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Family Interactions Among African Americans Diagnosed With Type 2 Diabetes

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Abstract

Purpose—The purpose of this study was to examine the impact of family and friends on the management of persons with diabetes and their willingness to be involved in a culturally tailored program.

Methods—This qualitative study was based within a larger quasi-experimental study that focused on the impact of a culturally tailored group intervention compared with individual standard diabetes education on the outcomes of self-management and glycemic control among rural African Americans with type 2 diabetes. Twenty-one participants were randomly assigned to an individual education group or a culturally tailored intervention group. Family members/peers (n = 6) attended invited group sessions to obtain information about diabetes and family/peer support. The facilitator of the invited group sessions used a guide to help with group discussions. The investigators used an iterative approach to enhance the examination of the responses from the discussion guide, thus identifying recurring themes within the participants' responses.

Results—The data revealed that family and friends made a difference in the diabetes management of individuals with diabetes. Although family and friends may have been helpful at times, they also created moments of problems and an environment that made it more difficult to care for diabetes. The data also revealed that diabetes is hard to manage and control. Participants reported that taking medications and being aware of types of foods to keep a well-maintained glucose level were often challenging.

Conclusions—These findings confirm that family and peers greatly influence diabetes management among rural African Americans. The study's results will help health care providers understand the importance of involving family members and friends in the treatment and diabetes management of individuals with type 2 diabetes, particularly within rural African American communities where resources are limited.

It has been estimated that 3.2 million or 13.3% of all African Americans aged 20 years or older are diagnosed with diabetes, and many more have undiagnosed diabetes. The American Diabetes Association estimates that individuals aged 60 years or older represent approximately 20.9% of all people in this age group who have diabetes.¹ African Americans with diabetes have higher rates of stroke, coronary heart disease, and end-stage renal disease, and thus they live shorter and less healthy lives.²

Landmark studies such as the Diabetes Control and Complication Trial³ have demonstrated the value of optimal glycemic control to prevent complications of diabetes.⁴ However, recent studies show that a significant number of adults with diabetes do not achieve recommended target blood glucose level, blood pressure, and/or serum lipids, placing them at a high risk for complications such as cardiovascular and renal disease.^{5,6} Several researchers⁷⁻⁹ have identified factors affecting the management of diabetes in the African American community, including unhealthy foods that have cultural importance, poor or lower access to proper care and education, and problems of trust between health care providers and African Americans. An estimated 80% of people with diabetes receive health care from primary care providers, who cannot provide comprehensive education for self-management of diabetes because of lack of time and experience.¹⁰ It is estimated that only about one third of people with diabetes receive diabetes self-management education.¹¹ Such education is rarely available to rural African Americans and may not be culturally relevant, reducing its effectiveness. Culturally tailored approaches (eg, storytelling) have shown promise in managing diseases such as diabetes, particularly for rural African Americans, who typically have limited resources and other barriers to health care.¹² In addition, support from family and friends may play an important part in the lives of African Americans with diabetes, especially in rural areas.

Support protects individuals from potential harm and facilitates coping.¹³ For example, having someone who can provide resources may be enough to improve the stressed individual's ability to cope with a stressful illness.¹⁴ Langford et al¹⁵ described social support as having 4 components: emotional support (support for self-esteem and psychological well-being), instrumental support (provision of tangible goods and services), informational support (information to assist one to problem-solve), and appraisal support (affirming the appropriateness of acts or statements made by another). Family and friend social support may help individuals with diabetes cope more effectively with the daily struggles of having diabetes.

However, few studies have examined the impact of family and friends on the management of diabetes, and even fewer studies have examined the influential relationships of family and friends for rural African Americans with diabetes. Friends and family networks have been shown to be important sources of social support for African Americans; therefore, they need to be studied in relation to diabetes.^{16,17} This study therefore examined the impact of family and friends on the management of persons with diabetes and their willingness to be involved in a culturally tailored program.

Methods

Sample, Setting, and Procedures

The study was part of a larger study of the effectiveness of culturally tailored interventions conducted during 2005 and 2006 in a rural county in Virginia, at a community center accessible to rural residents. The larger study has been reported elsewhere.¹⁸ The larger study used a quasi-experimental design to determine the feasibility of conducting a trial to compare the impact of a culturally tailored group intervention to individual standard diabetes education on the outcomes of self-management and glycemic control among rural African Americans with type 2 diabetes. Outcome measures consisted of an empowerment scale, rating of personal goal achievement, a self-care activities inventory, a hemoglobin A1c measure, and a satisfaction with diabetes education questionnaire. Each measure in the larger study was collected at baseline and 3 months after baseline. Eligible participants were randomly assigned to the culturally tailored education group or the individual standard education group.

