
Participants' Assessments of the Effects of a Community Health Worker Intervention on Their Diabetes Self-Management and Interactions with Healthcare Providers

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Background: The specific ways in which community health worker (CHW) programs affect participants' healthcare behaviors and interactions with their healthcare providers, as well as mechanisms by which CHW programs influence these outcomes, are poorly understood. A qualitative descriptive study of participants in a successful CHW diabetes self-management program was designed to examine: (1) what gaps in diabetes care, with a focus on patient–doctor interactions, participants identify; (2) how the program influences participants' diabetes care and interactions with healthcare providers, and what gaps, if any, it addresses.

Methods: From November 2005 to December 2006, semi-structured interviews with 40 African-American and Latino adults were conducted and analyzed. Participants had diabetes and had completed or were active in a CHW-led diabetes self-management program developed and implemented using community-based participatory research principles in Detroit. Interviews were audio-taped, transcribed, and coded through a consensual and iterative process.

Results: Participants reported that prior to the intervention they had received inadequate information from healthcare providers for effective diabetes self-management, had had low expectations for help from their providers, and had not felt comfortable asking questions or making requests of their healthcare providers. Key ways participants reported that the program improved their ability to manage their diabetes were by providing (1) clear and detailed information on diabetes and diabetes care; (2) education and training on specific strategies to meet diabetes care goals; (3) sustained and nonjudgmental assistance to increase their motivation and confidence; and (4) social and peer support that enabled them to better manage their diabetes. The knowledge and confidence gained through the CHW intervention increased participants' assertiveness in asking questions to and requesting necessary tests and results from their providers.

Conclusions: Study findings suggest ways that CHW programs that provide both one-on-one support and group self-management training sessions may be effective in promoting more effective diabetes care and patient–doctor relationships among Latino and African-American adults with diabetes. Through these mechanisms, such interventions may help to mitigate racial and ethnic disparities in diabetes care and outcomes.

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Background

African-American and Latino adults with diabetes experience a higher burden of illness and mortality from diabetes,^{1–5} have worse glycemic and blood pressure control, and report experiencing more barriers to diabetes self-management than non-Latino white adults.^{6–8} To address such disparities, Detroit was one of 40 cities funded by the CDC as part of the Racial and Ethnic Approaches to Community Health 2010 (REACH) Initiative. In the REACH Detroit Partnership, community, health system, and academic

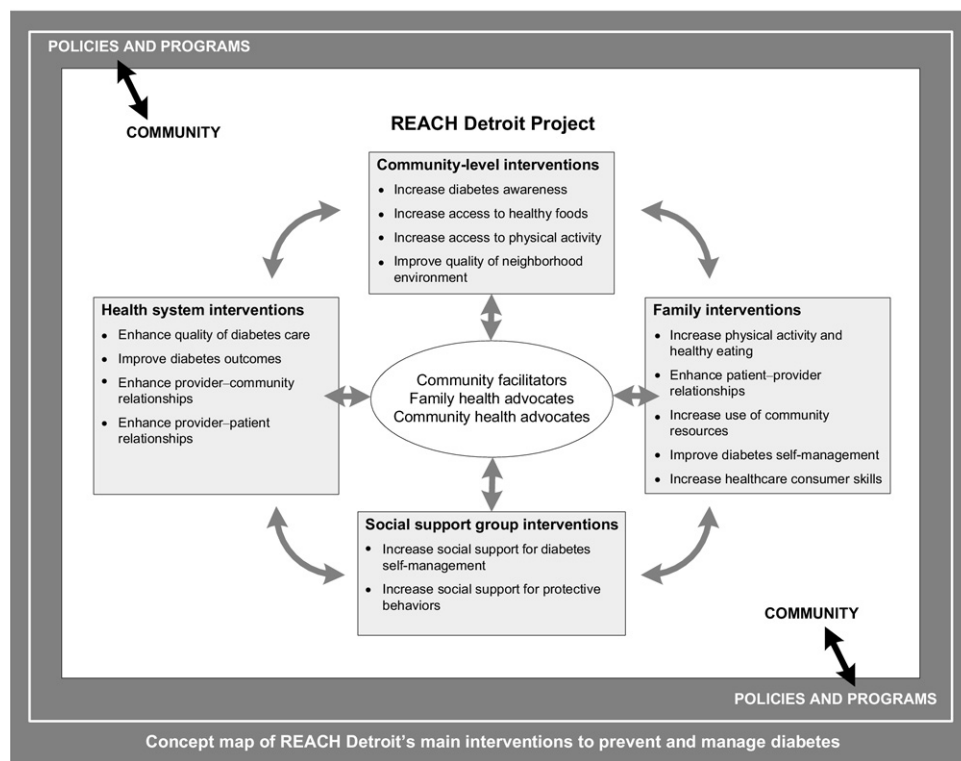


Figure 1. Social-ecologic framework for targeting sources of disparities at multiple levels

