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Facilitators and Barriers to Self-management of Type 2 Diabetes Among Urban African American Adults

Focus Group Findings

Purpose

The purpose of this study was to identify facilitators and barriers to self-management of type 2 diabetes mellitus (T2DM) among urban African American adults.

Methods

Thirty-eight African American adults with T2DM were recruited from 1 of 3 health care agencies in a midsized city in the southeastern United States. Qualitative data were obtained using focus groups, wherein each participant engaged in a 60- to 90-minute audio-recorded session. Focus group data were transcribed and analyzed using Atlas ti 6[®] data analysis software. Demographic and medical history information was also collected.

Results

Factors relating to external locus of control primarily facilitated adherence to T2DM self-management behaviors. Support from family, peers, and health care providers positively influenced adherence behaviors by providing cues to action, direct assistance, reinforcement, and knowledge. Internal factors were primarily described as barriers to self-management behaviors and included fears associated with glucose monitoring, lack of self-control over dietary habits, memory failure, and perceived lack of personal control over diabetes.

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Conclusions

African Americans perceived external factors as facilitators of their T2DM management behaviors and internal factors as barriers to self-management. Further research is necessary to design and test interventions that capitalize on the external facilitators while helping African Americans to overcome perceived barriers identified in this study.

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In 2007, approximately 23.6 million persons in the United States (7.8% of the population) had type 1 diabetes mellitus or type 2 diabetes mellitus (T2DM),¹ with 90% to 95% of the cases being T2DM.² T2DM is associated with relative insulin deficiency and/or insulin resistance rather than a total deficit.³ African Americans are disproportionately affected by diabetes: 14.7% of all African Americans are living with diabetes, compared with 9.8% of their non-Hispanic white counterparts.⁴ Moreover, compared with other racial groups, African Americans experience higher rates of 4 diabetes-related complications: blindness, kidney disease, amputations, and cardiovascular disease.⁵ There is a growing concern among health care providers about the rising prevalence of diabetes-related complications among African Americans. Despite medical advances and available health care, African Americans continue to experience preventable life-threatening diabetes-related complications. There is a definite need to better understand the underlying mechanisms for this health disparity. This study examines facilitators and barriers to T2DM self-management.

T2DM is a complex disease to manage, with most of the care involving self-management. The current literature suggests that African Americans are significantly less adherent to self-management recommendations than non-Hispanic whites, possibly accounting for increased complications and mortality rates among this population.^{6,7} Shenolikar et al⁶ found that African Americans with T2DM had significantly lower medication adherence and significantly fewer prescription refills than non-Hispanic whites. Similarly, African Americans exhibited a lower intensity self-monitoring of blood glucose during a study's 5-year follow-up than did non-Hispanic whites.⁷

Several studies have found that culture influences T2DM self-management behaviors in ethnic minority

populations.^{8,9} In studying the beliefs and experiences of African Americans, American Indians, and Hispanic/Latino and Hmong adults with diabetes, Devlin et al⁸ found that study participants expressed major concerns about their loss of health, the loss of community health, and their mistrust of and lack of confidence in the medical system. African American and Hispanic/Latino participants specifically identified that belief in God was a source of strength and an important resource for diabetes management.⁸

Another source of variation in self-management is fatalism. Powe and Weinrich¹⁰ defined fatalism as a complex psychological cycle characterized by perceptions of powerlessness, hopelessness, and despair. Egede and Bonadonna⁹ found that fatalism was negatively associated with self-management among African American adults with T2DM. Participants indicated that diabetes is uncontrollable, that the disease is an inevitable generational fate, and that the disease is a death sentence.⁹

