People with Diabetes: Knowledge, Perceptions, and Applications of Recommendations for Diabetes Management

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The purpose of this paper is to report results of the People with Diabetes survey conducted as part of the REACH 2010: Charleston and Georgetown Diabetes Coalition. The pilot data revealed that African Americans (AAs) ($N=80$) reported fewer A_{1c}, lipid, and kidney testing, feet and eye exams, and less nutrition and diabetes self-management counseling during 1999–2000 than did Caucasians (Cs) ($N=23$). The survey was repeated in 2002 when data were collected from a convenience sample of 160 AAs and 150 Cs using the revised self-reported survey instrument. African Americans (AAs) were significantly likely to report that their understanding of results for the kidney function test were good as compared to Cs ($P<.001$) and were more likely to report receiving nutrition education ($P=.003$). Otherwise, there were no significant differences between AAs and Cs on the remaining items in the survey. Since REACH 2010 was actively involved in the AA community for 2 years between the pilot survey and the repeated survey, these results were anticipated and are also reflected in results of chart audits conducted within healthcare systems used by the same AA population. (*Ethn Dis.* 2004;14[suppl 1]:S1-129–S1-134)

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Introduction

Diabetes mellitus affects approximately 18.2 million people in the United States, or 6.3% of the population.[1] Since 1991, the number of adults in the United States with diabetes has increased by 61% and is projected to double by the year 2050.[2] About 11.8% of the African-American (AA) population is diagnosed with diabetes, making this population group 1.6 times more likely than Caucasians (Cs) to have this disease.[1] Incidence rates for the years 1997 to 2000 reflect increases for Cs (4.8/1000 to 5.6/1000), AAs (9.3/1000 to 10.6/1000), and Hispanics (7.5/1000 to 9.7/1000).[3]

Data about diabetes in South Carolina (SC) indicate that the state continues to have one of the highest rates of diabetes in the country.[1,4] The number of people living with diagnosed diabetes in SC has increased from an estimated 144,000 cases in 1994 to 249,000 cases in 2002.[5] Thus, 8.5% of the population had diabetes, with approximately 120,000 more undiagnosed cases. Local studies have found that about 13.6% of AAs in Charleston and Georgetown counties of SC have reported that they have diabetes.[6] The complications from diabetes are on the rise in the state, increasing at rates of 20%–27% since 1994 (5.6/100 population in 1994 to 8.1/100 population in 2002).[3] Significant health disparities exist among minority populations in SC[3,7] and in Charleston and Georgetown counties.[6,8] In SC, AAs make up about 30% of the population. In Charleston County, 35% of the population are AAs and, in Georgetown County 39% of the population are AAs. Based on a 2-county assessment related to diabetes completed by the REACH 2010: Charleston and Georgetown Diabetes Coalition, the disparities for AAs with diabetes include: decreased diabetes care; education; medications and treatment for diabetes; an increased emergency department use; increased hospitalizations and costs of care; and increased complications, especially amputations, renal failure, and cardiovascular disease.[6,8]

Racial and Ethnic Approaches to Community Health (REACH) 2010 is a national demonstration project based on *Healthy People 2010* priorities. Across the United States, 7 communities are funded by this project to reach the goal of identifying and evaluating interventions designed to reduce healthcare disparities for diabetes among minority populations. Another 10 projects address health disparities for both cardiovascular disease and diabetes.[6] REACH 2010: Charleston and Georgetown Diabetes Coalition, one of the 7 REACH coalitions focusing on eliminating diabetes health disparities, is a community-driven, multidisciplinary project working to eliminate health disparities of more than 12,000 AA adults diagnosed with diabetes mellitus. The Coalition, which was formed in 1999 and consists of more than 28 organizations and agencies, is funded by the US Department of Health and Human Services through the Centers for Disease Control and Prevention and is supported by the Diabetes Initiative of South Carolina, a state-funded program with more than 40 participating organizations.[6,8]

The goals of REACH 2010: Charleston and Georgetown Diabetes Coalition are: 1) to increase by 5% annually the number of AAs with diabetes who receive annual feet examinations, dilated eye examination, A_{lc} test, lipid profile and kidney test for microalbumin; 2) to eliminate specific disparities between AAs and Cs with diabetes; 3) to improve diabetes control by increasing the percentage of persons reaching targeted levels of A_{1c}, blood pressure, and lipids; and 4) to improve diabetes nutrition and self-management education.[6,8] The project is designed to work in partnership with the healthcare systems, communities, and AAs living with diabetes to improve access to quality care and thus, reduce the disproportionate rates of diabetes complications among this population.