partners together developed a social-ecologic framework to target sources of health disparities at multiple levels. The partnership used community-based participatory research (CBPR) principles to guide development, implementation, and evaluation of all programs: involving all partners equally in setting priorities and executing tasks, strengthening local capacity, and equitably sharing power and resources.⁹ After an extensive process of community planning and input described elsewhere,^{10,11} interventions were developed and conducted to increase diabetes awareness, community resources, and social support for healthy lifestyles, and to strengthen the capacity of healthcare providers and African-American and Latino adults with diabetes in eastside and southwest Detroit to manage and improve diabetes outcomes (Figure 1).

Interventions using community health workers (CHW) have demonstrated promise in improving health behaviors and outcomes, particularly for racial and ethnic minority communities with poor access to high-quality healthcare.^{12,13} CHW interventions enlist and train community members who work as bridges among their ethnic, cultural, and/or geographic communities and healthcare providers.^{14,15} In a 2006 systematic review of CHW programs,¹⁵ with adults with diabetes, it was found that CHW programs led to improved diet, physical activity levels, and other self-care behaviors. To date, however, few studies have explored the mechanisms by which CHW interventions lead to changes in participants' diabetes care.^{16,17} Moreover, little is known about which specific

elements of interventions contribute to success, or whether—and if so how—these interventions influence participants' relationships with their healthcare providers.

One hypothesized mechanism by which such programs improve diabetes care processes and outcomes is by helping empower patients to be more knowledgeable about their diabetes care and more assertive in requesting information and recommendations from their healthcare providers.^{1,18} African-American, Latino, and Asian patients report more difficulties in communication with healthcare providers than non-Latino white patients, reporting less information provided¹⁹ and fewer participatory clinic visits.^{20–23} Moreover, African-

American and Latino patients tend to be less assertive in their encounters with providers than white patients.^{1,24,25} Such disparities may contribute to inequities in information exchange, poorer medical decisions, and less patient satisfaction and commitment, all of which may result in worse health outcomes^{26–31} (Figure 2).

In the REACH Detroit Partnership's Family Health Advocate Intervention, trained CHWs, known as Family Health Advocates (FHAs), are assigned to adults with diabetes to promote healthy lifestyle and diabetes self-management behaviors, and to help participants navigate the healthcare system and be more active in clinic visits, with a focus on the patient behaviors listed in Figure 2.^{32–35} Ten FHAs from the target communities were hired, and after intensive training, they conducted a culturally tailored diabetes self-management and lifestyle education curriculum: the English-language "Journey to Health" and the Spanish-language "El Camino a la Salud." The curriculum is based on collaborative "empowerment" models that actively engage patients in setting their own self-care goals and developing problem-solving skills and self-efficacy.^{36–38} The 11 group sessions lasted 2 hours and were held every 2 to 4 weeks at community locations. The development, implementation, and evaluation of these curricula are described elsewhere.^{11,39} FHAs also worked individually with participants to help them know their target risk-factor levels and when they were due for neces-

