Barriers to Self-management of Diabetes: A Qualitative Study among Low-income Minority Diabetics

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Objectives: Diabetes self-management is a key element in the overall management of diabetes. Identifying barriers to disease self-management is a critical step in achieving optimal health outcomes. Our goal was to explore patients' perceptions about barriers to self-management of diabetes that could possibly help explain poor health outcomes among minority patients.

Study Design: Four focus groups were conducted among 31 predominately African American patients with diabetes who were enrolled in the Baltimore Cardiovascular Partnership Study, a NIH-funded multiyear prospective partnership study. The topic guide consisted of a series of open-ended questions about knowledge of current health status, medication use, continuity of care, blood glucose level and nutrition.

Results: The focus groups confirmed that previously reported barriers to self-management persisted and identified new concerns that could be associated with poor health outcomes among minority patients with diabetes. Attitudes, perceptions and behaviors surrounding diabetes and self-management of the condition did vary across individuals, however, the variation appeared to reflect the individual's knowledge and opinions rather than patient's age, sex, or culture. The primary barrier to diabetes self-management resulted from lack of knowledge of target blood glucose and blood pressure. Several participants found some of the health information to be quite confusing.

Conclusions: Diabetes is a major public health concern and the lack of awareness of target blood glucose and blood pressure further complicates the problem. The limited health literacy seen in this study could help explain several of the barriers to self-management. The barriers to self-management identified in this qualitative study are amenable to intervention that could improve health outcomes. (*Ethn Dis.* 2011;21:27–32)

Key Words: Diabetes, Self-management, Barriers

INTRODUCTION

Diabetes is the fifth leading cause of death by disease in the United States.[1] The burden of diabetes disproportionately affects minorities. The prevalence of diabetes is about 11% in African Americans and 8% in Caucasians and is about twice as prevalent in African American females (14%) as in Caucasian (7%) females.[2] The incidence of type 2 diabetes is 4 times higher for African Americans than for non-Hispanic Whites.[3] Genetic and lifestyle factors, such as history of gestational diabetes, excessive food consumption and physical inactivity, are likely to account for the increased prevalence of type 2 diabetes among ethnic minorities.[4] Numerous studies have documented a higher prevalence of insulin resistance in minority groups after controlling for diabetes, obesity and lifestyle factors.[5–7] Socioeconomic factors such as income may also play a role in the increasing prevalence of diabetes and diabetes related complications.[4,8]

Socioeconomic status (SES) is a determinant of health and a significant contributor to health disparities.[9,10] Typically, SES is associated with poorer access to health care; however, healthcare access and utilization among diabetics is high.[11] Yet despite the high rates of healthcare access and utilization among diabetics, health status and outcomes seen in low income minorities is unsatisfactory.[12–14] One possible explanation for the poor health outcomes among patients with diabetes is poor self-management practices.[11,15–18] Poor adherence to standard diabetes care recommendations is associated with adverse outcomes in clinical practice.[13,14] Suboptimal adherence to standard diabetes care recommendations is frequently observed in patients who have poor communication with their provider, lack of understanding/knowledge of the disease, polytherapy, suboptimal self-monitoring of blood glucose and psychosocial factors such as depression.[14–24]

Suboptimal adherence, once viewed as a patient problem, is now seen as an indication of patients' self-management of chronic disease within the interactive framework of providers, healthcare systems, families and communities.[25] Within this framework, the dynamic interaction of patient, healthcare providers and systemic factors can influence the overall management of diabetes.[26] The care of patients with diabetes has largely encompassed new and more efficacious diabetic treatments and improved medication delivery systems,[27] but literature highlights the importance of integrating self-management education.[26,28–33] To adequately address barriers to diabetes self-management and identify strategies to overcome them, it is important to examine whether there are additional barriers that still exist.

The University of Maryland Baltimore (UMB), the research intensive medical center, partnered with the Bon Secours Baltimore Health System (BSBHS), the minority serving system, as part of a NIH-funded multi-year prospective study. The partnership was intended to offer a unique opportunity to investigate how a partnership be-

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tween BSBHS and UMB, supported by the community, can provide a platform to improve patient, physician and system adherence. The study enrolled primary care physicians and patients of these physicians. Patients were recruited from both clinics. Within each clinic, they were randomized to either patient education group or to the control group.

To underscore the collaborative partnership and the interactive learning between the two institutions, complementary disease areas were examined where UMB focused on hypertension and BSBHS focused on diabetes. As part of this partnership study, the overall objective of this research was to explore the patients' perceptions about barriers to self-management of diabetes from the target population. Several focus group interviews of the target population were conducted and this article presents the methodology and key findings of the four focus group sessions.