In addition, some studies have discussed the barriers to self-management among African American adults with T2DM.¹¹⁻¹³ El-Kebbi et al¹¹ found that lack of family support, family pressure, expense of food, and lack of taste of low-fat and sugar-free foods were barriers to dietary adherence among urban African Americans with diabetes. El-Kebbi et al¹¹ also found that adult participants had difficulty following the diabetes diet and analyzing food labels. In another study, African American women indicated that the unrealistic weight goals set by health care providers and the lack of provider empathy concerning their fear of diabetes complications were major barriers to their diabetes self-management.¹² African American women with T2DM were motivated to prevent diabetes-related complications but felt that a lack of knowledge about the importance of screening for diabetes-related complications and the importance of foot care were major barriers to their diabetes self-management.¹² Lack of motivation, cultural traditions, lack of affordable and accessible restaurants and stores, and accessible recreational facilities have also been identified as barriers to adapting health behavior regimens for African Americans with diabetes.¹³ Costs of medications and supplies, living with diabetes every day, managing other chronic conditions, complexity of diabetes management, sleeping problems due to blood glucose fluctuations, and stress were barriers identified by African American adults living in a rural community.¹⁴ Chlebowy and Garvin¹⁵ suggested that although African Americans experience higher rates

of diabetes-related complications than non-Hispanic whites do, the difference may possibly be due to other factors such as financial barriers, heredity, or inadequate health care.

In determining factors to consider in planning a diabetes education program, Blanchard et al¹⁶ found that African Americans identified a sense of personal powerlessness and a fear of diabetes-related complications when discussing diabetes management with their health care providers. Similarly, Anderson et al¹⁷ conducted focus group research and found that urban African American adults with diabetes discussed the need to learn more about diabetes and diabetes-related complications and how to more effectively interact with health care providers. The importance of diet in African American culture and the need for support in managing diabetes-related psychosocial issues were also identified as issues of significance to the study participants.¹⁷ Similarly, knowledge, psychosocial support, and religious practices were identified as facilitators to self-management among African Americans living in a rural community.¹⁴

There are few published studies that have addressed the facilitators and barriers to self-management among African American adults with T2DM. Identifying these facilitators and barriers will yield new knowledge relevant to self-care management among this population. An understanding of these facilitators and barriers will help in the design of tailored interventions to improve the lives of African Americans living with T2DM.

Like others with T2DM, African Americans are presented with the challenges of managing health behavior regimens to prevent or minimize diabetes-related complications. Self-management regimens include (1) engaging in daily physical activity, (2) following a prescribed diet, (3) administering oral medications and/or insulin, (4) performing blood glucose monitoring, and (5) managing daily stressors and life events. Health care providers must find ways to help individuals adapt to health behavior regimens in an effort to prevent life-threatening diabetes-related complications. Understanding the facilitators and barriers to self-management is essential in helping African Americans to adapt to these health behavior regimens.

Study Purpose

The purpose of this study was to identify facilitators and barriers to self-management of T2DM among African

American adults living in an urban community in the southeastern United States. In this study, a facilitator was operationally defined as any situational or personal factor identified by the study participant that assists with adhering to the diabetes health behavior regimen. A barrier was any situational or personal factor identified by the study participant that acts as an obstacle or difficulty in adhering to the diabetes health behavior regimen. The study addressed the following question: What are the facilitators and barriers to self-management among urban African American adults with T2DM?

Research Design and Methods

Sample and Setting

The sample consisted of 38 voluntary participants receiving care at 1 of 3 health care agencies in a midsized city in the southeastern United States. Inclusion criteria for participation were (1) 18 years of age or older, (2) African American, (3) diagnosed with T2DM, and (4) English speaking. The sample was composed of 27 women and 11 men ranging in age from 44 to 87 years, with a mean age of 66 years (SD, 11.93). Thirty-three percent of participants were widowed, and 20% were married. The sample was educated, with 82% having a high school education or above, although 18% had some high school education or less. Most participants (89%) reported having insurance coverage. The duration of T2DM among participants ranged from less than 1 year to more than 25 years, with a mean of 10 years (SD, 7.91). Most participants (89%) reported taking medications for diabetes management, with 40% taking oral agents only, 20% taking insulin only, and 29% taking oral agents and insulin.

Instrumentation

A mixed method approach was used in this study. Quantitative data were obtained using a 10-item survey to obtain demographic and medical history information. Demographic data collected included information such as sex, age, marital status, educational background, monthly income, and type of health insurance. Medical history data included information such as duration of T2DM, pharmacologic management of diabetes, and history of other chronic illnesses.

In obtaining qualitative, descriptive data, focus group sessions were employed to identify facilitators and

Table 1

Focus Group Session Questions

Briefly introduce yourself. Tell us a little bit about your diabetes, eg, how long you've had it and how it is treated.

