



Published in final edited form as:

Diabetes Educ. 2009 ; 35(1): 117–123. doi:10.1177/0145721708327535.

Health of Gullah families in South Carolina with Type 2 diabetes: Diabetes self-management analysis from Project SuGar

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Abstract

Purpose—The purpose of this study was to describe diabetes self-management practices and service utilization among Gullah families in South Carolina.

Methods—Data were obtained from 1,276 persons with type 2 diabetes through interviews using the Family Health History Questionnaire. This was a primary analysis of a project conducted in conjunction with a parent study (Project SuGar) which focused on the molecular aspects of diabetes. Descriptive statistics were used for data analysis.

Results—Diabetes self-management behaviors were not consistent with recommendations from the American Diabetes Association. Over half (55.6%) reported exercising, but only 27.7% reported self-glucose monitoring. Service utilization was poor, less than half, (41.1%) reported referral to a diabetic class/diet, 32.8% reported making yearly visits to the ophthalmologist; 22.3% reported visiting the dentist, and only 12.8% reported visiting the podiatrist.

Conclusions—Although some self-management behaviors were identified, Gullah family members remain at risk for preventable diabetes complications. Education must reflect behaviors and beliefs valued by Gullah individuals. Culturally appropriate educational programs may increase use of health care services aimed at decreasing preventable complications of type 2 diabetes in the Gullah population.

Introduction/Purpose/Background

Most individuals trying to integrate major life changes are likely to encounter barriers to care that pose major challenges in adhering to self-management programs. Patients’ adherence to self-management programs are affected by barriers to care, service utilization, culture, ability to understand and implement the program.¹ Self-management programs are often complex, time consuming and patients are faced with making multiple daily decisions affected by current knowledge, attitudes, resources, support systems, culture, and beliefs.¹⁻³

In spite of widespread consensus that self-care management practices play a crucial role in the management of chronic illness such as diabetes, little is known about the self-care management practices of rural African American families with diabetes. Moreover, even less is known about the self-care management practices and services utilization among Gullah families in South Carolina with Type 2 diabetes.

The word “Gullah” refers to the unique cultural and linguistic patterns of Africans Americans living on the Sea Islands of South Carolina. Cultural and historical records link the Sea Islander/Gullahs to rice-cultivating cultural groups in Sierra Leone and other countries in West and Central Africa.⁴ The population was isolated (both cultural and geographical) for many years from the mainland and has maintained many characteristic of ethnic groups from the West Coast of Africa.

In 1995, Timothy Garvey received funding from W. M. Keck foundation to determine if a genetic basis existed for metabolic disorders and obesity within the Gullah population in South Carolina.⁵ This population was chosen because of 1) minimal genetic admixture, 2) large stable multi-generational families, 3) high prevalence and relative risk for T2DM, and 4) uniform diet and lifestyle, which maximize expression of disease in patients with susceptibility genes. The study was known as Project SuGar (Sea Island Genetic Africa American Registry). The overall goal was to isolate and identify genes contributing to common complex diseases in the Sea Islanders. The scientific objectives were to 1) create a registry of Gullah families with T2DM, 2) ascertain sib-pairs and pedigrees with T2DM, 3) phenotype all participants, 4) obtain anthropometrics, lipids, and clinical assessment, 5) conduct a whole genome-scan on affected sib-pairs. The service objectives were to 1) provide free health education, and disease screenings to the community, 2) participate in health fairs and, 3) make appropriate referrals. From 1995-2004, this community based research project was successful in recruiting 630 African American Gullah families. Specific recruitment strategies were published and can be found elsewhere.⁶

While the health of the United States has improved over the last two decades, there continue to be striking disparities in the burden of illness and death experienced by various racial and ethnic populations.⁷ Improving diabetes care in the U.S. is a major concern for health care providers. The Diabetes Report Card, a summary of the quality of diabetes care in the United States, was developed using a set of standard measures to document levels of diabetes care.⁸ Results from the CDC Report Card indicated that: 18 % of the national sample had HbA_{1c} > 9.5mg/dl, 34 % had blood pressure >140/90 mm Hg, less than 50 % (45%) receive foot examination in the previous year, and 37% did not received an annual dilated eye examination.⁸ These staggering results are not consistent with ADA recommendations.

An unpublished observation (N= 1,322) conducted by Spruill and Reigel documented the following results among the Gullah families: 30.2% had HbA_{1c} levels > 9.5 mg/dl, and 29% had blood pressure > 140/90 mm Hg. Other results from the study indicated that 45.9% complained of neurovascular complications defined as foot pain. Sixty-eight percent had fasting glucose levels > 126 mg/dl.⁹ These results among the Gullahs were worse than the national sample reported by the Diabetes Report Card. More importantly, less is known about the self-care management practices and services utilization among Gullah families in South Carolina with Type 2 diabetes. This study will report results from an analysis of selected data from Project SuGar research participants. The specific aims are to 1) Describe diabetes self-management practices and 2) service utilization among Gullah families in South Carolina with type 2 diabetes.

