



Facilitators and Barriers to Type 2 Diabetes Self-Management Among Rural African American Adults

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## Facilitators and Barriers to Type 2 Diabetes Self-Management Among Rural African American Adults

### Abstract

**Purpose:** The purpose of this study was to identify facilitators and barriers to self-management of type 2 diabetes mellitus (T2DM) among African American adults living in rural communities. Research indicates that African Americans experience higher rates of T2DM and diabetes-related complications than other ethnic groups. In Kentucky, diabetes is now the fourth leading cause of death by disease among African Americans.

**Methods:** Twenty-two African American adults with T2DM were recruited from three churches in rural communities in Kentucky. Three focus groups were conducted to identify factors that made managing diabetes easier (facilitators) and factors that made managing diabetes more difficult (barriers). Demographic data were collected using a 15-item survey, focused on the participants' personal, social and medical history related to T2DM.

**Results:** Support was the primary facilitator of self-management. Support from family, friends, and health care providers which encouraged them to seek information and adhere to diet and medications helped with management. Identified barriers to self-management included fear, perceived beliefs about their health status, and difficulty making lifestyle changes.

**Discussion and Conclusion:** T2DM is a serious health problem in the African American population. Interventions should be designed that focus on providing support for African Americans with T2DM. Additionally, interventions should focus on overcoming the identified barriers to assist them in taking control and feeling empowered to effectively self-manage T2DM.

### Keywords

diabetes; self-care management; rural; health disparities

### Cover Page Footnote

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## **Facilitators and Barriers to Type 2 Diabetes Self-Management Among Rural African American Adults**

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### **ABSTRACT**

**Purpose:** The purpose of this study was to identify facilitators and barriers to self-management of type 2 diabetes mellitus (T2DM) among African American adults living in rural communities. Research indicates that African Americans experience higher rates of T2DM and diabetes-related complications than other ethnic groups. In Kentucky, diabetes is now the fourth leading cause of death by disease among African Americans.

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### **INTRODUCTION**

The Centers for Disease Control and Prevention ([CDC], 2011) defined diabetes as a disorder in which the body's cells do not use insulin properly. The hormone insulin is needed by the body for metabolism of carbohydrates, fats, and proteins. Type 2 diabetes mellitus (T2DM) results from both insulin resistance at the cellular level and a relative insulin deficiency. As the need for insulin increases due to insulin resistance, the ability of the pancreas to meet the demand diminishes resulting in an insulin deficiency (Chlebowy & Wagner, 2005). The primary risk factors for T2DM include: over the age of 45, being overweight and above-normal body

weight, having a body mass index of 25 to 29.9, physical inactivity, and having a family history of diabetes (American Diabetes Association [ADA], 2015a). It has been estimated that 29.1 million people or 9.3% of the U.S. population have diabetes (CDC, 2014). Diabetes is the 7th leading cause of death in the United States (CDC, 2014). Research indicates that African Americans experience higher rates of T2DM and its complications as compared to other ethnic groups (CDC, 2014; Office of Minority Health, 2013). The incidence of T2DM continues to rise in African Americans. In addition, African Americans experience a higher rate of diabetes-related complications (e.g., kidney disease, blindness, and amputations) than other ethnic groups (ADA, 2014). Many of these complications are preventable with appropriate diabetes self-management and blood glucose control. Reducing glycosylated hemoglobin levels can lead to a reduction in diabetes-related complications or slow the progression of complications in persons with T2DM (ADA, 2015b).

Incorporating diabetes self-management techniques into an individual's lifestyle in order to achieve consistent blood glucose control may prevent complications; however, this may add to the complexity of their treatment, reduce quality of life, and in some cases be life-threatening. The American Association of Diabetes Educators (2007) stated that seven self-care behaviors can be used as measurable outcomes of effective diabetes education. These self-care behaviors include: being physically active; eating healthy foods; taking prescribed medications; monitoring blood glucose, weight, and blood pressure; problem solving when glucose levels are high or low; reducing diabetes complications risks; and practicing healthy coping. Self-management of diabetes required for effective glycemic control includes a regimen that is both complex and time consuming. Patients are instructed to follow a daily exercise program, follow a prescribed diet, take prescribed oral and/or injectable medications to reduce blood glucose levels, and perform self-blood glucose monitoring (Leeman, Skelly, Burns, Carlson, & Soward, 2008). Adherence to the self-management program requires motivation and commitment for long-term success.