Does anyone regularly help you with your diabetes management? If so, explain the role of this person in helping you manage your diabetes.

What has been most helpful to you in managing your diabetes?

What has been most difficult for you in managing your diabetes?

What parts of your diabetes management have been the easiest for you? Tell us why.

What parts of your diabetes management have been most difficult for you? Tell us why.

Can you remember a specific time when it was difficult for you to manage your diabetes? What made this situation so difficult?

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?

barriers to self-management of T2DM among participants. The focus group research design provided the opportunity for the researchers to examine the points of view of participants as they shared their concerns and opinions.¹⁸ Focus group interviews provide rich in-depth information that can help researchers clarify the multiple dimensions of complex phenomena.¹⁹

Procedure

After receiving approval from the Institutional Review Board at the University of Louisville, study personnel recruited potential participants by asking them if they had T2DM.

Through face-to-face contact, study personnel explained the study and its voluntary nature, as well as the responsibilities of the study participants. Informed consent was obtained from all participants. The study personnel read the consent form and demographic survey to the study participant if the participant was unable to adequately read English. The study personnel were not the participants' health care providers; therefore, there was no potential for coercion, although each participant was compensated with a \$25 gift card to a local retailer upon completion of involvement in the study.

Questions specific to identifying the facilitators and barriers to self-management of T2DM were asked during the focus group discussions by an experienced focus group facilitator (see Table 1). Each of the 7 focus groups was composed of between 3 and 6 participants. Three focus groups were conducted with male participants, and 4 focus groups were conducted with female participants. Each focus group lasted between 60 and 90 minutes and

was facilitated by the principal investigator. All discussions were audio recorded, and a trained observer was present at each of the focus group discussions. The observer took detailed written field notes during the focus group sessions, noting characteristics such as participants' body posturing, tone of language, and facial expressions. Trained study personnel listened to each audio-recorded focus group discussion and transcribed each discussion into text format. Participant confidentiality was ensured with the assignment of unique identifier codes in place of names.

Data Analysis

Quantitative data collected in this study from the demographic survey were analyzed using SPSS (version 17.0, Chicago, Illinois)²⁰ software. Data were analyzed using descriptive statistics and reported as means (\pm SD) for continuous variables and proportion and frequency for categorical variables. Chi-square analyses were performed on categorical data, and *t* tests were used to analyze continuous data.

For the qualitative analyses, content analysis was used to assign codes to passages in the transcribed text.²¹ The text was uploaded into qualitative data analysis software (Atlas Ti[®], version 6, Berlin, Germany),²² and codes were assigned to each text passage using open coding. The codes *barrier*, *adherence*, and *medication* were simultaneously entered in a search to locate quotes that described barriers to medication adherence. The *barrier* and *adherence* codes were also simultaneously entered in separate searches with the *diet/nutrition* and *physical activity* codes to assess perceived barriers to nutrition and

physical activity recommendations. Similarly, the *facilitator* and *adherence* codes were simultaneously entered in separate searches with *medication*, *diet/nutrition*, and *physical activity* to locate text that discussed facilitators to adherence to medication, diet, and physical activity recommendations. Variables identified as barriers and facilitators to adherence were then categorized as being *internal factors* or *external factors*.²³ Deci and Ryan²³ called these autonomous factors (vs controlled factors), indicating the degree to which participants perceived to have volitional control over the variable. Internal factors were perceived as being under the control of the individual, while external factors were controlled by sources other than the individual (eg, social or environmental influences).²³

Results

Participants' perceived control was found to be associated with their adherence to T2DM self-management behaviors. External factors primarily were seen by participants as facilitators to T2DM adherence behaviors in African Americans (see Figure 1). Specifically, support from family, peers, and health care providers influenced adherence behaviors by providing cues to action, direct assistance, reinforcement, and knowledge. In contrast, internal factors were primarily described as barriers to adherence (see Figure 2). These variables included participants' fears associated with glucose monitoring, lack of control over dietary habits, memory failure, and perceived lack of control over diabetes. Knowledge was described as being influenced both by internal and external factors.

