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Diabetes Connect: African American Men's Preferences for a Community-Based Diabetes Management Program

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Diabetes is a serious health issue impacting populations worldwide, including more than 25.8 million people in the United States.¹ More than 7% of adults in the United States have been diagnosed with type 2 diabetes, with 11% of all U.S. health care expenditures going to diabetes related care.² African Americans are disproportionately affected by the diabetes epidemic, with 18% of individuals aged 20 years or older with diabetes.¹ They are nearly two times more likely to suffer diabetes-related blindness and undergo lower extremity amputations than non-Hispanic whites, as well as two to six times more likely to experience kidney disease.^{3–7}

Diabetes self-management education (DSME) is considered to be a “critical element of care for all people with diabetes” by The Task Force to Revise the National Standards for Diabetes Self-Management Education Programs and evidence has shown the effectiveness of DSME in type 2 diabetes, particularly in the short term.⁸ Self-management practices are often sub-optimal due to a combination of individual, environmental, and healthcare system-based factors⁹; however, the barriers to self-management are more pronounced in underserved, minority communities. African Americans face more problems with diabetes self-management than non-Hispanic whites for a variety of reasons, including disparities in

access and delivery of care, communication and health literacy barriers, and mistrust and cultural beliefs regarding the medical system.¹⁰

Synergy between clinic-based efforts and community-based strategies can facilitate a more comprehensive approach to diabetes management but is often hard to achieve in real world settings. Increasingly, the community health worker (CHW) model has been implemented in an effort to link community and clinical efforts to improve health outcomes in underserved populations. CHWs are trained lay individuals who work to help improve self-management through provision of diabetes education, assistance with goal setting, problem solving, and social and emotional support; their shared cultural identity and community ties provide a unique and crucial link between the community and health care system.^{11,12} CHW interventions have been shown to promote lifestyle modification, improve self-management and medication adherence, glycemic control, and reduce the number of emergency room visits.^{13–15}

While diabetes CHW interventions in the literature have been successful, the majority of CHWs as well as the participants in those studies have been women.^{9,16} Studies suggest that diabetes self-management recommendations should include gender-specific strategies; unfortunately the evidence-base for such strategies is very limited.¹⁷ For example, only a few studies have investigated gender specific barriers to diabetes self-management. One such study focusing on African Americans living with type 2 diabetes found that for men, lack of time at work, lack of family support, and lack of knowledge were the most frequently cited barriers, while for women barriers included lack of finances, embarrassment, negative outlook, and perceived lack of disease control.¹⁸ Understanding gender-specific differences could facilitate the creation of tailored interventions that may resonate more with the intended audience and lead to improved self-management practices and health outcomes.¹⁸

In order to most effectively design a community-based, CHW-delivered intervention for diabetes and maximize male participation, this qualitative study explores African American men's perceptions of how community-based, community-health worker (CHW) delivered diabetes interventions might best be implemented.

METHODS

Study Design

For this study we used focus groups to collect data on perspectives related to diabetes self-management, perceived needs as well as potential benefits and risks related to community health worker interventions. We used a qualitative approach in order to capitalize on the rich experiential data of African American men living with type 2 diabetes. Focus group methodology involves a planned series of discussions designed to obtain perceptions from a group of individuals on a particular topic of interest in an open-ended, non-threatening way. It is often employed when investigators are interested in soliciting a range of feelings on a topic and differences in perspectives as opposed to creating consensus. As opposed to individual interviews, the group discussion allows for synergy to develop and individuals can build on or expand on ideas brought up by others that they may not have thought of on their own.¹⁹ The study was approved by both Cooper Green Mercy Health System and UAB

Institutional Review Boards, and each participant provided written informed consent prior to focus group participation.

Sample and Recruitment

The study was conducted in partnership with a local safety-net health system that provides care for residents of the Birmingham-Hoover Metropolitan Area and a faith-based 501 (c) 3 organization dedicated to promoting health equity among community members. Participants were recruited from within the safety-net health system. Cooper Green Mercy Health System provides medical care to residents of Jefferson County based on a sliding fee scale to uninsured/underinsured patients and insured patients.