The performance of self-management is an important component of maintaining health for individuals with diabetes (Sklyer et al., 2009). Participating in self-management of diabetes has been associated with improved glycemic control and may prevent diabetes-related complications, hospitalizations, and mortality (Sklyer et al., 2009). Identifying those factors which create barriers or facilitate self-management of diabetes is beneficial in developing strategies that empower individuals to better care for themselves. A number of studies have looked at barriers and facilitators of self-management of diabetes in the African American population in both urban and rural settings (Chlebowy, Hood, & LaJoie, 2010; Utz et al., 2006). Utz, et al. identified cost of treatment, the complexity of the regimens, and the unremitting nature of the disease as some of the barriers to self-management in one rural setting.

The purpose of this study was to identify facilitators and barriers to self-management of T2DM among African American adults living in a rural mid-southern community. While there are studies (Chlebowy et al., 2010; Utz, et al., 2006) that have identified barriers and facilitators in rural and urban settings, this study gives the opportunity to determine if identified barriers and facilitators are consistent across other rural settings. Identification of the facilitators and barriers to self-management of T2DM may aid health care providers in assisting this population with self-management regimens specific to their culture and needs. This study may provide health care providers and nurse researchers with information that is useful when designing interventions to improve the health status of this at-risk population and help reduce health disparities.

## **METHODS**

### Sample and Setting

Focus groups were held in rural African American churches in the southeastern United States. The convenience sample consisted of 22 participants. Participants were either members of the church or recruited by members of the church for participation. Inclusion criteria for participation were: (1) 18 years of age or older; (2) report being African American; (3) diagnosed with T2DM; and (4) English speaking. The sample was composed of 9 men and 13 women ranging in age from 41 to 78 years, with a mean age of 60 years (SD = 12.05).

### Methods

This study was a replication study of a larger study that was conducted in an urban setting using a similar population and similar questions (Chlebowy et al., 2010). The members of the research team conducted the focus groups. The participants openly shared their thoughts and feelings about barriers and facilitators to managing diabetes. While the researchers were not the same race/culture as the respondents, the participants were very comfortable discussing their disease management with the research team. Key individuals from each community assisted in organizing the focus group sessions which provided entre for the research team. Institutional Review Board approval was obtained from Murray State University. Focus groups were held in churches which provided convenient, non-threatening environments for the participants. Before each focus group started, the researchers explained the study and participants were reminded that participation in the study was strictly voluntary and that they may withdraw at any time. The researchers read the consent form and demographic survey to the participants. Participants were given the opportunity to ask questions while completing the consent forms and demographic questionnaires.

Interview questions were specific to the study objectives and developed to obtain information about facilitators and barriers to self-management of T2DM (see Table 1). The interview questions used in this study were the same questions used by Chlebowy et al. (2010) in a previous study that identified facilitators and barriers to self-management of T2DM among urban African American adults. The study design remained true to phenomenological method as data collection and analysis occurred simultaneously. Three focus groups were conducted at separate sites and separate times. Each focus group lasted between 60 to 120 minutes and was facilitated by the nurse researchers. All interactions were audiotaped, transcribed and analyzed by the researchers.

**Table 1.** Focus Group Session Questions

<p>Briefly introduce yourself. Tell us a little bit about your diabetes (e.g., how long you've had it and how it is treated).</p> <p>Does anyone regularly help you with your diabetes management? If so, explain the role of this person in helping you manage your diabetes.</p> <p>What has been most helpful to you in managing your diabetes?</p> <p>What has been most difficult for you in managing your diabetes?</p> <p>What parts of your diabetes management have been the easiest for you? Tell us why.</p> <p>What parts of your diabetes management have been most difficult for you? Tell us why.</p> <p>Can you remember a specific time when it was difficult for you to manage your diabetes? What made this situation so difficult?</p> <p>If you could go back to the day you were diagnosed with type 2 diabetes, would you now do anything different in managing your diabetes?</p> <p>Chlebowy et al. (2010)</p>
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Participants in this study completed a 15-item questionnaire to collect demographic data such as: age, gender, marital status, educational background, monthly income, and type of health insurance coverage. Medical history questions were included pertaining to duration of T2DM, pharmacologic management of diabetes, and history of other chronic illnesses. The demographic data were analyzed using frequencies and means to describe the study sample.