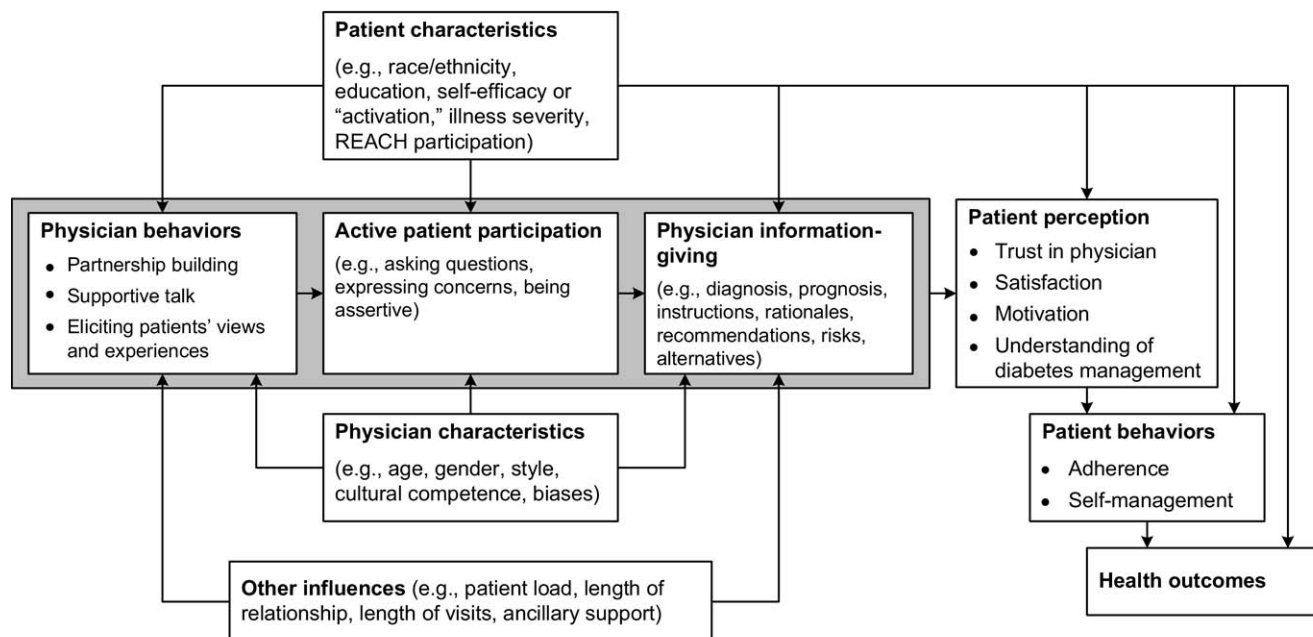


Figure 2. Conceptual model of key domains of patient–doctor interactions for health outcomes REACH, Racial and Ethnic Approaches to Community Health 2010

sary diabetes screening tests, and to set and follow through on specific behavioral change goals. FHAs encouraged clients to discuss the goals they set with their providers, ask questions about their treatment plans, and alert their providers about screening tests that were due.

Two cohorts of African-American and Latino adults with physician-diagnosed type 2 diabetes living in east-side or southwest Detroit were recruited from two health systems. Recruitment methods, participant characteristics, and intervention outcomes for the first cohort have been described elsewhere.¹¹ Briefly, participants in both cohorts made improvements compared to a control group in several measures of healthy behaviors, diabetes-related emotional status, and HbA1c levels, following 6 months of participation in the intervention.⁴⁰

In response to the achieved improvements in diabetes outcomes, the REACH Detroit Partnership Steering Committee requested that we conduct a qualitative descriptive study. The aim was to use study findings to inform continued refinement of the program and other efforts to reduce racial/ethnic disparities in diabetes outcomes. In consultation with community members and FHAs, two study questions were identified: (1) What gaps in diabetes care, with a focus on patient–doctor interactions, do REACH Detroit participants identify? (2) How does a CHW diabetes self-management program influence participants' diabetes care and interactions with healthcare providers, and what gaps, if any, does it address?

Methods

Sampling and Data Collection

From November 2005 to December 2006, semi-structured interviews were conducted with 20 African-American and 20 Latino adults who had diabetes and had completed or were currently active in the FHA intervention. With input from FHAs and community members, interview guides were developed in both English and Spanish to elicit descriptions of participants' self-management activities and needs; their interactions with their FHAs and with their healthcare providers before, during, and after their participation in the Detroit REACH program; and their experiences with and evaluation of the FHA intervention (often called "REACH" by participants). Trained, graduate-level student research assistants from ethnic backgrounds similar to those of participants conducted interviews lasting 60–90 minutes in participants' homes; interviews with Spanish-speaking participants were conducted in Spanish. Participants received \$30 and completed written informed consent. The study was approved by the IRBs of the University of Michigan School of Medicine and Henry Ford Health System.

