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Diabetes Connect: African American Women's Perceptions of the Community Health Worker Model for Diabetes Care

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Abstract

Background—Community health worker (CHW) interventions have potential to improve diabetes outcomes and reduce health disparities. However, few studies have explored patient perspectives of peer-delivered diabetes programs. The purpose of this qualitative study is to investigate possible benefits as well as risks of community health worker-delivered peer support for diabetes from the perspectives of African American women living with type 2 diabetes in Jefferson County, Alabama.

Methods—Four ninety-minute focus groups were conducted by a trained moderator with a written guide to facilitate discussion on the topic of community health workers (CHWs) and diabetes management. Participants were recruited from the diabetes education database at a safety-net hospital. Two independent reviewers performed content analysis to identify major themes using a combined deductive-inductive approach.

Results—There were 25 participants. Mean years with diabetes was 11.2 (range 6 months to 42 years). Participants were knowledgeable about methods for self-management but reported limited resources and stress as major barriers. Preferred CHW roles included liaison to the healthcare system and easily accessible information source. Participants preferred that the CHW be

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Compliance with Ethical Standards

Research Involving Human Subjects: The study and procedures were approved by both Cooper Green Mercy Health System and UAB Institutional Review Boards. All participants provided written informed consent prior to commencing study-related measures and procedures. All study procedures comply with the Declaration of Helsinki.

Informed Consent: All participants provided written informed consent prior to commencing study-related measures and procedures.

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knowledgeable and have personal experience managing their own diabetes or assisting a family member with diabetes. Concerns regarding the CHW-model were possible breaches of confidentiality and privacy.

Conclusion—The self-management strategies and barriers to management identified by participants were reflected in their preferred CHW roles and traits. These results suggest that African American women with diabetes in Alabama would support peer-led diabetes education that is community-based and socially and emotionally supportive.

Keywords

Community-Based Participatory Research; Community Health Workers; Diabetes; Health Disparities; Women's Health

Introduction

Diabetes prevalence and its related morbidity are disproportionately high among racial and ethnic minorities. African Americans are twice as likely to develop diabetes, tend to have worse glycemic control, and are more likely to suffer from diabetes-related complications such as limb amputations, ESRD, stroke, and blindness when compared with whites [1–5]. Despite numerous treatment strategies available to delay and prevent diabetes and its associated co-morbidities, there is often a considerable gap between recommended diabetes care and received care amongst minority populations [6–8]. Disproportionate poverty rates and limited access to health care services and education all contribute to observed disparities, including diabetes-related disparities.

In recent years, the Community Health Worker (CHW) model has been used to improve access to and implementation of diabetes management programs, especially for underserved populations [9, 10]. A CHW is typically a lay-person who is a trusted member of their community, either has diabetes themselves or is intimately familiar with its day-to-day management and can help to provide informational support and bridge the gap between the community and healthcare providers [11]. Deriving expertise through a combination of training and shared experience, the CHW can help empower patients to better manage their disease and improve communication challenges between patients and their care teams [12]. This could lead to improved patient adherence to recommended treatment and self-monitoring strategies and reduce complications. In fact, studies have demonstrated changes in self-care behaviors, glycemic control, health care utilization and quality of life [13–15]. Thus, integration of the CHW model into interventions aimed at reducing health disparities seems to be a promising strategy.

However, the roles and responsibilities of CHWs within or alongside health care teams and specifically diabetes management programs have not been standardized to date. In the last few years, the Department of Labor created a classification entitled Community Health Workers (21-1094; U.S. Department of Labor, 2010). More recently, the national health care reform bill (PPACA) classified CHWs as “primary care professionals” under the purview of the National Health Care Workforce Commission (sec.5101(i)(1)) [12]. As the medical field adopts a more patient-centered approach, it is important to develop a clear understand

patients' hopes, expectations and concerns for community programs, including those that employ CHWs. For example, a previous review of CHW-delivered diabetes programs suggested patients have some concerns about peer-delivered programs; one investigator reported having been told by community members "I don't want my neighbor teaching me about diabetes" [13]. While in a separate study assessing participant satisfaction with a CHW diabetes management, participants regarded CHWs as an invaluable asset in learning how to navigate the health care system and being better able to care for themselves with CHW support [14].

Despite the growing number of CHW-based diabetes programs that have been implemented across the US, few studies have explored the perspectives of African American patients on the use of CHW-delivered diabetes self-management programs. The objective of this qualitative study was to investigate potential benefits as well as risks of CHW-lead diabetes education from the perspectives of African-American women living with type 2 diabetes in a southern city. This formative work will be used to develop a community health worker-delivered program aimed at extending diabetes education and services into the community and creating better linkages to care.