Potential participants were identified through the health system's diabetes education database. The database was queried for patients with a type 2 diabetes diagnosis and had received care within the health system between 2009 and 2011. Investigators sent letters to potential participants informing them of the study purpose and providing them the opportunity to opt out of future communication about the study. Men were then contacted by telephone and provided with additional information about the study along with an invitation to participate in a focus group. Men were included if they were African-American, had a physician diagnosis of type 2 diabetes and had received care within the health system between 2009 and 2012.

Data Collection

Prior to the focus groups, each participant completed a brief interviewer-read questionnaire for demographic information. Afterwards, an African American male moderator trained in qualitative methods led the group using a guide; a designated note-taker was also present to capture comments on a flip chart and to keep track of non-verbal behavior and level of engagement on various topics. To develop the moderator's guide, content was based on that of the National Community Health Advisor study, a survey published in 1998 by Rosenthal and colleagues to explore and define how community health workers view their work and their field.²⁰ The guide included questions on potential CHW roles, responsibilities, perceived strengths of the model as well as potential concerns. Questions regarding diabetes self-management and barriers were also included (Table 1). Audio from all focus groups was recorded and transcribed. Debriefing sessions attended by the project investigators, moderator, and note taker were held immediately following each focus group to compare notes on the overall process and impressions unique to each group.

Data Analysis

Descriptive statistics were computed to characterize the sample using SAS version 9.3. Qualitative content analysis was conducted to identify major categories and substantive themes.²¹ To begin, an initial transcript was read in its entirety by three independent reviewers to gain an over-arching sense for the conversation. Afterwards, each reviewer went through the transcript, identifying meaning units in the forms of phrases and sentences. Meaningful units were further condensed and codes were created and assigned to each meaning unit. Authors then met to discuss codes in order to reach consensus on a codebook that would be applied moving forward. Codes were further categorized and themes were

identified based on the data. Two authors applied the codebook to each subsequent transcript, noting emergence of any new themes, with coding discrepancies decided by the third independent reviewer. Upon completion of the fourth focus group, saturation of themes was achieved and no further groups were conducted.

Several strategies were employed to enhance rigor and ensure trustworthiness of the data.^{22,23} To reduce researcher bias, multiple independent coders participated in the analysis, including a medical student, a graduate student in public health and a physician investigator with expertise in community-based research and qualitative methods. During the review phase, preliminary data were presented to the full research team for peer review and reflection on potential researcher bias. Additionally, a confirmatory focus group was conducted for respondent validation of focus groups findings, also called “member checking”. All focus group participants were invited to attend a follow-up focus group; 14 participants provided feedback confirming the results.

RESULTS

Four focus groups were conducted with a total of 25 male participants. The sample group had a mean age of 53, ranging from 38 to 66 years. Mean years living with diabetes was 9.6, with a range from 1 to 20. Twenty-one percent reported being married or living with a partner, and 12% was employed. Sixty-five percent of the group completed high school or college/technical school, 26% some high school, and 8% less than ninth grade.

Themes arose in three overarching domains. The first domain was participants’ perceptions of ways one can manage their diabetes. The next domain included hardships of living with diabetes and barriers to self-management. The final domain was perceptions surrounding CHWs and community-based interventions.

Diabetes Self-Management Strategies

The participants discussed various methods of self-management, addressing both medical strategies and lifestyle changes. Included in medical strategies, participants expressed the importance of attending their doctor appointments. One participant suggested, “The main thing is see your doctor.” The group also discussed the need for medication adherence, as one participant explained, “the first thing you need to do is take your medication.” Another participant added, “try to take your medication at the same time.” Another commonly cited approach to self-management was glucose self-monitoring. As one participant stated, “keep checking on your blood sugar.”

The participants also discussed a number of lifestyle modifications to improve their diabetes self-management. These included diet modifications for healthier eating habits, exercising more, getting adequate rest, and managing stress. As one participant described, “[if you keep] fighting it and exercising and not stressing about it, you know, you’re going to pull it out.” Other participants noted the importance of diet, saying “You got to eat the right thing... eat regular, you know, balance your meals.”

Hardships of Living with Diabetes

Participants described several hardships of living with diabetes that present barriers to self-management. Within this domain, several themes emerged, including emotional frustrations, dietary challenges, physical manifestations of the disease, and institutional frustrations with the medical system.

