not at All")	Patients *N*=79 % Responding "A Lot" (Other Choices were "Somewhat" or "Not at All")	
		African-American *N*=39	Latino *N*=40
In general, how interested do you think older Latino/African-American adults in this community would be in participating in an empowerment program such as this?	94	80	93
In general, how much do you think an empowerment program such as this would help older Latino/African-American adults in this community come up with ways to cope with their feelings about diabetes?	94	87	100
In general, how much do you think an empowerment program such as this would help older Latino/African-American adults in this community come up with better ideas for taking care of their diabetes?	81	95	98
In general, how much do you think an empowerment program such as this would help older Latino/African-American adults in this community improve their self-care of their diabetes?	88	82	100
For older Latinos/African Americans in this community, how much do you think each of the following parts of the proposed intervention would help them improve their self-care of their diabetes?			
Opportunity to ask questions from an expert	88	92	100
Opportunity to share personal problems with the group	75	82	100
Help others in a group solve problems	81	80	100
Have support from other group members	94	87	100
Watch videotapes about diabetes problem-solving	63	87	98
Seeing personalized clinical data sheets	75	N/A	N/A
Seeing a slideshow	44	N/A	N/A
Reading a photonovella	25	N/A	N/A

intervention highest in all categories; African Americans rated the intervention slightly lower, with 80%–95% of respondents giving the highest rating. Despite strong support for the use of the videos, fewer than half of health educators felt a slide show or photonovella format would enhance the effectiveness of the intervention.

Table 2 illustrates the results of the analysis of the closed-ended items on the transcript coding form. As described above, only when at least two of the three independent coders gave the exact same response to an item was it counted as an occurrence of intercoder agreement. Thus, as many as 11 occurrences of intercoder agreement could be on a single item, and 10 out of 12 (84%) of the items had at least one occurrence of agreement. As illustrated in Table 2, transportation was most frequently rated as a strong barrier to participation, followed by language barriers (Latino groups only), family influences, and competing responsibilities for time. Codes also rated functional disability and visual and hearing impairments as barriers to participation.

Consistent with the survey results, coder responses to the open-ended items on the coding form described strong endorsement of the empowerment intervention (verbatim responses not shown, but summarized in Table 3 as described below). Participants from both African-American and Latino groups felt that dietary education was the most important content area for the intervention. Many participants from both the African-American and Latino groups viewed their family members' lack of knowledge about diabetes as a personal barrier to participation in self-care. Coders found participants not only lacked knowledge regarding their disease and its management but also held many misconceptions that could interfere with optimal self-care, for example a belief that insulin causes blindness. Coders also identified new content areas—disability and forgetfulness—that participants viewed as important.

Table 3 summarizes the focus-group findings from all data sources and illustrates how these findings are synthesized into planned modifications to the proposed empowerment intervention. A sample quotation for each finding is shown; though using individual comments to illustrate a theme does not distinguish between single-person comments and those expressed by many persons across groups, each of the findings listed in Table 3 was supported by interpretations made by at least two of the three reviewers who independently concluded that this was a theme expressed in the open-ended coding analyses. As illustrated, seven findings were related to the content of the proposed intervention, six of which led to planned mod-

Table 2. Results of transcript analysis identifying and ranking barriers to participation

Potential Barrier	# Focus Groups (Out of 11) in Which at Least 2 Out of 3 Reviewers Gave Particular Identical Rating				
	Very Large Barrier	Somewhat of a Barrier	Very Slight Barrier	Not a Barrier at All	Never Addressed*
a. Not enough time to participate/too many other commitments	0	3	0	1	1
b. Lack of interest	0	0	0	8	0
c. Not culturally-relevant	0	0	0	7	0
d. Not age-appropriate	0	0	0	2	7
e. Too sick to participate	0	0	0	0	11
f. Hearing impairment	0	0	2	0	9
g. Visual impairment	0	0	1	0	10
h. Functional impairment, ie, difficulty with daily activities	0	1	2	0	7
i. Family influence	1	2	1	6	1
j. Doctor influence	0	0	0	0	11
k. Transportation	8	0	0	0	0
l. Language barriers	3	0	0	5	1

* Never addressed=this particular barrier was not brought up for discussion in the focus group.

ifications that will expand the content of the intervention. Specifically, we plan to expand the formal educational content, add hands-on demonstration of meal preparation, and add modules addressing time-management skills and the geriatric issues of disability and forgetfulness. Likewise, seven findings were related to the proposed intervention format, all of which led to planned modifications as illustrated.