Data Analysis

Interviews were audiotaped and transcribed verbatim into English or Spanish. All investigators discussed each interview in regular team meetings and developed themes iteratively and through consensus.^{41,42} Near the completion of the interviews, the team developed a codebook based on these themes (e.g., need for self-management strategies, help received from REACH), again using a consensus and iterative process to ensure that codes were clearly defined and could be applied consistently to the data. Twenty-five of the 40 transcripts were coded by two investigators, who reconciled

discrepancies through consensus.^{41,42} The remaining 15 transcripts were coded by one coder. QSR NVivo 2 qualitative data analysis software was used to sort text segments so that all segments with the same code appeared in one report. Each coding report was then summarized by a team member; summaries included key themes and text evidence for those themes. Illustrative quotes in Spanish were translated and back-translated by at least two bilingual team members. These were then shared with native Spanish-speaking REACH steering committee members to confirm accuracy.

Results

Sample Description

Telephone calls were placed sequentially using a list of 151 eligible participants, placing up to five calls to 91 participants. Of the 75 who could be reached, 52 agreed to participate; 12 of the completed interviews were unusable as a result of audiorecording errors. Refusers most often cited time constraints as the reason for refusal. Interviews of 40 participants were completed and audiorecorded. Eighteen of these participants had completed the program, and 22 were participating in the second cohort. It was then concluded that a thematic saturation had been achieved (i.e., no new themes were identified) and no further calls were made to eligible participants.

Twenty participants were Latino, and 20 were African American, with 32 women and 8 men. These percentages reflected the composition of participants in the FHA intervention. The age of interviewed participants ranged from 38 to 72 years. Six interviewees were aged <40 years, six were aged 40–50 years, 19 were aged 51–65 years, and nine were aged ≥66 years. There were no differences between interviewees and eligible non-participants in race/ethnicity, age, or gender, or in reported baseline self-management behaviors and attitudes. Participants interviewed were more likely to have attended more of the group classes (a mean of five versus three classes) than those not interviewed, and 70% of those interviewed had been accompanied to at least one doctor's visit by their FHA, compared to 45% of those not interviewed. The following convention is used to indicate number of participants: a few=1–5, some=6–10, a number=11–19, half=20, a majority=21–25, many=26–34, almost all=35 or more (Table 1).

The principal deficiency that participants identified in their diabetes health care prior to participation in REACH was the low quality and quantity of information from their healthcare providers about how to care for their diabetes (Table 1, Quotes 1–4). At the same time, participants were reluctant to criticize their providers for this. Almost all participants reported feeling that their providers were trying to do a good job in the face of difficult circumstances with very limited time.

A majority of participants voiced low expectations that their providers could take the time to provide more comprehensive information on diabetes, with some participants explicitly placing the onus for the quality of their diabetes care on themselves (Table 1, Quote 2). Almost half of the participants felt that the most they could expect from their doctors was to receive the medications they needed. A few participants noted, however, that their providers did not provide key information on medications, such as when to take them (Quote 3). A number of participants stated that because providers had so little time, they expected them to provide only basic information and to put them in touch with other resources to learn what they needed to know (Quote 5).

Even given limited time, some participants expressed the belief that more could be done by providers, patients, or both, to improve interactions. Some participants lamented that they did not know what to ask their providers in order to improve self-management, or how to gain their provider's complete attention during a visit (Table 1, Quote 6), describing the latter as their responsibility rather than expecting it from a physician. A few participants, however, expressed higher expectations (Quote 4).

A few participants described interactions in which physicians took the time to explain and answer questions about their diabetes management (Table 1, Quotes 7–8).

Almost all participants reported that the REACH program improved their ability to manage their diabetes by providing knowledge and emotional and social support (Table 2). New knowledge included (1) rationales that connected self-management tasks to diabetes outcomes; (2) education and training on specific strategies to meet diabetes care goals; (3) sustained and nonjudgmental assistance to increase their motivation and confidence; (4) social and peer support.

Racial and Ethnic Approaches to Community Health 2010 Provided Rationale for Performing Self-Management Tasks and Specific Strategies

Participants reported that REACH provided the “whole picture,” a broader context that connected self-management tasks to their effects on diabetes, to help participants understand the rationale for recommendations (Table 2, Quotes 9–11). In addition, participants described learning specific strategies from their FHAs to accomplish recommended tasks. While healthcare providers told participants what they needed to do to manage their diabetes (e.g., lose weight, eat a healthier diet, exercise more), they rarely provided concrete, feasible strategies to achieve these goals. As one participant put it: “You can tell me all day to do something, but it's not going to help if I don't know *how* to do it.” Many participants noted that from REACH they learned specific information on what to eat; appealing healthy

Table 1. REACH participants' expectations for and assessments of their interactions with physicians around diabetes care

Patients received inadequate information from their physicians on how to manage their diabetes

Quote 1

My doctor is maybe 90% medicine and very little information of what to do . . . other than medicine . . . what I need from the doctor is writing a prescription and . . . giving me an exam to see what's happening here and there on what part of the body. But as far as the other things that go along with diabetes like exercise and eating, I don't get that from the doctor.