Emotional Frustrations—Participants expressed emotional hardship, including depression, denial, and fear as factors contributing to the burdens of living with diabetes. One participant explained how depression affected his physical state:

And I personally believe that the depression directly affects my health, my mental status... as well as my physical being. If I'm not feeling...normal, whatever that may be, then it affects my overall physical health, you know.

Another added, "I have that blue feeling or depression kind of thing... When my blood sugar level is high...that's when it affects me. I feel, you know, depressed." Weight gain and medication were cited as factors contributing to depression, as participants commented, "I'm getting big, so that makes me depressed", and, "The medicine makes some of those people depressed." Lack of acceptance of diabetes and fear of complications of the disease also affected participants emotionally. One participant explained, "...I was in denial for two years...I said it just has to be somebody else not me." Another added, "Yeah...I was in denial because I just didn't want to be diabetic." Fear of death due to diabetes was also mentioned. One participant described his fear by saying, "I don't want somebody to come and knock on my door and find me dead up in my place. That's what happened to that fellah...and he was a diabetic."

Dietary Challenges—Much of the discussion surrounding hardships involved diet. Some subthemes related to diet included dietary restrictions, food preferences, and cost.

Participants explained the many dietary restrictions and modifications that burdened them. For instance, one participant commented, "Since I have diabetes...I cannot have certain spicy foods, and I can't have certain fried foods." Another added, "I had to start drinking diet drinks." Another participant explained the difficulty of having such dietary restrictions, saying, "What makes it hard for us [is] when we watch what others eat...we might be a little jealous because we can't have those things as a diabetic." Others commented on the quality of taste, as one participant stated, "You know you got to eat healthy, then some foods just don't taste right."

Cost was also identified as barrier to dietary adherence. One participant stated, "Most of the food that they tell you to eat is too expensive for you to buy." Another explained, "Cheaper food, you get them for a dollar, but the good stuff costs you way more."

Physical Manifestations—Many participants noted the burden of physical symptoms as a hardship of living with diabetes. One participant explained his struggle in dealing with chronic pain, noting, "You'll never get rid of the pain, but you learn to bear with [it]." Others described specific manifestations: "Diabetes also affects your eyesight", "Your foot goes to sleep because your sugar is going high", and "I'll have pain in my legs and feet and fingers

and heart palpitations.” Some participants attributed their physical symptoms to their diabetes medications. For example, one participant stated, “The medicine makes me want to vomit, get dizzy, and I have to go lay down.” Another commented, “That medication...they put me on, it messes with my body. It makes me feel bad.”

Institutional/organizational frustrations with the Health System—Participants in the group expressed frustration with several aspects of the health system, including physicians and overall organization and communication. Some participants noted irritation with their doctor’s lack of knowledge and experience. One participant remarked, “A lot of these doctors don’t know anything about diabetes...They always refer you to somebody else.” Another added, “My doctor don’t understand diabetes too much. He’s kind of young, and he’s medically trained, but he ain’t seen enough in life.” One participant expressed frustration with the provider’s communication skills, stating, “A nurse or doctor...they talk at you, not to you. Because of their higher education, all they know how to do is talk at you, not to you.” A general lack of organization and communication between the system and participants contributed to their frustrations. Participants expressed the desire for diabetes education but felt discouraged by the lack of organization and correspondence regarding scheduling and availability. For example, one participant said “They offered education...but all of us can’t make it...We wait...[but] we probably is going to have it take it upon ourselves.” Another added, “That’s probably the route that we’re going to have to take because we don’t know—like once we leave here, we still probably won’t know.”

Perceptions Surrounding the CHW and Community-Based Interventions

Several themes surfaced during the focus groups regarding CHWs and community-based interventions. Themes were organized in the following way: CHW roles, preferred CHW traits, concerns and apprehensions, communication and group dynamics.

CHW Roles—Participants outlined several ways CHWs could help support their diabetes management. They first wanted the CHW to educate them about diabetes, including management skills, diet and cooking techniques, and medication side effects. For example, one participant said the CHW should “teach them how to manage their diabetes.” Another participant stated, “The community health worker would be able to advise on the side effects on the medicine...” Several participants expressed the need for dietary and cooking education. For instance, one participant said, “I need to know the proper way to cook food by being a diabetic.” Others commented, “Cooking classes are very helpful...knowing what to put in your food is better than just eating out all the time”, and “Teach us how to still enjoy the stuff that we like to enjoy, prepare it a different way.”