REACH 2010: Charleston and Georgetown Coalition interventions are designed to increase the knowledge and practice of diabetes care and self-management in the community. Partnerships among community members and organizations, academic institutions, government agencies, community health systems, and local community institutions facilitate culturally grounded strategies for educational programs and materials. Lay community health advisors (CHAs) work with community leaders to decide educational methods and sites for activities, while REACH health providers ensure that programs interpret evidence-based, quality diabetes care. In other words, the community decides on the type of activity and the site, and assists the CHA in identifying content for the activity, while the health provider ensures evidence-based diabetes management.

South Carolina AA culture forms the basis of community-driven diabetes educational programs. New translations of traditional lowcountry foods, religious practices, and social conventions support redesigned, peer-led nutrition and exercise programs. For example, physical activity routines, known as Praise-er-cise, incorporate Praise-Dance movements, meanings from religious ceremonies, Afro-centric scarves, and senior-acceptable, low-impact, synchronized group exercises. Also, walking and talking groups provide physical activity and information about diabetes self management. Healthy food demonstrations show how to prepare traditional food with herb seasonings and healthier cooking techniques. Increased requests for diabetes resources and new programs indicate a growing interest and satisfaction in collaborative, culturally relevant, diabetes education programs.

Educational programs and activities take place where people live, work, worship, play, and seek health care. Of particular note is a series of classes regularly scheduled at community health centers representing the health systems' partners of the REACH 2010 Charleston and Georgetown Diabetes Coalition. These classes provide information that is focused on answering 4 questions: What do I need to do to take care of my diabetes? How can I help my healthcare provider take better care of my diabetes? How do I manage the symptoms of diabetes and prevent problems? Where do I turn when I need help? Four modules cover diabetes basics, healthy eating, physical activity, and diabetes resources. An American Diabetes Association (ADA)-certified curriculum is presented through experiential learning techniques, team-taught by lay community health advisors and professional diabetes educators. Other examples of successful culturally based educational programs are a womanless wedding at a church, a diabetes luncheon in a city park, and a diabetes family fun day.

Additional educational materials tailored to the culture of lowcountry AAs include web-based storyboards developed from the tradition of Gullah storytelling, and *My Guide to Sugar Diabetes,* a basic diabetes self-care manual developed with community guidance and written in first-person active voice. The Gold Card, a patient mini-record, is distributed at educational classes and community events to encourage personal knowledge, acceptance, and practice of recommended diabetes healthcare regimens. The card also serves as a vehicle to enhance patient-provider communication concerning schedules, test results, and targets for weight, blood pressure, blood glucose, A_{1c}, foot exam, dental exam, dilated eye exam, cholesterol, triglycerides, microalbumin, and flu vaccination.

To evaluate the effectiveness of project activities, a series of surveys was developed to gather data from the community. The People with Diabetes Survey (PWD), administered to AAs with diabetes in the 2-county area, was one of the methods used to determine the knowledge, perceptions, and application of knowledge in improving diabetes control. The purpose of this paper is to present data from the PWD survey regarding knowledge, perception, and application of specific ADA guidelines for diabetes management of blood glucose, blood pressure, cholesterol and lipid control, kidney function, eye and foot care, nutrition education, diabetes education, and smoking cessation.

METHODS

Research Question

Are there differences in knowledge, perceptions, and ability to apply new knowledge about one's health status (laboratory tests and health assessments) and self-care management (diabetes and nutrition education) between AAs and Cs living with diabetes?

Sample

Within the 2-county project area, there were approximately 12,000 known AAs living with diabetes and an unknown number of Cs with a diagnosis of diabetes. A convenience sample (N=308) was drawn from this population. Participants for the convenience sample were recruited from community

and senior centers and community activities, such as health fairs, and clinics. Eligibility requirements were: a diagnosis of diabetes; ability to read and speak English; and a willingness to complete the survey. If eligible, participants completed a self-report survey designed to elicit responses related to diabetes knowledge, perceptions, treatment, adherence to guidelines, and outcomes. A total of 159 AAs and 149 Cs participated in the study.