Methods

Study Design

Focus groups were conducted in Jefferson County, Alabama in 2012. 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.

Community Partners

This study was conducted as part of a partnership project involving the University of Alabama Birmingham, Congregations for Public Health and Cooper Green Health System (CGHS). CGHS is a public safety net hospital that provides care for residents of Jefferson County using a sliding scale based on income level. In response to the increasing burden of diabetes and its complications in Birmingham, CGHS has placed special emphasis on developing enhanced education services to support its patient base with diabetes. Congregations for Public Health (CPH) is a 501(c)3 organization whose mission is to reach out to surrounding neighborhoods with services to promote health equity. CPH consists of 8 African American churches located in some of Birmingham's oldest and poorest neighborhoods. CPH builds on the existing experience of their CHWs, who manage operations, communications, program activities, and community outreach within each church's one-mile radius. For nearly a decade, they have been working in surrounding neighborhoods to promote health and reduce disparities.

Sample and Recruitment

Potential participants were identified using the diabetes education referral database at CGHS. Potential focus group participants were sent a letter describing the purpose of the study and giving them the opportunity to opt out of future calls. Study candidates were then

contacted by telephone and formally asked to participate in the study, which included a telephone questionnaire and group discussion. Women were eligible 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. CHWs from CPH helped in the recruitment of participants for the study and also secured space and times for the focus groups to be held at the churches. All potential participants were guaranteed anonymity, confidentiality, and the right to withdraw from the study at anytime according to IRB protocol. Participants were also fully informed of the risks and benefits of the study and signed an informed consent form prior to the beginning of the focus group.

Moderator's Guide

To develop an interview 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 [15] The interview 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.

FocusGroup Procedures and Data Collection

Focus groups were held at churches belonging to the Congregations for Public Health, were conducted by a trained moderator accompanied by a note-taker, and lasted approximately 90 minutes. The moderator and the note-taker greeted each participant upon arrival, spoke with her about the risks and benefits of participation, and obtained written consent. A trained interviewer administered a short questionnaire prior to focus groups to collect demographics. These data included age, education, marital and employment status, and time with diabetes.

Healthy snacks were provided, and participants received \$20 in cash for their participation. All groups were audiotaped, transcribed and translated verbatim. The note-taker reviewed the transcripts and added information about participants' nonverbal behavior and level of engagement during the discussion.

Data analysis

Descriptive statistics were computed to characterize the sample using SAS version 9.2. Qualitative content analysis was conducted to identify major categories and substantive themes [16]. 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 [17, 18]. To reduce researcher bias, a multidisciplinary, racially diverse team of reviewers (multiple independent coders) participated in the analysis and included a medical student with a background in biology, a post-doctoral fellow in nutrition with a research focus on health disparities, 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

Demographics

A total of four focus groups were conducted with a total sample size of 25. The number of participants in each group ranged from 6 to 9. All participants were female. The mean age of participants was 52 (range 31–72, Table 1). Less than half of the participants were married, living with a partner or widowed (32%). The majority of participants had obtained at least a high school diploma or GED (64%) and most reported being currently unemployed (20%) or unable to work (40%). Participants reported an average monthly household income of 1.3K (range 300–1.8K). On average, participants reported a mean of 11.2 years since their diabetes diagnosis.

Barriers to Diabetes Self-Management

Participants recognized key aspects of diabetes self-management (diet, exercise, medications, and self-monitoring), but experienced difficulties in executing these strategies, particularly with diet modification. Themes that emerged with regard to barriers included temptations, traditions and food preferences. In the face of these barriers, participants described difficulty adhering to prescribed treatment plans despite knowledge of its impact on their disease progression. For example, one participant said, “I know what I’m supposed to eat. I have about three or four charts, and I’m -- I’m still doing wrong with the food because I love grits.” Another participant explained, “The last three weeks in a row I went -- I went to a bridal shower, a baby shower, every kind of shower, and there’s always food there. And I’m just eating it because it’s there and everybody else is eating it.” Breaking habits is difficult, as one participant reported, “I’m struggling to get out of my, you know, the way I was raised eating... I’ve put a lot of things behind like the neck bones and things like that, you know... But trying new things is kind of hard for me.”

Stress was also perceived as a barrier to good self-management. Participants described stress related to work, caregiver responsibilities, and diabetes itself. All forms of stress were felt to negatively impact DM control. For example, “But stress will bring it -- will take my diabetes as high as I don’t want it to go, just everyday living, everyday life, trying to make it, trying to do the right thing, trying to live right, trying to raise your children, trying to, you know, get back in school at 50 plus and stuff like that, you know, stress.”

Limited resources and transportation problems also emerged as barriers to self-management. One patient summed it up "I often have trouble getting back and forth to the appointments."