Another preferred job of the CHW included holding support groups. One participant said, “Support groups...would lend credence to, you know, helping a person feel better about him or herself.” Participants felt support groups would facilitate camaraderie and provide a way for them to help each other in times of need. For instance, regarding another participant who had run out of diabetes testing strips, one participant explained, “...If we had a support group then...one of us could have came over to get him some test materials.” Another participant suggested, “Like a central base, like if all the gentlemen that’s here now were

invited to a support group to report twice a month...make sure nobody's, you know, in the freezer, so to speak."

Participants identified the need for coaching and help staying on top of daily activities. One participant identified the wish for "Someone to keep up with like what went on with you that day, like what you ate, what particular activities you did, and how you felt and what was your sugar after all that." Another participant stated, "What we really need is somebody to keep up with us because we ain't doing a good job."

Help navigating the system and linking to resources was another role the CHW could fill. For example, one participant suggested, "The CHW could link people to places that can help you be able to afford your medication." Another desired "some kind of way helping with those that are not financially able to afford this price of insulin." Another participant suggested the CHWs could help link back to the clinic, "make sure that you got appointments...and provide reminder [calls] for your appointments."

Preferred CHW Traits—The men desired that CHWs be knowledgeable about diabetes. For example, one participant commented, "They would have the basic knowledge of what we need." Another stated, "They definitely should be knowledgeable about diabetes."

Participants also felt the CHW should be able to relate to them, whether in a general sense or have experience as a diabetic themselves or caring for a diabetic family member. One participant commented, "We can bond better knowing that that individual can identify with what's being said." Another explained, "It would help if somebody could understand it just like you."

CHW gender preference varied among focus groups. Some participants preferred either female or male CHWs, however there was no overriding preference.

Concerns and Apprehensions—Few concerns regarding CHW's roles emerged during the discussions. One participant voiced his hesitation regarding confidentiality, stating "don't talk to the whole community about me." Another potential concern was a fear of being talked down to as a patient. As one participant put it, "Don't talk at me, you know", while another participant added, "[Do] not preach at me." Others mentioned concerns about stereotyping alluding to the need for individualized attention, for example "You can't have a [community health worker] assume that just because we are African American males stemming from 35–65 that we are all going to follow the same pattern."

Preferred CHW Interactions and Group Dynamics—The men described several potential modes for communicating with the CHWs as well as discussed a loose structure for support groups. One preferred method of contact with the CHW was via telephone. One participant said, "...It would be nice, you know...[if] they'd probably call you and say "Hey, how are you doing today? Have you checked your [sugar]", you know." The need for face-to-face communication in the community was also discussed, as participants suggested, "Use the neighborhood center", or "Even the church in your community." Additionally, local

libraries, gyms, or anywhere within walking or bus ride distance were selected as potential locations for support groups.

Participant discussed preferred group dynamic and composition, noting a stress free and safe environment was important. Preferred times varied for participants. The groups proposed family, friends, potential diabetics, community members, doctors, dieticians, and exercise experts among those invited to support groups. They stressed the importance of a family-focused dynamic. For example, one participant reported, "It would be nice to have your family because that way, they can get the knowledge of what you are going through." Another participant explained, "It should be a family thing because all of you got to sit there and eat the same thing, and you can't go and have three different meals...you get to cook one meal."

DISCUSSION

This qualitative study explored African American men's perceptions surrounding community-based diabetes self-management interventions and CHW roles using focus group methodology. Participants expressed their desire to participate in a community-based intervention and stressed the importance of accessibility. Men noted significant emotional hardships they face in living with type 2 diabetes. Preferred CHW duties and traits were identified as well as management strategies and barriers that hinder achieving them.