Low expectations—patients expect physicians to give information on medications but not on other areas of diabetes care

- I didn't get [information on complications diabetes can cause] from my doctor. . . . He never took the time to explain all these things . . . doctors don't have that kind of time anymore and I realize this. I don't hold him responsible for that. You got to do some of these things on your own. . . . If you take care of your own self with what little knowledge he gives, you know, he gives you the information and you have to apply it. But I never did get that type of information. I might have gotten bits and pieces here and there, but to sit down and have somebody to discuss with you pros and cons—no, I didn't get that from my doctor. . . . He's only concerned mostly about the medication. (Quote 2)

Even information doctors give on medication may be limited

- I wouldn't change anything [about how my doctor treats me] . . . well the one thing and that's about how often the medication is supposed to be taken, how many hours in between instead of just telling me that you take this one twice a day and this one once a day. Can you take two at one time or is there a certain length of time in between before you take the others? That part of it I would like for the doctor to explain. And not only to explain, but to have it in writing for me so that I can follow that. (Quote 3)

Doctors provide information only if patients know what to ask for

- My doctor, Dr. [Last Name of Doctor], she's swish—a fast doctor, you know. . . . When I say a fast doctor, she's in there—okay, listening to my blood pressure, listening to my pulse, my breathing. Okay, lie down and rub your stomach. What do you need? Medication. Okay. And sometimes—I'm not saying she's not a good doctor, but when I try to slow her down . . . if I know what to ask her for, she'll give it to me. But as far as—I think the doctor should share more information with the patients. Now see . . . : I think Dr. [Last Name of Doctor] should tell me more about what I need to do to kind of fight this diabetes. (Quote 4)

If doctors cannot take the time themselves to provide information, they need to direct patients to other resources

- . . . I could be wrong, but I don't think the doctors now have the time to just sit down with each patient, sit down for 10 or 15 minutes and talk about diabetes. . . . They need to tell you where you can go though, how you can get it. . . . He was the first one that told me about going to class. He gave me the pamphlets and told me to go to classes . . . you get most of your information, more about diabetes when you're able to go to class. (Quote 5)

Even if doctors do not have a lot of time, they can do the best they can with the available time

- . . . I want to learn how to . . . when I'm the person that you're seeing, that you give me your undivided attention . . . give me that 5 or 10 minutes that you in there with me, I want you to be concerned about my issue . . . so that they can let me know what's best for me. And if they're not concerned, they not going to. You know, I'm just a number—you punch in number three! Four! . . . You can put out something good in 20 seconds and you can put out something bad in an hour and a half. (Quote 6)
- My sugar was still somewhat high and the reason it was is because I wasn't taking medication the way I was supposed to take it. And I tried to explain that when I take medication, most of the time I don't want to eat. I don't have an appetite. He says I have to eat anyway. Why do you have to eat when you're not hungry? I couldn't understand that part. Because you have to feed your medicine whether you're hungry or not. So that defeats the purpose of not wanting to gain weight, but then you don't if you exercise. So I asked questions and got answers. (Quote 7)
- [Reflecting on why she likes her new doctor better than her first doctor] Both of them was good. And my other one I talked to too, but this one it seems that I talk to her more. I don't know why. I guess it's because she spends more time. Maybe it's not because she's black. Maybe it's because of the time you know, she sits in there with you longer. Where before you was all in a rush because they have appointments and just got to go. . . . So they won't be in there with you too much like maybe 15 minutes. And with her she sits in there longer. . . . My other doctor, she has her nurse come back in and telling you what to do. She comes back in there rarely. This doctor comes back in there and she tells you. . . . She talks to you if she has something else to say to you or whatever you need. She talks to you again and then she says my nurse will be out and give you the rest of your stuff. So maybe that's what it is, she spends more time. . . . And if there something that maybe you didn't tell her, then when she comes back or something that she might have missed, she'll come back and ask you again. (Quote 8)

recipes and cooking techniques using foods and approaches they had grown up with; shopping for food; and reading labels (Quotes 12–14). They also reported learning how to access neighborhood resources (e.g., locations for better deals on medications and affordable eyeglasses, grocery stores with discounted produce, and exercise classes).