In this portion of the larger study, only the family and friends of the individuals who were in the culturally tailored education group (intervention group) were invited to selected sessions where they had an opportunity to speak about the experiences they had with the individual with diabetes. A qualitative research design was applied to this study to help explore, interpret, and describe complex and not already fully explored experiences. The participants were encouraged to express their experiences in narrative form and explain the setting in which events happened during their experiences. This segment of the larger study was evaluated using facilitated invited discussion sessions throughout the study, in which participants could verbalize their experiences with diabetes management and family/friend impact on the disease.

Participants were recruited by flyers, church announcements, and radio announcements in rural African American communities. Participants had to meet the following criteria: (1) 18 years of age or older, (2) African American, (3) diagnosed with type 2 diabetes, (4) resident of a designated rural county in Virginia, and (5) able to give informed consent (eg, with no evidence of dementia or mental illness as determined by routine screening).

The larger study had 2 culturally tailored intervention groups (1 in fall 2005 and 1 in spring 2006) and 1 individual standard group for comparison (in spring 2006). In the fall of 2005, the culturally tailored intervention group did not have a comparison group because of a small sample size ($n = 6$). In the spring of 2006, a sufficient sample size was available for both groups ($n = 7$, intervention group; $n = 8$, individual group). A total of 21 adult participants (5 men, 16 women) were recruited. The diabetes education intervention was called “Taking Care of Sugar: African Americans Deal With Diabetes.” As for group size, Krueger¹⁹ recommended an ideal group size between 4 and 12 to enhance participation. Groups were conducted in conference rooms within the designated rural county’s community center that is centrally located and well known among the rural community to help facilitate participants’ comfort during the study. In addition, groups were conducted in the evening to accommodate work schedules of participants and research team members. The culturally tailored intervention group sessions were held weekly over an 8-week period and taught by a certified diabetes educator. The participants in the individual standard group also met with the certified diabetes educator 3 times over an 8-week period separate from the intervention group.

Each participant in the culturally tailored intervention groups had the opportunity to invite a family member or a friend to one of the intervention sessions. During this session, family members and friends were given a “Helpful Hints for Family Members” guideline developed by 2 of the study’s authors (Williams and Hinton) about how to be supportive to the person with diabetes. The guideline consisted of 11 tips that family members could use to help their loved ones manage diabetes. The guideline encouraged family members and friends to place themselves in their loved one’s shoes, learn more about diabetes, offer advice in the form of questions to maintain respect and empowerment, and keep a positive attitude. Along with the guideline, the family member or friends had an opportunity to view 3 videos. *Eat for Life*²⁰ demonstrates how a mother and her daughter and grandson interact with each other as they experience conflict about what to eat for a healthy diet and still maintain a good taste of food. *Emotional Aspects of Diabetes*²¹ depicts how family members express and cope with a range of emotions that surround diabetes. *Walk Down Your Blood Sugar at Home*²² illustrates simple physical moves for individuals with diabetes to perform in order to become more active in their daily lives. In addition, family and friends were invited to participate in a cooking demonstration by a dietician to show how to cook healthy meals that are easy and taste good.

There were 6 family and friends (n = 2 in fall 2005, n = 4 in spring 2006; 1 mother, 1 adult son, 2 friends, 1 adult daughter, and 1 wife) who came to the 4 invited sessions. The family and friends did not receive monetary compensation for attending these sessions, but several of the individuals expressed that they did appreciate the opportunity to attend 1 session with their loved one to understand diabetes better. As a debriefing mechanism, the family and friends had an opportunity to ask questions and voice their experiences with the skilled facilitator. The facilitator used the “Helpful Hints for Family Members” guide to initiate the discussions within the invited sessions. The discussions revealed much about how the interactions between individuals with diabetes and their family members/friends affected diabetes management. While an experienced facilitator (who is trained in running groups and a group facilitator trainer who uses *The Focus Group Kit*²³) from the research team facilitated the audiotaped sessions, 3 other members of the research team recorded field notes about the environment and the participants’ nonverbal behaviors to capture detailed descriptions of the setting, participants’ nonverbal actions, and other observations that were important but not revealed by the audiotape.