The lack of male participation in community-based interventions is notable, yet the underlying cause of their low numbers remains elusive. The men in this study expressed enthusiasm regarding CHWs and welcomed the idea of a community-delivered diabetes management program. While their stated excitement implies a willingness to participate, the dearth of male participants historically in CHW interventions suggests there must be other factors affecting their involvement. Chlebowy et. al (2013) found that African American men with type 2 diabetes cited lack of time at work, lack of family support, and lack of knowledge as the most frequent barriers to achieving self-management.¹⁸ While men in our study also identified the latter two as challenges, lack of time at work was not discussed as a barrier; in this sample nearly all of the participants were unemployed. The importance of convenience and ease of access emerged as key factors for participation in a community-based intervention. The need for knowledge, information, and intervention to be delivered to the men was apparent through their preferences in communication, interaction, and support dynamics. Although transportation was never explicitly discussed as a barrier during the focus groups, the men's emphasis on community-located programs accessible by bus or on foot implies that transportation, or lack thereof, is an important issue that should be considered in the development and planning of community-delivered diabetes management programs.

Another striking feature of this study is the extent to which the men discussed the role emotional hardships play in their ability to manage diabetes. Several studies exploring gender differences in diabetes self-management have found that women with type 2 diabetes face more depressive symptoms than men.^{24,25} Uden et al. (2008) found that men with type 2 diabetes reported fewer diabetes-related worries and better coping abilities than men,

while Chlebowy et al. (2013) reported men were more likely to use more problem-focused and less emotion-focused methods for diabetes self-management.^{18,26} The participants in our study frequently cited low self-esteem, depression, denial, and fear as emotional hurdles. Additionally, some of the greatest needs that emerged from the focus groups included emotional support and support group meetings. While our results are not consistent with the findings from the above studies, our study population draws from an underserved community. Epidemiological evidence has shown that depression, obesity, and diabetes are associated with socioeconomic position, with the greatest burden falling on the least well off.²⁷ The findings in our study underscore the importance of creating a community-based interventions in the context of serving its target population, including factoring in both gender and socioeconomic status. As other studies have stressed, our study also suggests that an understanding of gender differences could facilitate the design of interventions with a higher likelihood of improving diabetes self-management skills and diabetes-related health outcomes than one-size-fits all interventions.^{18,28,29}

This study has limitations. The sample size was small, consisting of 25 male participants; thus, these results should be interpreted with caution. Additionally, this was a convenience sample from a rather homogenous sample of underserved, primarily unemployed African American men referred from a resource-limited safety-net health system in Birmingham, AL. Therefore, these results may not be easily generalized to other subsets of African Americans or the general population in the U.S.

African American men in this qualitative study identified critical self-management strategies but endure hardships that present barriers to achieving them. Many of the strategies and barriers to self-management that participants identified mirrored their preferred CHW duties and traits. The men voiced their openness to participate in a CHW intervention that promotes working toward healthy lifestyles and diabetes self-management skills to improve health outcomes.

RECOMMENDATIONS/IMPLICATIONS

This study has several implications for practice. Given the limited track record of male participation in community-delivered programs, it is crucial to solicit men's input during the program development process in order to maximize participation and effectively impact diabetes-related health outcomes. In this study, men emphasized the need for education and programs located within their community in order to increase accessibility. Men also expressed a desire for practical education and support from someone with a shared experience, citing that many times health professionals speak "at" not "to" them. While it may not be feasible for all practices to engage community health workers in diabetes programs, alternative mechanisms such as support groups and peers support can be employed to allow for sharing of best practices and problem solving among patients. Finally, it is important not to assume that just because a patient is male that they are not grappling with some of the emotional challenges related to their diabetes. Screening for depression and diabetes distress uniformly may help to uncover barriers to disease management and improved quality of life in the process.

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Table 1

Selected questions from the guide used in the focus group meetings held in Jefferson County, Alabama between September and October 2011.

1	What sorts of things can a person do to manage their diabetes?
2	What kinds of things do you think a community health worker could do in your community to support people trying to manage their diabetes?
3	What sorts of things would you rather a community health worker not do?

Table 2

Characteristics of male participants (n=25) in the focus group meetings held in Jefferson County, Alabama between September and October 2011.

Characteristics (n=25)	Mean (range) or Percent (n)
Age (years)	53 (38–66)
Years with diabetes	9.6 (1–20)
Married or living with a partner (%)	21% (7)
Employed (%)	12% (4)
Years of education	
<9 th grade	8% (2)
Some high school	26% (9)
High school or college/technical school	65% (22)