Many participants noted that it was only through participation in REACH that they realized how much they had not known before about how to care for their

diabetes (Table 2, Quote 9). A number of respondents noted the importance of having FHAs devote time and effort to provide them with individual attention and to thoroughly review and reinforce information in-depth, providing specific examples of strategies to meet behavioral goals (Quotes 15, 16). However, a few participants, while expressing appreciation for their FHA's support, expressed concern about the depth of the FHAs' own knowledge about diabetes. As one participant explained, "They try to be helpful as much as they

Table 2. Ways the FHA intervention affected respondents' diabetes self-management and care

FHAs provided clear detailed knowledge on diabetes care that participants had not known before and had not even known to ask providers

- [Before REACH] I thought my doctor had explained what we needed to do and what we shouldn't do, and basically we were doing a pretty good job but . . . [REACH] just painted a clearer picture in your mind what you had to do and what you must do if you wanted to live longer and better . . . we learned a lot of things that I guess you could say the doctor didn't have time to sit down and explain to us. (Quote 9)

Provided big picture explanations so that participants could understand why it was important to engage in particular tasks to manage their diabetes

- [The FHA] drew a diagram, a pyramid. They put medicine at the top and then food and exercise . . . you have to do those three things in order to keep that sugar thing in control. If you don't do them, then you don't keep them in control. . . . When you die, you die from complications of diabetes, not from diabetes itself. But diabetes can cause so many other things to go wrong in your body. So one of them things that it causes, that's really what kills you. (Quote 10)
- I guess I wasn't paying attention to my doctor like I pay attention, since I've been going to the REACH program I'm taking things—it's coming to me better. I'm sitting here realizing if she's right, I'm going to go from here and I'll still be sick so if you don't do what she says to do, and she said sugar and high blood pressure is a silent death. And that's since I've been going to the REACH. I didn't know all that. (Quote 11)

REACH provided education and training on specific strategies HOW to meet specific diabetes goals

- I learned what to eat and how much to eat through REACH mostly. My doctor never told me what to eat and how much to eat. He told me to watch my diet, but he didn't say how. I guess he just look for granted that I knew. I also went to one of his dieticians, but they only spent 1/2 hour to 45 minutes with me. What can you learn from that? . . . But REACH taught me and are still teaching me not just what things I should eat and shouldn't, . . . [but also] how to prepare it, and what it does and what it doesn't do as far as diabetes is concerned." (translated from Spanish) (Quote 12)
- [My doctor] told me that the medicine—that's what he concentrated on, and he told me that the medicine goes along with exercising and diet. Now he didn't give me no program . . . for exercising. He didn't give me a program for eating. He just told me that I couldn't keep doing the things I was doing. So REACH took it from there. They told me the way I should exercise, the things I shouldn't eat like salt, fat, granulated sugar. (Quote 13)
- They were teaching how to prepare your food, what foods you are supposed to eat and what foods you weren't supposed to eat. I needed that information. That's what made me go and that's what keeps me going. . . . After I became a part of the REACH project and they began to educate us on proper diet and even including the proper way to take medication, things began to improve. . . . After I began to eat properly, I began to feel better . . . I started out with a very high glucose level and on Tuesday my doctor called me and told me that my hemoglobin was down to 6.3." (translated from Spanish) (Quote 14)

REACH Family Health Advocates (FHAs) took the time to really explain, demonstrate, and reinforce information

- There was enough time with REACH and with my FHA to really go over things. The more I learned the better able I am at least to be aware. They were right there with me. So I really think a lot of times you know what you're supposed to do, it's just doing it. And so motivation is really helpful to do it and then knowing the consequences if you don't do it. (translated from Spanish) (Quote 15)
- At the [REACH] sessions, all the people that be there, we were all saying the same thing and sharing things together. We're learning more and we're doing better because you're seeing it and you know it. [My doctors] might give you papers on it for you to sit there and read. You can read it all day long and do you understand it? Where with REACH [the FHAs] tell you details. They really explain things in a way you can understand—connecting it to your life. What you don't understand ask. Well, you might ask your doctor and she'll explain that a little bit. Okay. That's it. But that's not explaining everything that I've been reading. . . . To tell you the truth, [REACH] is helping me more than my doctor is helping me. It may be because they're sitting down, have more time with me to sit down and we read and we go over stuff and they tell you about exercise and stuff like that. (Quote 16)