All study participants were given diabetes education materials developed for African Americans by GlaxoSmithKline (copyright 2005) and brochures developed for African Americans by the American Diabetes Association (ADA). Study participants were given a total payment of \$75, gifts such as foot care kits, and a free *Soul Food Cookbook for People With Diabetes*²⁴ with recipes for African Americans with diabetes.

Data Analysis

Participants’ and family/friends’ actions and responses throughout the intervention sessions were audiotaped, and field notes were recorded through observations by research team members. The audiotapes were then transcribed and analyzed using a qualitative method, in which participants’ experiences were explored to find their meaning.²⁵ A descriptive qualitative approach was used to examine recurring themes in both verbal and nonverbal responses of participants. The study investigators examined the narratives from each invited session transcript using an iterative approach to enhance the understanding of family members’ and friends’ experiences with their loved ones’ diabetes management. The investigators examined the transcripts to identify keywords or phrases (“codes”) to use in the analysis of the content. Once the transcripts were coded, the strips were organized and placed in categories derived from the invited sessions. The categories described the commonalities within the collective strips. The categories were then placed into themes that were identified from the data. Once the initial themes were identified, members from the research team examined them to further refine the data and come to a consensus of the emerged themes.

Results

The participants’ ages ranged from 27 to 85 years, with a mean age of 62.4 in the intervention group and 56.6 years of age in the individual education group. Most participants had completed between 7 and 11 years of formal education and described themselves as being from rural areas but not on farms. Two thirds (n = 14) of the participants had public insurance, mostly Medicare. Nearly all (n = 19) reported a health history of high blood pressure, took oral medications (71.4%, n = 15), and exercised regularly (66.7%, n = 14) to manage their diabetes. Demographic details can be found in Table 1.

Family and Peer Involvement With Diabetes Management

Throughout the intervention group sessions, a prominent theme was family and peer involvement with diabetes management. Participants focused on issues about how their

family and friends interacted with them in relation to diabetes. The participants believed their family and friends were very supportive at times but also made things more challenging for them as they managed their diabetes. The participants spoke about their responsibilities and the role they had played in their family network, which sometimes kept them from taking optimal care of their diabetes. One woman said,

Working full-time being a mother, a wife, and I'm not going to say I don't have the time, but I just spend my time doing other things, such as running my daughter back and forth or my job requires me to work evenings a lot, so for me that's a challenge.

In addition, several participants discussed how they had to battle the sweets and unhealthy foods that were in the house because of other family members and sometimes because of their own temptations. It was difficult for them to resist some of the foods that they saw. One woman said,

I live in a house with junk-food junkies. I was thinking the other day at the store about buying some key lime pie. I'm like "why were you buying a key lime pie?" Well, I had to spend such and such on this, I can spend this on pie. That is not the point of it. The point is that you know you don't need it, not supposed to have it.

Another woman said,

My mother recently came to stay with us due to health issues and she also has diabetes, and so we are like this the whole time, "oh, don't eat that" or "are you eating again?" I think the part that I am most disappointed about is my husband. I go to the store, and I do not buy the chips, the cookies, or the ice cream. However, when he goes to the store, he will buy the chips, the cookies, and the ice cream. They [husband and daughter] are like junk-food junkies ... I guess I want him to be more supportive in terms of what he buys and what he brings in the home, but it's also nice when I need that cookie.

The attendance of family members and friends showed the importance with which they viewed the participants' battle with diabetes. Although some family members and friends may have made the participants' diabetes management more difficult, they appeared unaware of the level of difficulty of caring for diabetes. Family members and friends who attended appeared to want to better understand the management of diabetes in order to be more supportive to participants. For example, this family member expressed support for his mother to help her manage her diabetes better:

I went by to pick her up and her sugar had dropped so low but the insulin she had taken, living by herself like that. It is very dangerous, so I am here to support her. We have our battles. I do not know it all and sometimes we try to suggest things, and I do a lot of research on them just on the computer. ... I know she gets pretty irritated with me. She just does ... I am in total support with her and trying to learn more about the disease myself and how I can help her and how I can help myself and we can work through this thing.

Diabetes Is Hard to Control

Most participants in the culturally tailored groups and in the individual education group revealed the common theme, *diabetes is hard to control*. The participants discussed having a difficult time maintaining a "good blood sugar" on a daily basis. As 1 participant said,

One morning it [glucose level] might be 95, another morning it might be 200 or 150 but it might slightly be different ... I find it very frustrating.

Another participant talked about how hard it was to take medication for diabetes. The strict regimen needed to manage diabetes can be overwhelming for some people. This man said,

The thing about insulin, none of us like medicine but having to get up and make sure you take your medicine before you eat breakfast, then before you eat your dinner and watch your intake. ...