#### Data Analysis

The demographic data were analyzed using SPSS software and means and frequencies were calculated. Following each focus group, one of the researchers transcribed the audiotapes and the research team examined the data, continually writing, rewriting, reading and re-reading the transcripts. Two researchers coded the transcripts independently and developed a list of themes. A thematic analysis was conducted through constant review and comparison of transcripts. The transcripts were then reviewed by members of the research team and additional themes were added and categorized in consultations with the team. Transcripts of the focus groups were analyzed for repeating/enduring patterns, essential structures and emergence of a synthesis of unity. The researchers dwelled with the data in order to gain a full understanding of what the data meant. The coding was compared and discussed for consistency and to minimize any biases. This process enhanced credibility of the study findings.

## **RESULTS**

Seventeen percent of the participants were single, 56% married, 13% divorced, and 8% widowed. Fifty-six percent of the participants had some college education and only one participant did not complete high school. Eighty-seven percent of the participants were covered under medical insurance. Seventy-three percent reported having a family history of diabetes. Fifty-two percent of the participants reported having diabetes for greater than 10 years. During

the focus group sessions the participants openly communicated, were enthusiastic, and everyone shared their ideas and thoughts. The participants welcomed the members of the research team into the church and a meal was provided.

### Facilitators

Facilitators included family support, health care support, support groups and friends.

*Family Support.* Participants repeatedly discussed how family support was an important part of managing their diabetes. Some family supporters mentioned by participants included: spouses, children and other family members who have diabetes. Participants stated that these people helped them with a variety of management techniques such as preparing meals, serving as a reminder to check their blood sugar or performing blood glucose checks for them. One participant stated,

*I think a lot is people don't know and understand..... Like I said my aunts were a big help to me. They were a big help. I could call them and say hey, what do I need to eat to bring it down? What do I need to eat? That support helps.*

Another participant also discussed how family members often reminded them to take their medications, went to the doctor and helped with meals.

*My mother does, um she regularly set me up appointments to go the endocrinologist and um makes sure she checks what I eat and stuff like that.*

*Health Care Support.* Participants reported that health care providers facilitated their self-management by giving them information and direction. However, participants also talked about situations in which they did not feel comfortable confessing to health care providers when they had not followed their plan of care as prescribed. One participant stated,

*Then my doctor. I go see him on a regular basis, every 6 months unless something flares up. He and I we have good conversations, that's how I have kept up. Then if I have to be in his office or if I am somewhere and see materials dealing with diabetes I will pick it up and see where I fit.*

Another participant stated,

*That, you know having somebody to talk to and say hey you know have I messed up today because you don't want to call you doctor or nurse and say I did this or I did that you know and have somebody there that may have been through it and they can help you (you know) get through it.*

*Support Groups and Friends.* Support groups were identified as a common facilitator to self-management of T2DM. Participants talked about the need for more support groups to share ways to manage and cope with their diabetes. One participant stated,

*We probably need more support groups, you know we need just as many of us are here in church to start our own exercise program uh we can come together to talk about our food and help each other. So, I think more support would help.*

Another participant stated,

*One of the things that helps out the most is to have a support group where you can share what your mistakes are and you're getting information on how to correct those mistakes.*

### Barriers

*Lack of Self-Control Related to Food and Diet.* Participants spent a significant amount of time discussing food and dietary issues as barriers to self-care. Participants voiced frustration with dietary restrictions imposed by diabetes. They continuously discussed how they enjoyed food and felt that they had little or no self-control when it came to dietary choices. One participant stated,

*You know it's really hard though, it's like the pastor said over here, when you love food...I love to eat. Oh, I'm just as happy when I'm eating, I tell you, oh man! [Laughter] I am so happy when I eat...I'm serious. Did you know somebody that is so happy when they eat? I'm just telling the truth. I love to eat.*

In regards to dietary issues, another participant stated,

*I kinda joke and say that I wish I could have anything else besides diabetes. I enjoy eating. Uh, I enjoy, I think I'm like you, I'd rather have a slice cake [Laughter] instead of uh a whole meal but every now and then I may have a pain here or there but I think that has more to do with getting older than anything else but I live with it. I don't take care of my diabetes as the best that I know that I can. Sometimes I go in spurts. I may go a full month and do real well and I am so excited that I've done so well for the month that I treat myself and before I know it I'm off into exactly where I was. But I live with it and thus far, things are decent but not where they should be.*

Participants repeatedly talked about not buying certain types of food or having tempting foods in the house because they would have no self-control and eat all of it. One participant stated,

*Especially after you get to a certain age and you have been so accustomed to regular eating habits and someone tell you you can't have your pig meat, you can't have a lot of macaroni and cheese and you have been used to eating that you don't want to hear about that you can't have this you know...I haven't changed any of my eating habits; I just try to eat a little less of what I really enjoy.*

Another participant described not purchasing certain foods because of lack of self-control.