DISCUSSION

Using focus groups supplemented by surveys, we successfully elicited input from community-residing older African Americans and Latinos with diabetes to modify the content and format of an existing self-care empowerment intervention. The participatory methods we used differ from traditional research in that community members themselves shape the content and format of the intervention. Based on the findings from this study, we believe the modified intervention will better address the diabetes-related issues most valued by older African Americans and Latinos with diabetes in these communities. These findings illustrate a model of participatory research in which researchers and community-members work together to develop new interventions designed to enhance patient empowerment with the ultimate goal of improving the health of older persons with diabetes.

Consistent with previous studies, we found that transportation is a strong barrier for participation in the proposed intervention[16] and that many profound knowledge deficits and misconceptions exist regarding the etiology and care of diabetes.[12,17,24,25] Our findings suggest these health beliefs may represent important barriers to participation in self-care activities such as following a healthy diet, using medications correctly, and participating in regular physical activity.

Several of our findings are new, however, and carry important implications for the design and implementation of empowerment interventions designed to increase participation in self-care among older adults with diabetes. A recent study of younger African Americans with diabetes found that competing demands for time, including childcare, is a major barrier to care[26]; our work extends this important finding by demonstrating that competing demands for time persist into older age. Incorporating time-management training into self-care interventions may succeed at decreasing this barrier and ultimately improving health outcomes.

We also found the intervention should include content addressing functional, visual, and hearing impairment to be relevant to older adults with diabetes. Related to this was our finding that participants favored using video vignettes over audio or written tools to present concepts and generate group discussion. Though interest in including family members was great, many participants expressed concern that their family members were too busy to come to the group sessions. Expanding the intervention to include materials (possibly videos) that can be easily shared with family members at home may succeed to alleviate this problem.

Despite some evidence that matching facilitator and participants' sociodemographic characteristics may enhance effectiveness of some group-level interventions designed to improve health,[12] these focus-group participants did not endorse this requirement for the proposed intervention. Knowledge about diabetes and cultural competence, on the other hand, were viewed as critical characteristics of the facilitators.

Table 3. Summary of focus group findings and corresponding planned modifications to proposed intervention

Finding	Supported by				Sample Text from Transcript	Planned Modification to Proposed Intervention
	Patient Survey	Provider Survey	Closed-ended Coding Form Analysis	Open-ended Coding Form Analysis		
Findings related to content of proposed intervention						
Strong support for concept of empowerment intervention	x	x	x	x	''I like the group session . . . Once you listen to what other people have to say then you learn from each of us what to do. We just have to deal with (diabetes)''—African-American man	Plan to proceed with clinical trial
Diet education strongly desired	x	x		x	''. . . it says that you can eat a slice of bread—what does that mean in tortillas . . .?''	
					''. . . I can only eat one slice of bread . . . one piece of meat the size of my palm.''—Discussion between Latina women	Expand formal diet education portion of intervention
Strong desire to learn how to prepare healthy culturally-appropriate meals				x	''. . . it was hard for me at first not to put a ham hock in it but now I put a smoked turkey neck in it a smoked turkey wing part in that and have collard greens in there. And if you make cornbread from scratch don't put no sugar in it.''—African-American woman	Add hands-on demonstration of food preparation
Lack of knowledge of disease and disease management skills/ many misconceptions				x	"I would like to know what specific things to do if your sugar is low. You hear somebody go drink some orange juice, what if you don't have orange juice?"—African-American man	
					''The doctor said to me when they detected (diabetes) that my sugar was at 486. Then he said, ''Do you want insulin?,'' and I didn't want insulin because I have a sister and the insulin left her blind. And don't want that.''—Latino man	Expand formal educational content portion of intervention to address knowledge gaps and misconceptions
Many competing responsibilities for patients make practicing optimal self-care behaviors difficult			x	x	''I really need to exercise regular but one time I did it everyday—I could walk at least 3 and a half miles a day. I backed off 'cause my daughter had a baby, and everything just shut down 'cause I was helping her . . .''—African-American woman	Add time management skills training into intervention.
Disability and the use of assistive devices is a concern			x	x	''I think what my problem is, I have a problem of not wanting people to go out of their way because I have a walker, you know . . . I can't try to do things and walk by myself, and that's depressing.''—African-American woman	Add module to address disability including use of assistive devices.
Forgetfulness is common concern				x	''. . . but what you need to do is stop right then and there and write it down and make sure you take that paper to the doctor with you, because then the doctor—it gives him more insight of what's going on with you. But most of us will forget.''—African-American man	Add module to address forgetfulness.
Findings related to format of proposed intervention						
Transportation is the strongest barrier to participation			x	x	''. . . the ride is a problem because I don't have a car and sometimes because I don't work I don't have money for the bus.''—Latina woman	Conduct sessions at senior centers and churches (not clinics)/ link with community organizations to provide transportation