Another person agreed and added,

When I go out, I have to remember to fix my syringe for my evening ... I take my medicine a half an hour before I do anything and so it's a pain really.

One family member said he knew how hard it was for his mother to manage her diabetes. He was quite concerned about her, and he did not realize how difficult taking care of diabetes was until he saw his mother struggling with it. He said,

I have learned quite a bit this evening. And that's why I'm glad to be here with my mother. I think the last 2 months have been rough for her having to go from oral medication to insulin medication and having 2 significant events whereby she was not able to get out of the bed.

The loss of control was revealed among these participants as well. Diabetes was seen as an illness they wanted to control. Many participants did not see themselves as the type of people who would lose control over a situation or could not overcome an obstacle. One woman said,

I know for me, I am a person that really likes to be in control of things. I am. I really, really am. And I can remember when I was on dialysis, I really thought that there was something I could do to make it, and when I realized it was nothing could do to make it better and make the kidney function again, I began to say well I can make my body stay up to par so that when it is time for transplant and a kidney comes along that I will be able and ready. And so I really think that it is all about how you are here, mentally. And how you maneuver those situations. ... And that was my thing. I said I'm in control of this. ...

Another woman added,

You also have control and know how much you can take. I started looking at how many carbohydrates those cookies were, so then I would tell myself, "I'll skip the rice tonight."

Positive Attitude and the Use of Prayer

Although diabetes can be challenging to manage on a daily basis, several of the participants kept a positive attitude toward their illness and remained supportive to their family members and friends. The participants interacted with their family and friends with positive attitudes, often through religious influence. Religion and prayer appeared to have been used by the participants on several occasions to encourage and support their family and friends. One woman said,

I think the same thing ["don't say I cannot do something"] to my daughter ... I don't say it because of my spiritual background ... I can do all things with Christ's strength and I have that posted on my refrigerator. It's on a little sticky note that says I can do all things and Christ strengthens me. ...

Another woman added,

I'm guilty of that too, saying I can't. But I know like I tell my children, they say oh, I cannot do that, but I say don't say that, you can. Try it and think positive, do not say, "I can't." It is the word that we should not use; "I can't," even if you do try.

Several participants spoke about their use of prayer as a coping mechanism in managing their diabetes and being a support system for friends and family. In a study of facilitators and barriers for self-management among rural African Americans with type 2 diabetes, Jones et al²⁶ also noted the use of prayer as a coping strategy. In the current study, the majority of participants' prayer was a form of support that sometimes was intertwined with family, friends, or close members of the community, such as a pastor. One man said,

I pray that I will be healed. I believe. I have faith that God is going to heal me from this [diabetes]. I do not have my mind set that I am going to have diabetes the rest of my life. But I like to be in a quiet place, and I try to do it early in the morning. At my church, my pastors told us to have our own alter at home. Take your own alter at home. That is where I find a lot of peace. This praying, it helps me. ...

A woman also said,

I pray that God is going to give me the strength of mind to get me up to do that exercise. He helps me do what I am supposed to do, and exercise is one of those things that you could easily put off.

Discussion

Interactions With Family and Friends in Relation to Diabetes Management

Many of these participants noted the effects that their families and peers had on the management of their diabetes, either positively or as challenges. Most participants struggled with taking care of their diabetes and relied on their own actions or capabilities, as well as the support of their family and peers. These findings are consistent with the results of other studies,^{13,14} in which family and peer support was noted to help in the management of illnesses. There were no differences between the women and men in this study. Both men and women expressed a need for family and peer support with diabetes management.

Participants' Responses

The influence of family and friend involvement with diabetes management was very important for this group. Participants viewed the interactions between them and their family or peers as either positive or negative. Some participants saw that family members did not understand diabetes fully, so they were less inclined to adhere to certain rules such as not bringing in sweet or "junk" foods. This is consistent with the findings from a study of African Americans and diabetes,²⁷ which found that family, friends, and coworkers did not understand diabetes management well, which led to poor suggestions. However, in the current study, family members and friends wanted to learn about diabetes to help and support the participant with diabetes.