Survey Instrument

The PWD survey is a paper and pencil self-report questionnaire developed and pilot tested over a 2-year period by members of the REACH 2010: Charleston and Georgetown Diabetes Coalition team, including certified diabetes educators, nurses, registered dietitians, physicians, community health advisors (CHAs), and public health specialists. The original questions were compiled from a review of the care and management process for diabetes care, based on the ADA guidelines for care. The research team generated a structured series of questions for recommended tests (A_{1c}, blood pressure, lipid profile, kidney test, eye and feet exams) and for recommended counseling (self-management education, nutrition education, and smoking cessation). For each test, participants were asked the following questions:

- Have you had (test or counseling) in the past year?
- What were the test results (number)?
- Was the result good, fair, or bad?
- What were you told to do about the (test or counseling) results?
- Have you been able to implement the recommendations?

The original questions were reviewed for content and criterion validity by a panel of healthcare providers and educators specializing in diabetes care, health educators, researchers, and community health advisors/community members of the REACH project. The panel examined the questionnaire for clarity and language, as well as the relationship of the questions to ADA recommended clinical care and self-management guidelines.[9] Questions were clarified and language was simplified based on panel input.

Table 1. Persons reporting receiving ADA recommended tests, education, and counseling, 1999 pilot data (*N*=103; AAs=80, Cs=23)

Test Education Counseling	Percent (%) AAs Report Receiving Recommended Care	Percent (%) Cs Report Receiving Recommended Care	*P* Value (α=0.05)
A_{1c}	53	78	.027
Lipid	73	78	.580
Kidney	54	61	.545
Feet	79	96	.294
Eye	75	78	.748
Nutrition education	85	87	.815
Smoking cessation	38	100	.182*

AAs=African Americans; Ca=Caucasians.
P value calculated using Fisher Exact Test.

Pilot Test

The instrument was pilot tested (*N*=103) for reliability in fall 2000. Pilot test questionnaires were administered by CHAs and health professionals in respondents' community setting, home, or healthcare site. Responses were reviewed for consistency and item clarity. Revisions were made where indicated.

Data Collection

The final version of the questionnaire was administered in fall 2002 by survey administrators and CHAs working in Charleston and Georgetown counties of SC. Between August and September 2002, the survey was administered to 160 AAs and 150 Cs with diabetes. All respondents were given a choice to complete the survey either independently or with a same race, trained survey administrator. Although this method introduces different levels of respondent bias among participants, some participants refused to answer with an administrator, while low literacy or vision prevented others from being able to participate independently. Attempts to track which surveys had been answered independently and which had been answered with an administrator were unsuccessful, making comparisons of response differences between 2 administration methods impossible. Data were collected anonymously and all participants were read an Institutional Review Board (IRB) approved informed consent. Participants were made aware of a $15 incentive prior to taking the survey and were given the incentive after completing the questionnaire.

Data Analysis

Questionnaire responses were checked for clarity of response by a nurse/health educator with a masters degree. Data were entered into an Excel database. Items containing missing data, as well as questions with multiple responses, were excluded. Responses were numerically coded for data entry and exported into SPSS for final analysis.

The chi-square test was used for analysis of difference between AAs and Cs (*P*=.05). Two by two and 2 by 3 tables were created, with χ^2 calculated for each variable by race. Fisher's Exact Test was used in situations where there was insufficient data in one or more cells. For selected variables where there were 3 response choices and inadequate data in one or more cells, data were collapsed into a 2×2 table to calculate the

Table 2. Demographic description of survey respondents, 2002

	Mean Age*	Female† (N/%)	Male† (N/%)	Mean‡ Education	Median Income§	Seeking Employment (N/%)	Retired (N/%)	Not Working (N/%)	Medicare (N/%)	Medicaid (N/%)	Private Insurance (N/%	No Insurance (N/%	Other Insurance (N/%	Heard of REACH† (N/%)
AA	59.17	126/79	34/21	11.5	$15,180	1/0.6	64/40	37/23	24/16	14/9	51/33	13/8	9/1	94/59
C	59.12	87/58	63/42	13.7	$23,500	2/1.3	63/45	24/17	19/14	4/3	47/34	9/6	13/9	10/7

* SE for AAs=1.28; Cs=1.25.
† Significant at the $P<.001$ based on chi-square.
‡ 95% CI: AAs=14,752.4 – 21,034.4 (Min=$0; Max=$60,00); Cs=20,716.2 – 41,543.8 (Min=$3,000; Max=$200,000).
§ Significant at the $P<.000$ using Student *t* test, SD for AAs=3.3, Cs=3.3; SE For AAs=0.27, Cs=0.27.