METHODS

This was a qualitative study conducted among 31 predominately African American patients with diabetes who were enrolled in the multiyear prospective partnership study. Each participant was told the purpose of the focus group and asked to complete an informed consent to allow the tape recording of the focus group.

The overall objective of this research was to explore the patients' perceptions about barriers to self-management of diabetes from the target population.

Study Sample

The sample for this analysis was restricted to patients enrolled in the U-01 grant described in the introduction. The sampling technique used purposive sampling for the selection of individuals in order to yield some information about barriers to the self-management of their diabetes. The sampling method allowed recruiting participants who were more likely to participate in a focus group session and who possessed characteristics relevant to the aim of the study. To reach the target sample quickly and since sampling for proportionality was not a concern, we sampled participants with a diagnosis of diabetes enrolled in the U-01 grant who were aged 50–90 years and who were more likely to be available during daytime hours. A purposive sample of 150 participants was selected and contacted from a list of patients in the diabetes section of the U-01 grant.

Data Collection

To meet the objectives of this research, four traditional interactive and focused discussions were conducted between December 2007 and April 2008 with a minimum of five people in each group. Each focus group followed a similar format. The focus groups were used to explore perceptions about barriers to self-management of diabetes from the target population and to aid in the development of a quantitative access to care questionnaire. A structured topic guide that consisted of a series of open ended questions was used to collect information about knowledge of current health status, medication use, continuity of care, blood glucose level and nutrition. These topics were selected after careful review of the literature on diabetes self-management. Appendix A contains the topic guide used in the study.

The focus group interviews were moderated by a diabetes nurse educator and a graduate student. Discussions were audiotaped and written notes were taken.

Analysis

From the tape recordings of the focus group interviews, the extensive conversations were transcribed verbatim within the relevant response topics. An independent assessment of the transcripts by another researcher was not conducted; however, notes taken by the moderator and by the assistant were compared.

RESULTS

From the purposive sample of 150 patients in the diabetes section of the U-01 grant, all participants were contacted by telephone. After a series of follow-up calls, a total of 31 patients, 23 intervention and 11 non-intervention, participated in the four focus groups. Several patients did not participate due to refusal, change of address/number disconnected, and not being home at the time of the phone call. Four focus groups were completed where intervention and non-intervention participants were mixed to allow different opinions or views. The majority of the participants were African American and females. The mean age of the participants was 74, with a range of 43–81 years. None of the patients participated in more than one group. The majority of the respondents felt comfortable enough during the 60-minute session to discuss their opinions openly while others only responded when asked.

Knowledge of Current Health Status

Participants' understanding and knowledge about diabetes came from various sources. For example, participants identified the Bon Secours Health System, TV/Radio, physician, insurance company, library, pamphlets in the mail, glucose meter, diabetes clinic, church, a family member and the news as sources of health information. More participants identified their physician, insurance company and a family mem-

ber as sources of health information. The majority of the participants thought the health information received was great and very useful. One patient stated, "The information was very helpful and I'm always eager to read more." The patient went further to say that he eats three meals a day, exercises and watches his carbohydrate and sugar intake. The patient also mentioned that this led him to get involved in a community service program that grows organic vegetables and teaches people how to buy and cook healthy foods. Another patient said, "The information I received from my doctor was wonderful. It helped me to get my blood sugar under control." Although the majority of the participants made positive comments about the health information they received from their doctor, a few of the participants were not so pleased. One woman, who was newly diagnosed with diabetes, was disappointed with the lack of information she received. "I did not find the information I received from my doctor as useful. The doctor just wrote something down on a piece of paper and gave it to me." Another woman pointed out that her doctor is not very forthcoming with information. "It's like pulling teeth to get him to say something." Several of the participants mentioned that they try to exercise like the doctor told them, but their arthritis prevents them from doing so.

The participants' perceptions about eating habits seem to be quite diverse. "I have learnt how to discipline myself, so I can eat anything I want," said one patient. "I took myself off of red meat, so I don't care for it anymore," said another patient. One patient mentioned that she doesn't eat when she's hungry, but acknowledged that "skipping meals are not good." There seemed to be a general consensus about consuming little to no red meat. Spouses of two participants who also have diabetes heavily influenced their eating habits. The participants pointed out that, for the most part, they enjoy eating sweet and starchy foods, but try to keep it to a minimum by eating smaller portions.