Research Design and Methodology of Parent Study

This was a primary analysis of data from a project conducted in conjunction with the parent study (Project SuGar) which focused on the molecular aspects of diabetes. Project SuGar created metabolic profiles of complex disease, and conducted a genome-wide linkage scan on Gullah families affected with Type 2 diabetes. Since this was a primary analysis of selected data from a parent study, the author will provide a brief description of the parent study.

Parent Study Sample and Setting

Recruitment sites for the parent study included the nine counties (Beaufort, Charleston, Berkeley, Dorchester, Colleton, Horry, Hampton, Jasper, and Georgetown counties) that make up the Low Country also known as home of the Gullahs. Persons diagnosed with diabetes and a family history, or without diabetes but a family history were invited to participate in the parent study if they met the following inclusion criteria: (1) born or raised on the Sea Islands, (2) biological parents born or raised on the Sea Islands, (3) diagnosed with T2DM, or had two or more family members diagnosed with Type 2 diabetes, (4) siblings with same biological parents, (5) only one parent diagnosed with diabetes, (6) were over 12 years of age, and (7) able to participate in an informed consent process. Non-probability purposive sampling techniques were used for recruitment from (1) ambulatory clinics; (2) private clinics; (3) community, (4) faith community, and (5) health-related events.

Parent Study Data Collection Procedures

Study procedures for the parent study included three phases: an introductory phase, a pre-clinical phase, and a clinical phase. The introductory phase consisted of nurse/participant introductions, explanation of the study, and the informed consent process. The pre-clinical assessment phase consisted of collecting voided urine specimen, obtaining three blood pressure measurements, and anthropometric measurements. The clinical phase included administering oral glucose tolerance test (OGTT) on non-diagnosed persons and collecting multiple blood specimens from persons diagnosed with type 2 diabetes for clinical labs. During the two hours of the multiple timed blood draw, the research nurse would also update, validate, or complete the Family Health Questionnaire (FHQ) as some questionnaires were completed during home or clinical visits. Each participant was given an opportunity to obtain a free glucose meter, and participants without prescription coverage were referred to the social work student for assistance. Research participants also received basic diabetes education and handouts.

Parent Study Data Collection

The Family Health Questionnaire (FHQ) was designed for the parent study by the first author and the Project SuGar principal investigator. It included information on demographics, health status, diet and exercise, family history, diabetes history and beliefs. Some questions had yes or no responses; others were short answers and recall of information. The questionnaire was divided into three major sections: Section I, All about Me, i.e. (When did you learn you had diabetes?), Section II, All about My Diabetes, i.e. (When was the last time you saw a doctor about your diabetes?), and Section III, All about My Family, i.e. (Who else in your family have diabetes?). The interrater reliability percentage of the FHQ for the parent study was 90%.

The genetic content in the questionnaire was compared to and adapted from previous genetic tools used by the Project SuGar principal investigator in a genetic study on Pima Indians.⁵ The clinical parameters within the instrument were updated periodically to reflect current lab values for the management of patients, i.e. glucose <126 mg/dl the vs. 140 mg/dl, and blood pressure <130/80 mm/Hg vs. 140/90 mm/Hg.¹⁰ The questionnaire was pilot tested among the staff and research nurses. All questions were read in English by the nurse to the participant with some explanations (if needed) in the Gullah language. The project hired five local Gullah speaking

research nurses to administer the instrument and the semi-structured interview process lasted between 45 -60 minutes. An expert in how to collect sensitive genetic information and construct a pedigree trained all of the nurses. The first family member recruited and interviewed was known as the proband, and inclusion criteria included being diagnosed with T2DM or family history of T2DM. A FHQ was completed on all family members enrolled into the study. The parent study included analysis from participants (family members) with and without T2DM.

Current Study

Data Collection/Procedures—The first step in the data collection for this project conducted in conjunction with the parent study was to obtain permission to use the data set from the Project SuGar Citizen Advisory Committee, local academic IRB and the principal investigator. The last step involved formalizing the institutional agreements and obtaining authorized signatures. The current study only reported on participants diagnosed with T2DM (N =1, 276).

Current Study

Instrument—The data collection instrument for this analysis was the 22-page FHQ. Even though the FHQ was designed for the parent study, selected data from the FHQ were analyzed for this report. Subheadings of questions used for this analysis included: 1) Self-Management:/ Monitoring blood glucose/frequencies (We did not ask if they owned a glucose meter because the project made glucose meters accessible to all participants), exercise, type, use of home remedies, types, and beliefs about diabetes, and 2) Utilizations of services (referral to ancillary service). Examples of questions analyzed for self-monitoring were: How often do you check or monitor your blood sugar? Do you exercise? Do you use home remedies to treat your diabetes? Examples of questions analyzed for service utilization included: Have you been referred to a diabetes class or to a dietician? Were you referred to an ophthalmologist?