*You know I was talking to my dietician the other day, of course I just got one. And uh she was telling me how to eat in small portions and you know you can have 1 piece of bacon and I said no, I ain't gonna do that. You mean I gonna cook some bacon and have just one little slice? Uh uh. That's what I get for not even fooling with it... I don't even buy bacon... I know that I ain't supposed to have no cookies, so I don't buy em. Cause if I buy some cookies I don't know how nobody can sit there and eat one or two cookies. I'm not that well...I can't do that. So I just leave the cookies alone.... I tried to eat 2 potato chips and I said how can somebody just open the bag*



*up...but I have seen em do it cause I got a niece she'll do that. Open a bag of chips up and eat 2 and just wrap it up. I ain't that powerful.*

*Confusion and Forgetting.* Participants noted that confusion and forgetfulness were barriers to self-management of diabetes. Participants stated that they often were confused about exactly how to manage their diabetes. Participants stated that they became confused about the types of foods that they should eat and how much. They often forgot to check their blood sugar or take their medications. One participant stated,

*No, sometimes I get confused about exactly, I think that if I had a planned diet what I can and cannot eat, breakfast, lunch, dinner, snacks, I'd be okay. But since I have to figure out myself, it doesn't do to good because I know I end up eating foods that I shouldn't but anyway*

In regards to blood glucose monitoring, a participant stated,

*I get up early in the morning, I forget to take it, and maybe about 10:00 I take it, if I haven't eaten.*

In regards to medication adherence, a participant stated,

*Scheduling for me. I can forget to take the pill and sometimes I mess around and take it twice.*

*Inconvenience.* Participants repeatedly stated that diabetes was an inconvenience. Many stated that it was hard to self-manage T2DM and continuously think about having to take medications or watch what they ate. They felt that having diabetes interfered with their social life. Several participants stated that they hated checking their blood sugar. As one participant stated,

*I think it's most difficult not to get distracted after your meals and before meals to remember to take your pill or insulin injections whichever you take. I think that is most difficult to have it on your mind with 30 different things going on especially if it's a party and you're at someone's house and it's a get together or something. It becomes a hassle and an obstacle to overcome. Especially if you socialize in other places like that, it slips your mind. I think that is difficult trying to flip how you think, have it always on your head all the time, especially when there are other things going on.*

*Fear.* Participants also mentioned that they had fear of needles, fear of being on insulin and fear of the complication of diabetes such as blindness. One participant stated,

*I hate checking my sugar. [Another participant: I hate it too.] I hate it....It's just the idea of sticking myself every day, 2 and 3 times a day. That hurts, so I don't check it.*

*I don't take my sugar like I'm supposed to, I'm supposed to take it 3 or 4 times a day, I don't do that because when it's high, it'll worry me.*

*Self-Perception.* As one participant stated, “*I just go by the way I feel*”. Participants’ self-perception centered on thoughts such as... “*I’m okay if I feel okay,*” and managed diabetes by the way they felt that day. They felt that weight loss was bad. Participant stated that they were not going to “worry” about “it,” God would take care of them. One participant stated,

*And I still watch what I eat sometimes but I ain’t gonna lie, I don’t do it all the time. And I ask God to protect me and He does, He takes care of His children and I ain’t young, so. But um, I made it to 71 years old and I’ve had it a long time. So, it’s just how you feel, how your body feels, you know your body better than anybody else. Better than a doctor. So, I don’t watch it all the time, I fly by night.*

Another participant shared as long as they feel fine everything is okay.

*As long as I am feeling fine, all is well. I think that is why a lot of people don’t realize that they are diabetic.*

In regards to weight loss, one participant stated,

*I looked sick, people would say, ‘What’s the matter with you? What are you losing so much weight for?’ So, the most difficult for me is to follow that regimen of eating for the fact that I need some weight on me, it make me look a particular way.*

One participant shared that fear helps them manage their diabetes.