Fisher's Exact Test. For example, on the question asking participants if they were able to carry out the provider instructions, data in the "somewhat" category were moved to the "yes" cells.

RESULTS

Pilot Study

Results from the pilot test showed that AAs ($N=80$), when compared to Cs ($N=23$), reported fewer tests for A_{1c} ($P<.05$), lipid levels and kidney function, fewer feet and eye exams, and less nutrition and diabetes self-management counseling during 1999–2000. There were no significant differences in blood pressure measurements and smoking cessation counseling. Because of the small number of people responding to other questions and missing data, no other useful or significant conclusions could be made related to diabetes for the pilot study. These self-reported pilot study data are similar to the information reported for chart audits of care during the same time period. However, for the pilot survey, an even smaller percentage of AAs reported receiving recommended tests and counseling than found in the chart audits of care in the patient medical records. These data are reviewed in other publications.[6,8]

Current Study

Results of the current study are from the survey conducted in 2002. Table 2 displays the demographic description of the sample. Significant differences between the 2 groups (AAs and Cs) were noted for gender distribution ($P<0.001$, χ^2) and education ($P<.001$, *t* test). Caucasians (Cs) were more evenly distributed by gender than AAs and had higher levels of formal education. Additionally, Cs had a median income almost double that of AAs. African Americans (AAs) were also significantly more likely ($P<.001$, χ^2) to report that they had ever heard of the REACH 2010 project (59%) than Caucasians (7%). This, however, is expected since REACH 2010 is actively engaged in reaching out to the AA population through a variety of activities in the 2-project counties. There were no significant differences noted between the 2 groups in those reporting insurance coverage, although AAs were more likely to report coverage by Medicare, Medicaid, or a combination of the two Caucasians were more likely to report having private insurance or a combination of private insurance and Medicare.

On self-reported knowledge of whether a patient had received ADA recommended laboratory tests, screenings, and education, there was a significant difference between AAs and Cs for having received nutrition education. African Americans (AAs) were more likely to report having received nutrition education than Caucasians did.

Table 4 presents results of the analysis on self-reported knowledge of the results of laboratory tests and screening procedures. Subjects were asked to rate the results as high, normal, low, or good, average, and not so good. There was a significant difference between the 2 groups on the item on which the participants rated the results of the kidney function test. AAs were significantly ($P<.001$) more likely to report that their kidney test results were good compared to Cs. Data for feet exams and eye exams were not significant.

There were no significant differences between AAs and Cs on the survey items that asked if they were able to implement the instructions they received regarding the various laboratory tests, screenings, and educational programs. For this series of questions, the "somewhat" category, which had very few responses, was collapsed into the "yes category" to enable use of the Fishers Exact test.

DISCUSSION

In summary, this research explored differences in self-reported knowledge,

Table 3. Persons reporting knowledge of receiving test, exam, or education for 2002 survey

Test Exam Education	AA/C (*N*) Answering Question	AA/C (%) Reporting Receiving Recommended Care	*P* Value (α=0.05)
BP	156/150	94/93	.183
Kidney test	131/104	68/55	.607
A_{1c} test	114/115	64/69	.982
Lipids test	130/126	73/75	.9333
Feet exam	154/148	76/75	.160
Eye exam	153/149	81/80	.388
Nutrition education	151/142	86/74	.003*
Smoking cessation	142/139	14/13	.674

* Chi square calculated using 2×2 tables.

reported recall of test results, and ability to apply new knowledge to improve self-care practices and outcomes between AAs and Cs. While significant differences between AAs and Cs were found on a few items, most of the results showed no significant differences between the 2 groups. Two issues may have contributed to these results. First, this survey was completed 2 years into the REACH 2010 project, which, as noted above, has heavily penetrated the AA communities in the 2-study counties. A similar result is also reflected in the chart audit data from the first 2 years of the project. In an earlier paper reporting on the chart audit data, Jenkins, McNary, Carlson, et al[6] reported that after 24 months, "disparities related to diabetes care (testing, exams, and education) were not observed for AAs with diagnosed diabetes when compared to Whites and others." In a project such as REACH 2010, which is designed to reduce disparities between 2 groups, this is the trend that would be expected. Second, there were a number of survey items with missing data, which is a limitation of the study and may have contributed to the lack of significance on some items.