Preferred roles of the CHW

Participants described several themes related to ideal roles for a CHW, including coach, partner, and liaison. Participants wanted a CHW who could coach them through challenges in disease management in a peer-to-peer setting. As one participant described, "...someone who can come out and tell you some advice about your diabetes and whether you're eating right or not and maybe whether you're getting enough rest or not. They can monitor you..." Another explained, "They could give you information that may help you as far as your diet and what you should be doing to maintain your diabetes, and check and see if you do know how to test your blood sugar levels."

Participants also wanted someone who could encourage them in more of a partnership role. As one participant put it, "I mentioned partner but I...I really do like a partner because they can help you reach a goal and stuff." Another participant referenced partnership as a kind of shared experience working together, "Come out and exercise with you. You all go for walks and maybe a little jogging, and they'd keep you motivated to do your exercises..." Another said, "...Just keep you on track on all parts of your diabetes...like having a partner and you work together just kind of beneficially..."

Participants also described the CHW as an individual who could enhance communication serving as a liaison between the patient and the rest of the healthcare team. For example, one participant said, "...they can communicate to the person they're talking to as well as the nurse or the nurse practitioner that knows about it also." Other participants wanted linkages to resources. For example, "Okay, like for instance, help with transportation to your doctor's appointment, I mean, and then if you can't get your medicine, help with your medicines, you know, just help all the way around. Like, it's rather like a social worker, someone that can help you to help yourself. Because a lot of people try, but they don't really help..." And also, "Well, I don't know, I often have trouble getting back and forth to the appointments... [CHWs] could, you know, get together and can provide transportation."

Preferred traits of the CHW

Participants also described traits they would hope to find in an ideal CHW, including diabetes knowledge through shared experience, emotional supportiveness and availability. As one participant described, "Right, because you'd like to talk to somebody who is going through something similar that you are, sometimes it does help to encourage you...it helps me when somebody says, "Let's go walk. I'll walk with you," you know, if they're a diabetic because we can relate because they'll know what I'm going through because they're going through the same thing." Another said, "I mean, it's better always to talk to somebody with similar issues because they also know what you're going through. You know, it's hard to talk to somebody that's not going through what you're going through." One participant explained, "[With a non-diabetic] it's still not the same, it's not the same. They probably have the knowledge of it by being around it, but they actually don't have to deal with it and live with it, so they don't know what's going on with your body when they not dealing with

it in their own body.” Empathy also emerged as an important trait. Terms such as “relatable”, “understanding”, and “listener” were used to describe the ideal person.

Participants preferred that a CHW be approachable and easily accessible. For example, “Have [someone] you can call just in case you run into a problem with your diabetes.” Availability of ongoing support outside the hospital was mentioned as desirable, such as periodic meetings in the community. One participant suggested, “A place like this [church] or a community center...if the group is small, we probably could do it at somebody’s house every month or so.” It would be good to have someone to teach a class about diabetes within the community.

Patient Concerns and Apprehensions

Participants did voice some concerns around sharing health information with a CHW. Major themes identified were concerns about confidentiality and unsolicited advice. Participants were knowledgeable of their rights concerning health information and thought it would be important that a trained-peer be aware of health information protection policies. One participant said, “[Don’t] call my sister and my brother and let them know that I was calling concerning my diabetes...acknowledge the HIPPA policy”

Although participants preferred easy, unlimited access to a CHW, they were cautious about how often and concerning what matters a CHW could contact them. One participant recommended, “Don’t give too much advice, you know. You may call for one specific thing and they go on and on about your diabetes, you know, asking a lot of questions, when you just called to ask just that one specific question. And not pry into your personal business when you call and ask a question.” Another didn’t want nagging, or as she put it, “Just hound you. Hound you, you know. Just stay on your back. And you know how like some people just call, call, call...”

Discussion

The goal of this study was to explore potential benefits and risks of CHW-led peer support for Type 2 Diabetes Mellitus among low-income African-American women in Birmingham, AL. A qualitative approach was taken to explore patient perspectives on peer-supported diabetes management, utilization of diabetes self-management strategies, the deficits in their exposure to said strategies. Participants in this study identified common previously reported barriers to diabetes self-management and described roles and traits of CHWs that would be useful in a CHW-based intervention. Support through shared experience emerged as an important component for successful CHW interventions according to study participants. Uniquely, this study also identified patients concerns that could become possible limitations to a CHW-led peer support for this population, including issues related to privacy and intrusiveness.