Data Analysis

An analysis of data was completed using SPSS for Windows 13. Frequencies and percentages were tabulated for all categorical responses. Descriptive statistics were used to describe the self-management behaviors and service utilization.

Results

The social demographics of the Gullah population are similar to other African Americans with type 2 diabetes especially as it relates to education. Most were female; unemployed, insured, married and had some high school education. See Table 1. Most of the Gullah participants believed that diabetes was inherited and could be prevented. The participants from Gullah families may believe that diabetes can be prevented but they also believe that diabetes “runs in my families and I will get it anyway.” See Table 2

Table 3 and 4 describes utilization of services and self-management. Table 3 highlights utilization services. When asked about referral to diabetes education class, or adhering to a diabetic diet, only 41.1 % reported being referred to a diabetes diet class or for diabetes education. The greatest response for preventive follow up care (ancillary visits) were to the ophthalmologist (32.8%) followed by the dentists, 22.3 %, and least visits to the podiatrist 12.8 %. See Table 3.

Table 4 describes both the self-management and preventive behaviors of participants. Over 50 % reported exercising and the most common type of exercise reported was walking. Less than 30% reported checking their blood glucose daily and only 11 % check their glucose once a week. See Table 4. When asked about the use of home remedies to treat diabetes, over 20 %

did not answer the question. Of the 151 persons who responded to the home remedy question, the highest frequencies were among the following remedies: garlic, ho-hung tea, vinegar and water, aloe Vera, boiled celery, cherry bark, goldenseal, herb teas, peach kernels, and lemon juice. The lowest were found using the following remedies: bitter aloe, snakeroot, boiled grape peel, dandelion tea, devil's claw, and life everlasting, cinnamon, moss, celery apple, and carrots.

Discussion

The primary aims of this study were to describe the self-management practices and service utilization of Gullah families in South Carolina with Type 2 diabetes who participated in Project SuGar research study. This study explored selected data associated with beliefs, clinical data, and self-management behaviors ascertained from the Family Health Questionnaire. These analyses of findings from Gullah families as it relate to beliefs, self-management practices, ancillary visit and service utilization provide important background data that researchers and health care providers can use to tailor interventions unique to this culture.

Self-Management /Beliefs/Cultural Influences

This study reported that over half of the participants believe that diabetes can be prevented, yet when asked about self-management behaviors and services utilization less than 30 % monitor their blood sugar daily and less than 35 % follow up with ancillary services. One can speculate that beliefs are not readily translated into improved behaviors among the Gullah participants. Gullah participants also believed that diabetes was inherited, indicating that they cannot do anything about because it runs in my family. Others would simply say, I ain't claiming it. Although, The Euro-Centric Health Belief Model (HBM) has been used in patient education, it does not include the potential for culturally acquired strategies to reduce disease risk.

Although less than 15% of the respondents answered the home remedy question, it is possible that the use was more common in families. However, participants may have been hesitant to self-report for fear of chastisement from the provider. Gullah families are characterized as large and multi-generational. Programs such as the HBM¹¹ and the ones developed by the Secretary General Family Health Initiative (U.S. Health Human Services)¹² may not work well with members of this population because they lack culturally appropriate strategies and these programs may include a definition of family that does not extend beyond biological family to include the social family.

A strength reported by the families was the use of exercise. For example, over 50 % responded yes to exercise and walking was reported as the most common exercise. This could be used to support inclusion of walking programs, as a preventive culturally appropriate strategy as walking is an acceptable safe mode of transportation in this population.

The cultural and geographical isolation of the population from the mainland also had an affect on the beliefs system as it relates to the use of herbal and root medicine. Gullah families learn quickly to distinguish between natural and unnatural illness and seek the aid of local root doctors to treat unnatural illness. They learned to distinguish between diseases that need immediate life saving measures and illness that one could put off and learn to live with. Even though, some Gullah participants reported using home remedies to treat diabetes, very little is known about the effects of these products on glucose control. However, a study by Khan, Safdar, Khattak, and Anderson, among non-Gullah participants demonstrated that that the intake of 1, 3, or 6 g of cinnamon (*cinnamomum cassia*) per day reduces serum glucose, triglyceride, LDL cholesterol, and total cholesterol in people with type 2 diabetes (T2DM).