Participants in this study described health care providers as being an information source, thereby increasing knowledge but not reinforcement or encouragement. Participants indicated that their diabetes peers were a major source of reinforcement for self-management behaviors.

Perceived Facilitators

Family support. Participants' statements indicated that family support was a critical aspect of their T2DM self-management. In particular, participants discussed receiving support from female family members. Family support primarily served as a facilitator to medication self-management. Participants often discussed how family members provided direct assistance in administering medications, as well as providing cues to action to prompt participants to take their medications.

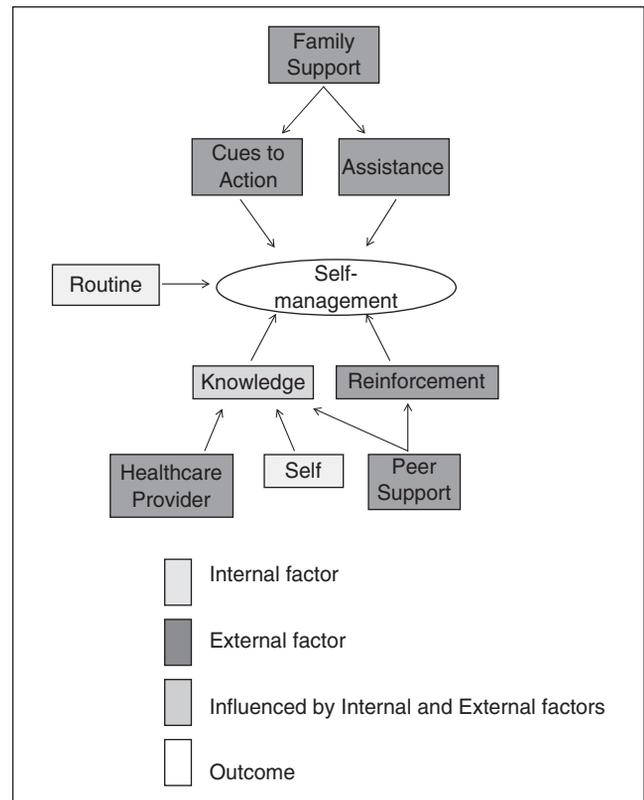


Figure 1. Facilitators to self-management.

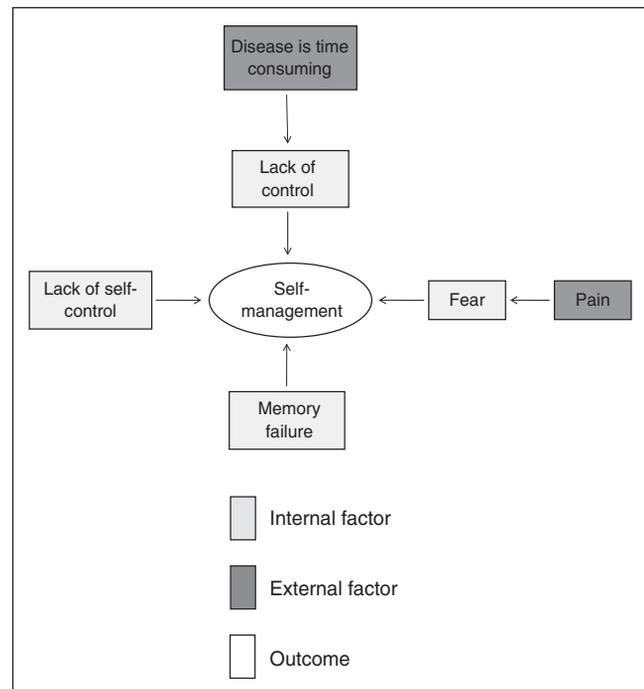


Figure 2. Barriers to self-management.

Male: My wife . . . she gives me my shots in my stomach and helps me to take my medicine.

Female: My daughter she helps me . . . she's got my watch going off at different hours telling me when to take this medicine so, she's got me set up right to take the medicine.

Routine. The presence of a daily routine or schedule was also identified as a facilitator to T2DM. Routines were primarily described as being a facilitator to glucose monitoring. Having a daily schedule promoted regular glucose monitoring among the participants and allowed them to be more aware of their glucose levels throughout the day.