Nearly all the participants in the focus group did find the health information they received from various sources as useful; however, several of the participants found some of the health information to be quite confusing. One participant talked about the information that she read on the label of products in the grocery store, "I read a lot in the grocery store, but I'm confused about the sugar alcohol labeled on some items." The same participant went on to say that she needed clarification on the controversy surrounding Splenda®. One female participant found her target number for diabetes and cholesterol to be confusing. The same participant was also confused about the difference between baby aspirin and regular aspirin. Another female participant, who acknowledged her caloric goal, didn't understand how to count the amount of calories she consumes per day. One participant expressed frustration with the fluctuation in his blood glucose levels, "I don't understand why my blood sugar is fluctuating. I don't feel I need to pay for my medicine if it's not working."

Identifying Medications and Understanding Prescriptions

The most common method of identifying medication for which the drug is prescribed was by looking at the name on the medication bottle followed by pill color, shape, size, and imprint. Looking at the name on the medication bottle and color was by far the most preferred methods of identification. More participants in the intervention group had a greater preference for the name on the bottle, while more of the participants in the non-intervention group had preference for pill color. One participant identified the use of a pill box, "I don't like it when the medicine changes," said one patient. "My doctor wants me to take generics and that messes me up…sometimes it's the same color." Another participant identified her medications by keeping them in separate places around the home. A few others mentioned that they have been on the medications for so long that they know what their medication look like. When asked if there was an alternative way they would prefer to identify their medication, some preferred drug name on the medication bottle, color, shape, size, imprint, asking a pharmacist, reading the package insert, looking at the actual pill or verifying based on strength. An overwhelming majority still preferred the name on the medication bottle and color.

Continuity of Care

The most common deciding factor that made participants visit their doctor for follow-up care was for an emergency followed by an appointment scheduled by the primary care physician. The most common type of health reason mentioned that made patients visit their primary care physician were diabetes, hypertension, eye problems, arthritis and prescription refills. One patient stated that he does not visit the primary care physician by scheduled appointments, but continuously because of his diabetes. Participants consistently stated that they see their primary care physician every three months. There seemed to be a variation in the responses to the question about how often they visit other healthcare providers because of a referral by a primary care doctor. The responses ranged from every two months to every year. A significant number of participants stated their physician does not ask about other medications they are taking. According to one participant, "If I don't take my medicines to my doctor's appointment, he/she doesn't ask." Besides the weather, all of the participants stated that they have no problem in keeping their scheduled appointments. "I'm a diabetic and it's important," said one patient.

Self Monitoring of Blood Glucose /Knowledge of BP and Glucose Goal /Management of High or Low Glucose Levels

Lack of awareness of target blood glucose and blood pressure goal was acknowledged by an overwhelming majority of both the intervention and non-intervention participants. At least two women spoke of how they came up with their own blood glucose goal, "I didn't get a number, but I read up on it myself." Another woman said, "My doctor didn't give me a target level. I developed one for myself." A few participants were only aware of their morning blood glucose level specified by their doctor while others were only aware of their after-meals value. Others stated that they could not remember what goal was specified for them. Nearly all participants stated that they have no problems in checking their blood glucose, however, a few participants didn't like the idea of sticking their finger because it was too painful or that the meter they used required a lot of blood. When asked about how they will respond to feeling shaky, hungry and sweaty or feeling thirsty, tired and weak, nearly all said that they will first check their blood sugar and then eat a piece of candy or drink orange juice. A few stated that they would proceed and eat something or drink orange juice.

Knowledge of Nutrition-related Goals /Weight Management

All participants agreed that they benefited from controlling their blood sugar through eating plenty of vegetables and less meat. They were aware of foods such as candy that increases their blood sugar. They were equally aware of foods that decrease their blood glucose such as vinegar, lemon juice, water, vegetables, broiled chicken, turkey bacon, and fish. "It's not so much the food you eat, but what you put on it," said one patient.