There were several limitations of the study that need to be addressed. First, the samples for the pilot and the survey were convenience samples recruited from healthcare systems and community activities (other than REACH). Also, the survey was a self-report tool with the option for self-administration. A well-known limitation of self-administered surveys is the inability of the researcher to ensure that all questions are answered. This probably contributed to the number of questions with missing data. Furthermore, the survey was completely anonymous, with no mechanism for following up with subjects who did not provide answers to all of the questions. In addition, this particular survey was administered at the end of a longer survey, which may have resulted in subject fatigue, thereby contributing to incomplete answers.

Finally, the survey design had some problems. Although the questions were reviewed and evaluated by a panel of experts and pilot tested, it was noted that some of the questions needed additional answer choices, such as "not applicable," "don't know," or "have not been told." For other questions, subjects were asked to respond to open-ended questions. For example, for each section of the survey, subjects were asked to respond to the open-ended question: What were you told to do about your (A_{1c}, cholesterol and lipids, kidney test, etc)? The number of subjects answering the questions was small. The most common responses were "take my medicine" or "follow my diet," or "get more exercise." Due to the overall length of the survey, the researchers may have obtained more accurate and complete data had answer choices been provided, rather than using open-ended questions, which can take more time and effort on the part of the survey respondent. The survey tool is currently undergoing revision to enhance ease of administering, whether self-administered or completed by an interviewer. The open-ended questions

Table 4. Respondents' self reported recall of test results, 2002 survey

Test Exam	AA/C (*N*) Answering Question	AA/C (%) Reporting High Results	AA/C (%) Reporting Normal Results	AA/C (%) Reporting Low Results	*P* Value (α=0.05)
BP	140/136	30/29	67/69	1/2	.872*
A_{1c}	63/94	22/31	72/66	6/3	.362*
Lipids test	93/108	41/30	67/54	3/5	.149*
		Good	Average	Not So Good	
Kidney test	97/78	87/51	11/35	2/14	.000
Feet exam	125/112	74/71	19/20	7/10	.694
Eye exam	124/118	60/63	24/20	15/17	.759

* 2×3 tables had one cell with inadequate data to meet test requirements for χ^2.

will be rewritten to provide choices for each question. Qualitative questions will be used to clarify information, rather than as the sole source of important data. In addition, each survey will be coded as self-administered or completed by a survey administrator. Also, the respondent will be asked to identify the place of administration or completion of the survey. This will eliminate the problems the researchers encountered in tracking surveys by method and site of administration, both of which have the potential for influencing answers.

Based on analysis of results, 86% of AAs, compared to 74% of Cs, had received nutrition education. Nutrition programs and education are the most frequently requested programs on diabetes. REACH has provided many health and nutrition education sessions in health centers, community and senior centers, and area churches. It is anticipated that the messages are reaching the targeted community members and trend data will help us continue evaluation on the effectiveness of these programs.

Further investigation is needed related to kidney test results. It is interesting that 87% of AAs (compared to 51% of Cs) reported good results for kidney testing, yet AAs experience significantly more renal failure than do Cs. Only 1% ($N=2$) of AAs (compared to 7% [$N=11$] of Cs) reported their kidney test as "not good." Based on chart audits, increased control of blood glucose, blood pressure, and blood lipids is needed if we are to achieve a reduction in renal complications of diabetes for AAs.

CONCLUSION

Although it is not possible to say conclusively that the decrease in disparities between AAs and Cs is a result of REACH 2010 Charleston and Georgetown Coalition activities, these data suggest that there has been an effect. This is a particularly interesting proposition given the similar trend seen in the chart audit data. Results of this survey suggest that the Coalition activities, possibly in conjunction with other initiatives in the community, are beginning to make a difference in eliminating healthcare disparities among African Americans with diabetes. There is, however, much work still to be done. The self-reported results are better than the national means reported in the recent *National Healthcare Quality Report* for A_{1c}, eye and feet exams, but significantly poorer than the reported mean for lipid testing. During a 2 year period, 94.3% of people with diabetes nationally reported lipid testing compared to a one-year period in the 2-county area, 73% of AAs and 75% of Cs reported receiving a lipid profile.[10–12] Now that access to care is improving, future efforts need to address continuing care and improved self-management and the continuing problems associated with diabetes—the long-term complications and disability that result.

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