*The things that helps me more than anything else is fear....Yeah, I’m aware of what side effects can be and when I think about them the main thing that bothers me is like uh one of the side effects is blindness and uh then there’s the side effect of having wounds that won’t heal and when I think about those things that has more effect than anything.*

## **DISCUSSION**

In this study, rural African American men and women discussed facilitators and barriers to managing their disease. Overall, support was the primary theme that emerged from the participants’ discussions. Participants stated the main facilitator to self-management of their diabetes was support from family members and friends. Family support was seen through a variety of behaviors and interactions including reminders to take medication, assistance with meal preparation, encouraging them to make healthy choices such as participating in physical activity, and monitoring their diet. The encouragement and support provided by their family members helped participants to make necessary behavior modifications to better manage T2DM. Many of the participants remarked that they had difficulty adhering to healthy eating and felt that family members encouraged them to make healthy choices. This finding has been supported by research conducted by Chlebowy et al. (2010) in an urban setting and is consistent with findings of Tang, Brown, Funnell, & Anderson (2008). This finding is in contrast, however, to a recent study conducted in Sri Lanka which found that participants felt that they had to eat what their family liked to eat and they were not able to follow their prescribed nutritional plans (Amarasekara, Fongkaew, Wimalasekera, Turale, & Chanprasit, 2015). In a seminal study conducted by Fisher et al. (1998), findings revealed that the family has the greatest, most

influence, and most long lasting effect on the management of T2DM. Family support is an important facilitator of self-management of T2DM in rural African Americans. In the current study, family and friends helped participants to make healthy food choices and decisions regarding diabetes management and were identified as the major source of support for the participant.

In addition to family support, participants identified social support groups and support from health care providers as facilitators to diabetes management. Participants identified the need for more support groups to help in managing and coping with their diabetes. One group discussed the difficulty with physical activity and felt that a group physical activity program in the church would be beneficial as a means of support to become involved in an exercise program. Participants reported that health care providers were facilitators by providing them with information and direction. However, they did not always feel comfortable telling the health care provider when they had not followed their plan of care. As a result they were more comfortable seeking information from the family/social support system. The findings from this study are consistent with previous studies that identified family, friends and peers as major facilitators of self-management (Chlebowy et al., 2010; Tang et al., 2008; Utz, et al. 2006).

Several barriers to self-management emerged from this study. These barriers included lack of self-control related to food and dietary choices, confusion and forgetting, and the inconvenience of diabetes self-management. Lack of self-control was identified as a barrier to self-management as participants repeatedly talked about not buying certain types of food or having tempting foods in the house because they would have no self-control and eat all of it. They mentioned that family members often helped them to refrain from eating foods not included in their dietary regime. Fear was also discussed as an aggregate barrier. The participants stated that they had fear of needles, fear of being on insulin, and fear of the complications of diabetes such as blindness. However, while they expressed fear of complications that fear was not adequate to motivate them to be adherent to their therapeutic regimen.

The self-perception of the participants' health was a strong barrier that emerged from the focus group discussions. As one participant stated, "*I'm okay if I feel okay,*" and then managing T2DM, either choosing to take or not take their medication by the way they felt that day. This is consistent with the findings of Bhattacharya (2012) in which feeling good and happy were found to equate with being healthy.

Participants felt that weight loss was bad and equated with poor health and being unwell. Religion and belief in God was important to help with management of T2DM. Some participants stated that they were not going to worry about having diabetes and God would take care of them. Many participants felt if the blood sugar was under 200 mg/dL their T2DM was well-managed.

## CONCLUSION

This study supported that rural African Americans with T2DM struggle to manage the disease. They find it difficult to adhere to nutritional guidelines and medications. Participants voiced the belief that management of their disease was out of their control. Some participants believed that God would take care of them and that it was not necessary to worry about their diabetes. Fatalism has been associated with diabetes self-management in African Americans and the sense that the disease was outside their control (Edege & Bonadonna, 2003). Recognizing this mindset as a driving force in decisions related to adherence to self-management of diabetes is important in planning education programs designed to encourage self-management. Readiness

to engage in the lifestyle changes required to self-manage diabetes is critical to successful management of the disease.

This study also revealed the participants had an overall sense of collectivism. They believed that support groups in the community or church were helpful for self-management of their disease. Based on this reliance on their support system and faith, including support groups and family in interventions and educational activities may help the individual make better choices related to self-management. For some individuals, church-based support groups may be effective in encouraging and facilitating T2DM self-management. In contrast to other studies, access to health care or the inability to purchase medication or supplies needed to manage diabetes were not identified by the participants as barriers to diabetes self-management.

Health care providers must be knowledgeable and culturally sensitive to facilitators and barriers to self-management among African Americans with T2DM in order to recommend therapeutic regimens that will be accepted by the individuals. It is important to be cognizant of these facilitators and barriers to best assist them with T2DM self-management.

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