They suggested that inclusion of cinnamon in the diet of people with T2D would reduce risk factors associated with diabetes, and cardiovascular diseases.¹³

People in the rural areas especially the elderly, are often involved with the natural elements, and participate in nature in ways that are not understood in urban communities.¹⁴ Blake spent many years studying the life and culture of Sea Island residents, and reported that their attitude toward health and health care is an extension of common attitudes about the natural elements. Most importantly, he reported that the Gullahs approach health care through a frame of reference that assumes nature has its own processes and that as actors, we must understand them, become a part of them, not alter, or try to master them. Thus taking the “needle” is viewed as unnatural to them, but drinking teas for ailment maybe viewed as natural. This is in contrast to the professional approach to health care that alters or in some way interrupts what Gullahs would consider a natural process. Consequently, the practitioner maybe seen as meddler, rather than a healer, particularly when he or she gives advice to that is contrary to traditional beliefs.¹⁴ Gullahs do not look at health in terms of absence of disease, instead they feel than they are in good health as long as they can live independently and meet their own needs, and when one is no longer able to maintain such independent, one is seen as “failing.”¹⁴ These insights suggest that the usual approaches to provide diabetes education may not be appropriate. Questions providers should considering asking are: Is the fear of needle related to an unnatural process for the management of diabetes among Gullah families? Moreover, how can practitioners use nature to treat diabetes?

Service Utilization

Limited formal education may be a significant barrier to service utilization because less than 50 % of Gullah families reported having some high school. The utilization of services by Gullah participant maybe affected by the number of minority providers serving the area. For example, The SC Office of Research and Statistics (ORS) reports that only 5.3% % of medical doctors in SC are African Americans.¹⁵ Consequently, one of the first priorities to increase preventive ancillary visits maybe to have sufficient numbers of minority health professionals that are distributed according to needs to provide quality ongoing cultural appropriate diabetes care. Nonetheless, the most reported ancillary visits by the families were to the ophthalmologist and the least reported ancillary visit was to the podiatrist. What account for more visits to the optometrists and less to podiatry and dentistry are unknown and a topic for future research.

Information gleaned from this study can provide a wealth of data to support interventions for rural isolated African American populations such as the Gullahs. Areas of limitations in this study includes self-report for management and service utilization. This study did not compare the Gullah families to any other African Americans rural or urban populations. In addition, the wording of some questions related to home remedies may have been confusing to the participants and may have resulted in under-reporting.

Implications for Practice

African Americans are disproportionately affected by T2DM and rural African Americans when compared to urban African Americans have higher blood pressure, worse glycemic control, and more complications when compare to urban AA.¹⁶ Empirical research is lacking with regard to the use of cultural approach to the treatment of T2DM in AA. Thus, a major challenge that remains for African Americans both rural and urban is utilization of service to prevent diabetes related complications. This study highlights the need to design and implement culturally appropriate diabetes educational programs to improve self- skills among Gullah families in South Carolina. Tailored program should be designed for this population that include group learning, cooking, tasting demonstration, family involvement, resources sharing,

skills development, testifying, and the proper use of commentary or alternative medicines. Gullah families should not be left alone to a self-fulfilling prophecy of getting the “sugar.”

Acknowledgments

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The Gullah families in South Carolina who participated in Project SuGar, and the Project SuGar staff (1995-2005)

Funding: NIH Research Grant 5 P20 NR008351-05/ National Institute of Nursing Research and the National Center for Minority Health and Disparities (NIHNR) and (NCMHD) and Postdoctoral Training Grant T32 NR007110

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Table 1
Social Characteristics of Gullah Families. (N= 1,276)

Variables	Percentages
Education	
Above High School	29.4%
Some High School	45.8%
Beyond Middle School	16.6%
Middle School	8.2%
Insurance Status	
Insurance	69.9%
No Insurance	19.5%
Marital Status	
Married (Widowed)	57.4%
Single (Separated)	33.2%
Employment Status	
Employed	40.1%
Unemployed	58.5%
Age	
Mean Age (years)	54 (14-92)
Gender	
Female	77.7%
(male /female)	280/991

Table 2

Beliefs about diabetes N= (1,276)

Variables	Percentages
Diabetes Inherited	
Yes	61.1%
No	10.7%
No response	28.2%
Diabetes Prevented	
Yes	66.6%
No	5.3%
No response	28.2%

Table 3

Service Utilization (N=1,276)

Variables	Percentages
Referrals to Diet/Diabetes Class	
Yes	41.1%
No	58.9%
Ancillary Visits	
Podiatrist	12.8%
Dentist	22.3%
Ophthalmologist	32.8%

Table 4
Self-Management and Preventive Measures (N = 1,276)

Variables	Percentage
Exercise	
Yes	55.6%
No	44.4%
Home Remedies	
Yes	11.8%
No	60.0%
No Response	28.2%
Glucose Monitoring	
Daily	27.7%
Weekly	11.1%
Monthly	1.6%
Intermittent	3.7%