The theme, *hard to control*, is consistent with the current literature.^{28,29} It is not easy for individuals diagnosed with diabetes to manage this chronic illness for their family and friends to help. Family and friends can create a positive as well as a negative environment. Management of diabetes does not rely only on eating the right foods at the right time, or exercising, or taking medications properly; it involves change of a complete lifestyle that is not easily done alone. The participants' feelings of losing control and being overwhelmed were seen as a burden. Participants appeared to be generally confident people, and the thought that they had moments of little control over diabetes was distressing to them. This is the time when family and friends can be of great assistance to individuals with diabetes by

learning more about diabetes and helping individuals stay optimistic about managing diabetes.

Most participants did have an overall *positive attitude* toward diabetes management and were also supportive for their friends and family members. Many of the participants used their determination to manage diabetes as a way to teach members of their family and friends that many negative situations can be overcome if an individual is optimistic and prays. The interactions between family/friends and participants thus went 2 ways, with both parties helping each other. This finding demonstrates how important a network of family and friends is, particularly for rural African Americans.

Conclusion and Implications

It is important to understand that diabetes is not a single person's disease; rather, it affects both the person with diabetes and the people in their environment, particularly family members. This study revealed the importance of understanding that the management of diabetes is a collaborative team effort, particularly for rural African Americans, who often have limited access to health care resources and count on family and friends for material help and psychosocial support.

Although more research is needed to determine whether these participants are representative of the larger population, this study's findings are important for health care providers caring for individuals with diabetes. It is suggested that health care providers include the patient's family members and/or peers (if the patient consents) in education about diabetes and how to control diabetes effectively. This will increase the understanding of people who surround the patient in his or her daily life and thus increase support and cooperation by the family or peers in the person's diabetes management. This study's findings can also be helpful to health care providers in culturally tailoring diabetes treatment plans.

The culturally tailored group intervention used here was well received by participants, who welcomed the involvement of family and friends in helping them manage their diabetes more effectively. Further studies are needed that focus on interventions tailored to rural African Americans and ways to involve family and friends in assisting with diabetes management. The goals are to help the participants improve their diabetes care and empower them to continue with a healthy lifestyle and gain more control over their lives. As noted by 1 woman in this study, "I'm working towards these goals and realizing that I am in control of my blood sugars. It has empowered me in a sense ... I have been really pleased with the results. I am just surprised. I did not know that I had that much power."

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Table 1

Sample Characteristics at Baseline (n = 21)

	All Participants	Intervention	Usual Care
Age			
Mean (SD)	60.2 (14.6)	62.4 (14.7)	56.6 (14.7)
Range	27-85	34-85	27-75
Gender, % (n)			
Male	23.8 (5)	23.1 (3)	25 (2)
Female	76.2 (16)	76.9 (10)	75 (6)
Education (highest grade or year completed), % (n)			
≤6	4.8 (1)	7.7 (1)	0
7-11	42.9 (9)	46.2 (6)	37.5 (3)
High school graduate	33.3 (7)	23.1 (3)	50 (4)
13-15	4.8 (1)	0	12.5 (1)
College graduate	9.5 (2)	15.4 (2)	0
17-18	0	0	0
>18	4.8 (1)	7.7 (1)	0
Type of insurance, % (n)			
Public insurance	66.7 (14)	69.2 (9)	62.5 (5)
Private insurance	47.6 (10)	46.2 (6)	50 (4)
No insurance	9.5 (2)	7.7 (1)	12.5 (1)
Residence, % (n)			
In a rural area (not a farm)	47.6 (10)	53.8 (7)	37.5 (3)
In a small rural town	33.3 (7)	23.1 (3)	50 (4)
In a small town	19 (4)	23.1 (3)	12.5 (1)
Diabetes history			
Years with diagnosed diabetes, mean (SD)	9.2 (6.9)	10.4 (7.1)	7.1 (6.3)
Has ever attended diabetes education, % (n)	57.1 (12)	61.5 (8)	50 (4)
Health history, % (n)			
Cardiovascular disease	33.3 (7)	30.8 (4)	37.5 (3)
High blood pressure	90.5 (19)	92.3 (12)	87.5 (7)
Eye disease	19 (4)	23.1 (3)	12.5 (1)
Kidney disease	9.5 (2)	15.4 (2)	0
Numbness/tingling in the legs or feet	23.8 (5)	15.4 (2)	37.5 (3)
Diabetes treatment and management, % (n)			
Takes oral medication	71.4 (15)	69.2 (9)	75 (6)
Takes insulin shots	38.1 (8)	46.2 (6)	25 (2)
Regular exercise	66.7 (14)	61.5 (8)	75 (6)
Special diet	52.4 (11)	53.8 (7)	50 (4)
Losing weight	47.6 (10)	53.8 (7)	37.5 (3)