Despite growing evidence supporting the effectiveness of the CHW model, widespread implementation of CHW strategies for chronic disease management has been hampered by a lack of clarity around CHW roles and responsibilities. To some degree, the lack of consensus exists because CHW roles and responsibilities tend to be context specific, dictated

by a combination of community needs and assets as well as the capacity of local health care providers and organizations. For example, in a qualitative study of programs utilizing the CHW model for diabetes, educator was the most commonly identified role.[13] Often this role was designed to achieve specific program objectives to deliver community-based education programs. Additional roles identified included case manager and advocate. Contrast that with the most commonly identified CHW role identified by participants in the current study that is the CHW as a major source of social support based on shared experience. A 2010 study identified patient appreciation for peer-support from individuals with first-hand experience of particular health behaviors; the same study also identified a lack of perceived sameness as a pitfall in study design.[19] Thus there is some data to indicate patient consensus on what the ideal function of the community health worker may be. However, for the CHW model to be most effectively implemented for patient support in diabetes self-management, there must be some agreement between patients, CHWs, and providers on the specific traits and roles of CHWs. Data from the latter is still lacking.

Patient self-identified barriers to successful diabetes self-management were reflected in the potential CHW roles they described as most desirable. For example, stress was identified as a major barrier to optimal diabetes management for this group of women. Thus it is not at all surprising that emotional supportiveness, availability and ongoing support outside of the medical system were identified as critical features of an ideal CHW-led program. Other barriers described by participants, such as limited transportation and difficulty accessing services within the health system could be addressed by the creation of community-based programs as suggested by the women in this study. In fact these are the strengths of the CHW model that have been highlighted in a number of previous comprehensive reviews [9–11]. For example, in our previous review of CHW programs, we reported the importance of strong community connection and residence in the community as key CHW recruitment criteria [13, 9]. The findings in this study suggest that patients realize the potential benefits of using a CHW approach to overcome barriers to diabetes management.

Few studies have explored the topic of negative patient perceptions of CHW-led peer support. This study made steps to identify possible pitfalls, as viewed by patients, of these types of community health intervention. It is evident from our study that patients are knowledgeable about their right to privacy surrounding their medical information. Without necessary steps taken to prevent patient's information from getting into unauthorized hands, they may be reluctant to take part in such peer support programs. This brings into question a potential obstacle for program design. In the future, research groups and community health organizations will have to balance the peer-to-peer foundation of their program with the laws in place concerning health information privacy.

Limitations

This study was designed to explore patient perceptions of peer-support for diabetes management in an underserved African-American female population in the Deep South. Therefore, the results of the study may not be generalizable to groups of African-American women with different geographic demographics. A population of similar racial and socioeconomic background in rural areas of Alabama or regions of the United States outside

of the South may experience different challenges to diabetes self-management and their needs for community-based peer support may not align with those described in this study.

Implications

Qualitative research provides the opportunity to gain community input prior to the development of health interventions, thus increasing the likelihood of intervention success [19]. The results of this study confirm community recognition of the potential roles community health worker roles can play within diabetes programs and creates a framework for the design of an intervention focused on community needs. Identifying socially-supportive qualities and skill sets that the population studied finds helpful will be essential to the design of programs that engender to greater patient adherence. Additional studies should be conducted to identify perceptions of CHWs among African-American males. Furthermore, qualitative research with primary care providers may be useful in establishing a program that both patients and providers find beneficial.

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Table 1

Selected questions from the guide used in the focus group meetings held in Jefferson County, Alabama in 2012

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 female participants (n=25) in the focus group meetings held in Jefferson County, Alabama in 2012.

Characteristics (n=25)	Mean (range) or Percent (n)
Age	38 (22–65)
Married or Living with a partner	44% (11)
Employed	64% (16)
Education (years)	
< Less than 9th grade	72% (18)
High school	16% (4)
Did not report	12% (3)
Body mass index	
Overweight (25–29.9)	31 (26–46)
Obese (> 30)	48% (12)
	52% (13)

Table 3

Thematic results reported by African American women with diabetes

Domain	Themes	Illustrative Quotes
Preferred CHW Roles	Liaison Sponsor Partner	“...they can communicate to the person they’re talking to as well as the nurse or the nurse practitioner that knows about it also.”
	Technical Support	“...some can come out and tell you some advice about your diabetes and whether you’re eating right or not and maybe whether you’re getting enough rest or not. They can monitor you...” “...Just keep you on track on all parts of your diabetes...like having a partner and you work together just kind of beneficially...” “Have a hotline you can call just in case you run into a problem with your diabetes.”
Preferred CHW Traits	Knowledgeable Shared Experiences Emotionally Supportive	“...as long as the provider has the knowledge and has some education on it, has knowledge about it...” If they’re a diabetic...we can relate because they’ll know what I’m going through because they’re going through the same thing “...and we can just talk about how we feel. To talk about what’s going on and how it feels to be sick.”