Male: I wouldn't say it's easy but it has gotten routine. First thing I do when I wake up in the morning is taking my blood sugar. It's just routine, [but] it's not easy.

Female: I check my diabetes every day. I make sure with the grace of God so I check it every day 2 or 3 times.

Knowledge. Participants reported that they gained knowledge about diabetes self-management through self-information seeking, health care providers, and their diabetes peers. Participants emphasized the importance of having general knowledge about T2DM as well as knowing how to manage the disease. Knowledge was associated with participants' perceived self-efficacy to manage their T2DM. Increased knowledge corresponded to better disease management.

Male: Once you begin to gain knowledge of what you are dealing with it makes it a little bit easier.

Female: You try to deal with it but you deal with it [within] reason because nobody is perfect. You try to do the best that you can and when you know better you do better.

Peer support. Peer support was a common theme among the focus group participants. Participants described peer support groups as an opportunity to share information and gain knowledge. In addition, participants expressed a desire for the presence of peer support groups to assist them in coping with diabetes.

Male: But a person just being diagnosed with the disease . . . it's like you don't have nowhere to go but to the family doctor, and he can only do so much. If I could go back that far, I'd investigate and see if there was support groups for diabetics.

Female: I think a buddy system is very good. . . . I have very important people that I call and talk to every day, a daily thing, and I'm finding out that more people are diabetic.

Peer support was also described as a reinforcement of recommended self-management behaviors, such as regularly engaging in physical activity. Participants indicated it was difficult to engage in physical activity alone and that going to the gym with a group made the task easier.

Male: It's hard to exercise by yourself. My basement looks like a gym; I don't exercise down there. I had to get with a group that's going to the gym and working out. . . . Somebody to encourage one another, that's what been beneficial to me.

Perceived Barriers

Time consumption. Participants expressed concern about being overwhelmed by the time-consuming nature of T2DM. They stated that the time consumed by T2DM management was often frustrating. This may have contributed to their inability to effectively self-manage their T2DM. Participants indicated that it was difficult to maintain daily or leisure activities and regularly practice T2DM self-management behaviors. Participants also indicated that the amount of time needed to manage T2DM caused the disease to control their entire day.

Male: You really have to change your lifestyle and some things that you love to do or like to do, uh, you just can't do it anymore. If you like to go to Churchill Downs when they are here, or if you like to go to church or Bible study some times, there's just not enough hours it seems, to have diabetes and stick yourself and take your medications the way you are supposed to, and do it all.

Female: But I'm gonna tell ya for about every 15 minutes out of the hour your diabetes has your time. . . . At least. . . . Every 15 if not more. It's the time for you to take your medicine, it's the time for you to eat, whether you want to or not . . . you don't have to be hungry, but if you take certain medications they'll make you sick as hell if you don't eat. So I'm still saying at least 15 minutes out of every hour I have to do something for my diabetes.

Lack of self-control. Lack of self-control was identified as a barrier to T2DM self-management. Participants specifically noted that it was difficult to follow T2DM dietary recommendations when food was present in a

social context, such as holiday celebrations or family gatherings.

Female: Sometimes you can make your own self sick, you know you ain't supposed to have that mess and you eat it anyways . . . especially holidays.

Male: Staying away from the foods that I love, staying away from that fried food. . . . Yes that's what hurt me so bad. I go over to my baby sister's and they have so much food. They have everything you want.

Pain. The pain associated with blood glucose monitoring was described as a barrier to self-management. Participants indicated that they monitored infrequently to avoid sore fingers. Several participants reported that they tested their glucose levels only when they experienced symptoms of their T2DM, such as dizziness and shakiness.

Male: I hate to prick my finger . . . I think that's why I don't test my blood sugar like I should and I know that but it's because of the pain.

Female: I'm a big sissy about pricking my finger . . . I still don't stick myself.

Memory failure. Several participants expressed that they sometimes failed to take their medicine or test their glucose levels regularly because they were forgetful. Participants also indicated that they forgot to eat regularly and would not remember until experiencing T2DM symptoms. Participants' lack of memory was commonly associated with the difficulty of remembering to manage their diabetes in the midst of other daily activities.