DISCUSSION

The focus groups did help to identify barriers to self-management that could be associated with poor health outcomes among minority patients with diabetes. Differences in sex, age, marital status and culture did not seem to have an impact upon the attitudes and behaviors toward the topics under discussion. Participants' understanding and knowledge about diabetes came from various sources. The participants' perceptions about eating habits were quite diverse, no sex difference was noticed. Nearly all the participants in the focus group did find the health information they received from various sources as useful, however, there were several of the participants who found some of the health information quite confusing. The limited health literacy seen in this study supports the results of previous studies that have shown that inadequate or marginal health literacy can limit a person's ability to care for their medical problems.[21,22] The most common method of identifying medication for which the drug is prescribed was by looking at the name on the medication bottle followed by pill color, shape, size, and imprint. Looking at the name on the medication bottle and color was by far the most preferred methods of identification. The most common deciding factor that made participants visit their doctor for follow-up care was an emergency office visit followed by an appointment scheduled by the primary care physician. This study also provides additional evidence that inadequate health literacy can lead to an inefficient use of health services.[34,35] Lack of awareness of target blood glucose and blood pressure goal was acknowledged by an overwhelming majority of both the intervention and non-intervention participants. The lack of awareness of target blood glucose may provide a possible explanation for suboptimal self monitoring of blood glucose seen in previous studies.[17,18]

Differences in sex, age, marital status and culture did not seem to have an impact upon the attitudes and behaviors toward the topics under discussion.

CONCLUSION

The focus group discussions revealed many similar experiences and perceptions among the 31 participants, yet there also were important differences across certain issues. Several themes relating to barriers to self-management of diabetes were highlighted during the focus group discussions. First, several of the participants found some of the health information received on diabetes to be quite confusing, despite the source of the information. Secondly, physicians are not forthcoming with information pertaining to diabetes. Lastly, a lack of awareness of target blood glucose and blood pressure goal was acknowledged by an overwhelming majority of participants.

The aim of these focus groups was to identify perceptions and behaviors related to diabetes self-management that do exist in the real world setting, and possible explanations for these behaviors. There are many documented factors that contribute to successful blood glucose control, but the ability of patients to manage their diabetes is critical because adherence with therapeutic regimens may prevent or delay the onset of complications and improve health outcomes. The key to successful diabetes management is heavily dependent upon the education, knowledge and diabetes self-management skills of each individual. Interventions directed towards improvement of outcomes in diabetes management should focus on behavioral change, which is developed

on the basis of self efficacy in the context of social cognitive theory.[36] Motivation and self efficacy in the management of chronic illnesses are known to be important determinants of patients' performance of self care. A patient's ability to care for themselves is enhanced by first identifying barriers and developing effective strategies to overcome them. The findings of this research indicate that most patients do not know their target blood glucose and blood pressure goal and/or the importance of those values. Physicians should inform their patients that knowledge of target blood glucose and blood pressure goals is necessary for effective diabetes self-management but is not sufficient to achieve successful health-related outcomes.

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APPENDIX A

Knowledge of current health status

1. Let's talk about where you get information for diabetes. Where do you go to get information about your diabetes?
2. What do you think about the information you received?

   Probe:

   How useful was the information you received?
   What was not useful about the information you received?
   How satisfied were you with the information you received?
   How helpful was the information in addressing your medical problems?

3. What information about your diabetes do you find confusing?

   Probe:

   What makes the information confusing?

Ability to identify medication and condition for which the drug is prescribed /Ability to read and understand prescription instructions

1. Some of you may have other health problems in addition to your diabetes. How do you identify which of your medications are used to treat diabetes?
2. Some of you mentioned that you identify the pill based on _____ _____ . If there were another way, how would you prefer to identify it?

Continuity of care

1. For the following questions, I want you to think about those visits to your doctor related to your diabetes. If you saw a doctor for both your diabetes and another condition, that would still count as a visit related to your diabetes. What makes you decide when you should go to visit your doctor for follow-up care?

   Probe:

   What types of health problems make you visit the primary care doctor?
   How often do you visit your primary care doctor for regular check-ups?
   How often do you visit other health care providers because your primary care doctor has referred you?

2. How often does your primary care doctor ask about other medications you are taking?

3. What problems do you face when trying to keep your doctor appointments?

   Probe:

   What is it about your doctor's _____ _____ that make it difficult for you to keep appointments?
   In what way will having _____ _____ help you to keep appointments?
   How does the _____ of the office visit make it difficult for you keep appointments?
   What do you think will make it easier for you to _____

Self monitoring of blood glucose / Knowledge of BP and glucose goal / Management of high or low glucose levels

1. What blood sugar level has your doctor suggested is good for you?
2. Do you face any problems when checking your blood sugar?
3. What do you do when you feel shaky, hungry and sweaty or when you feel thirsty, tired and weak or what do you do when you don't feel well?

Knowledge of nutrition-related goals / Weight management

1. What do you think about controlling your blood sugar through healthy food choices?

   Probe:

   What do you mean?
   In what way will _____ make it easier for you?

2. What food choices would make a difference in your blood sugar control?