Table 3. Continued

Finding	Supported by: Patient Survey	Supported by: Provider Survey	Supported by: Closed-ended Coding Form Analysis	Supported by: Open-ended Coding Form Analysis	Sample Text from Transcript	Planned Modification to Proposed Intervention
Many competing responsibilities for patients make attending group difficult			x	x	''I would have to be available to return to my house by noon or by one because sometimes I have to go to work early afternoons''—Latino man	Schedule both morning and afternoon sessions
Strong desire to include family members in intervention, but difficult due to time-constraints of family members				x	''I think it's very important that the family participate because my brothers first got diabetes and I didn't have it . . . but when it happened to me, you try to understand because you get depressed the moment they say diabetes, it's like saying the end of the line . . . People don't understand but those around you understand.''—Latino man	Expand focus of intervention to more explicitly include family members in all aspects of intervention, for example including copy of video to take home to family members unable to attend the group
High prevalence of hearing impairment makes audio-only intervention tool far less desirable than video		x	x	x	''Sometimes they all have their work or my sister Rosa is in school and my other sister does things with their church, so one would have to ask if they would like to come.''—Latina woman ''I can't hear very well . . . it's nice to hear sometimes but you also like to look at things, because it grabs your attention for the time being. Sometimes when you listen to something, you get bored and the video is more captivating.''—Latina woman	Drop plan to possibly develop audio-only tool/apply for additional funding to develop videos for Latinos
Strong support of personalized lab data sheets as educational and motivational tool	x	x	x	x	''Sometimes you don't understand what your doctor is saying. And they just don't . . . a lot of times they don't try to help you understand''—African-American man when asked if he thought learning to understand the lab sheets would be helpful	Proceed with plans to include personalized data sheets as educational and motivational tool
Once a week is too frequent for group sessions				x	''Do it twice a month—once a week is too much.''—African-American woman	Change meeting frequency to every 2 weeks
Age and ethnicity of facilitator is not important as long as can communicate well and understands culture				x	''. . . any person as long as they know the language.''—Latina woman ''No, race has nothing to do with this''—African-American woman ''I would have to say that it has to be somebody who understands what we are . . . Latinos . . . Our culture, the way we are, and how we interact . . . if he understands our culture it doesn't matter what color he is.''—Latina woman	Drop plans to attempt to match age and ethnicity of facilitator with group members

Our study has a number of limitations. Most importantly, findings from this convenience sample of 95 participants from a single geographic urban region are not intended to generalize to all African-American and Latino seniors, and the specific characteristics of this sample may have influenced the findings, including some we did not measure such as level of education and acculturation. Because we decided not to include doctors in this study, findings cannot be generalized to represent views of physicians. However, participants were recruited from the settings where the intervention will be evaluated and are likely to represent the views of minority seniors who frequent those settings. Though the issues raised across groups were similar, given the small sample size, other important content ar-

Incorporating time-management training into self-care interventions may succeed at decreasing this barrier and ultimately improving health outcomes

eas not raised during these sessions may exist. Because one of the study's recruiters did some of the transcriptions, her personal recollection of interactions with participants could have caused her to edit comments while she transcribed. We also acknowledge the subjective nature of qualitative analysis of transcripts, which we sought to minimize by using three independent coders. The high ratings on the survey given by Latinos could possibly represent participants giving socially desirable responses,[27] but the written nature of the survey should have minimized this effect. Psychometric differences may have existed between the Spanish and English versions of the surveys.[28]

In conclusion, we used community-based participatory research—in the form of focus groups—to allow members of the community of interest to modify an empowerment intervention to improve self-care among older African Americans and Latinos with diabetes. We believe these modifications will enhance the relevance and impact of the intervention.

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