Male: I think one of the difficulties is when you first start using your pills. . . . I forgot to take my pills. I got the morning, I just couldn't get the afternoon together cause I'm not always in a place to do it.

Female: Believe it or not I forget that I'm a diabetic, you know I forget to eat. I look at the clock my watch and go, oh my God, it's 2 o'clock and I ate a egg for breakfast . . . you know I'm still not real comfortably aware of the condition until I feel bad.

Discussion

Managing diabetes is time-consuming and burdensome for all persons. However, for many African Americans with T2DM, the burden is too great and their disease is poorly managed. The consequences of poor management include a disproportionate number of African

Americans suffering diabetes-related complications, including kidney disease, amputations, and cardiovascular disease. In this study, African American men and women discussed the factors that helped or limited their ability to self-manage T2DM.

The self-management of T2DM requires regular monitoring of blood glucose levels; participants in this study found it difficult to establish a routine schedule for doing so. Those who were successful mainly identified external prompting, either by peers and family or mechanical devices such as programmable watches, to remind them to adhere to monitoring. Yet even when monitoring was remembered, some participants stated that pain and/or fear of pain associated with glucose monitoring led them to not performing this necessary behavior.

Some participants found behavioral modifications difficult to make alone. One participant indicated that having his spouse perform the insulin injection made it much easier for him. Other participants expressed similar dislike of self-administering insulin injections. In addition, exercise was commonly mentioned by participants as being best done with a group or peer. At meal time, especially during special events, some stated a lack of personal willpower to skip the types of foods not allowed on their diets. The presence of a peer or family member who encouraged healthy eating motivated some respondents to adhere to their dietary regimens. This study's finding that social support is a critical influence of T2DM self-management is consistent with previous studies.²⁴⁻²⁹ Positive social support was associated with increased adherence to blood glucose monitoring, diet, and physical activity recommendations among African American adults with T2DM.²⁴ Lack of social support and social networks can negatively influence recommended self-care behaviors.

Considered in the aggregate, the responses of the 38 participants were not surprising. Many people, irrespective of age, race, or gender, have difficulty making the necessary behavioral modifications to effectively manage T2DM. What emerged in this study was that participants felt unable, or lacked the personal or internal control, to overcome the barriers to adhere to self-management protocols. For instance, participants expressed feeling overwhelmed by the amount of time needed to manage T2DM. They avoided inflicting pain upon themselves and felt apprehension at the thought of the pain. And without reminders, they found it difficult to remember the complex schedule of taking diabetes medications and

performing blood glucose monitoring. In previous studies,^{30,31} perceived control has also been associated with adherence to diabetes self-care behaviors; women who had a strong sense of control had better metabolic control than women who expressed a negative sense of control.³¹

For some participants, external factors did help with T2DM self-management. These factors included peer and family support for diet and exercise and mechanical aids such as programmable watches for keeping a schedule. Those who had external help reported less anxiety and feeling more in control of their self-management.

Information and knowledge were related to both internal and external factors. The participants' health care providers were seen as sources of information; however, the advice and input from diabetes peers was equally valued. Participants with information-seeking skills found the ability to gather information as empowering. For those without, the locus of control over their knowledge was external. Similar to previous findings,^{12,14} participants stated the presence of knowledgeable and trusted peers, family members, and health care providers as helpful for managing their T2DM. Absence of these supporters made it more difficult. Among this sample of African Americans, knowledgeable and trusted sources of information were said to be insufficient.

Implications

This study showed that African American adults with T2DM perceive many of the barriers to self-management to be outside of their personal control. Interventions should be tailored to offer these persons the necessary skills to ask for peer support, to seek out relevant knowledge and external support, and establish routine monitoring schedules. Interventions should include not only the person with T2DM but also the person's self-identified social support network. This social network should be educated about diabetes self-management and given the necessary tools to assist the person with T2DM to manage the complex, uncomfortable, and time-consuming regimens. Examples of these tools include information and resources needed to help the individual with T2DM self-manage glucose levels and medications, adhere to dietary and physical activity recommendations, and cope with the daily stressors associated with having a chronic disease. An educated member of the social network can help the individual with T2DM best manage the disease and overcome diabetes-related barriers as they arise.

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