REACH provided focused support and assistance to increase participants' motivation and confidence necessary to improve their diabetes self-management

- Now you know I feel that the REACH program has a little, I see a little glimpse of hope there where at least they're acknowledging me. . . . They've [the FHAs] been reaching from the very first minute that I got the phone call. I like that because it lets me know that somebody else is concerned about your health. You don't have to sit here with all these confusions going on in your mind. There is somebody that can answer these questions for you or somebody that can direct that energy to something that I think will be viable in the future. I really feel that. (Quote 17)

FHAs served as effective "coaches" to help motivate them and follow their progress closely, providing supportive and nonjudgmental assistance

- My weight has been varying for 20 years or more. I just couldn't understand why, you know, how it had come about. [My FHA and I would] . . . go over the daily diets and I think that perhaps when you know—well, with me anyway, I know what to do, but I think perhaps that when someone is monitoring (laughter) you know, when I got a little watchdog there I tend to do better. (Quote 18)
- It is not helpful when my doctor just says get your sugar down, lose weight, and go to this nutritionist and make appointment with this—do this, do that. I need to feel I can talk to him and he is trying to understand me. I need to feel he is interested in my health or something—not just all business and busy. . . . I just went along with this, oh well, you know, I'll do my best. And I would hate to go to the doctor because I was like he's going to be mad because my sugar is low or high. . . . But with [my FHA] I feel comfortable explaining the problem to her and hopefully do better. . . . I always feel comfortable with my FHA. I can tell her anything and she understands and accepts me. (translated from Spanish) (Quote 19)
- I know everybody messes up sometimes. But with REACH, if you mess up, then go back on it tomorrow. And that's what I've learned. When I mess up I'll say I'll do it next time. You know, it goes on. But with my FHA. . . . I say yeah, I messed up. She says what did you do? I say I did what you said to, go back on it tomorrow and start over the next day. . . . Where with my doctor, do it this way, you know, stuff like that. He would just say you messed up. Oh, you messed up. And I'd say I did it again. But with this if I do mess up, I just go back on it the next day. (Quote 20)

REACH groups provided social and peer support and informational exchange that enabled participants to better manage their diabetes

- It's been really exciting [to be part of REACH] because it's been so very lonely. . . . Now I have the chance to call [other people with diabetes that I met at REACH] and talk to them . . . and I know that what I say will help somebody else who's coming in. . . . I guess I can't do it by myself. I don't know, because you need someone to help you to get over fences. . . . My FHA checks up, she makes sure I'm doing what I need to do and helping me. (Quote 21)
- My doctor had told me about it [problems you could get from diabetes], but REACH was more better, understand—and really made it hit, what they call hit home, you know. [In the group sessions] there were people like me explaining things and making it hit home for me. (Quote 22)
- You get to meet friends at the REACH groups and when you get to talk about diabetes with a group of people that have diabetes, it helps a whole lot too. Because there's something she might know that I don't know, and something I might can tell her and she don't know. Like that Mrs. Dash. I didn't see what nobody get out of that Mrs. Dash . . . they give us a little sample of stuff like that for us to try instead of salt. [After] I tried it I said I don't want no more of that stuff. So I went back and I told them. . . . And then this other girl told me, she said she used three different kinds that she used to put on her meat. So I try three different kinds and it gave it good seasoning. But the original one, it don't give it no taste. (Quote 23)

know, because they're really just learning themselves, I think . . . some things that maybe they couldn't really give you the answer to, which I think they should know a little more . . . I think we asked her something one time and I can't remember what it was that she couldn't really answer either."

Participants Received Vital Emotional and Informational Support from Their FHAs and the Community of REACH Participants

A majority of participants noted the importance of the emotional support they received from both their FHAs

and other REACH participants. Some participants described FHAs using terms such as “caring,” “the friendliness of her voice,” and “I felt a connection.” Some participants spoke specifically of the role of FHAs as coaches to help motivate them and follow their progress closely, providing supportive and nonjudgmental assistance (Table 2, Quotes 18, 19). A few participants explicitly noted how they trusted their FHA not to judge them when they “messed up,” which helped motivate them to just keep trying to do better next time, in contrast to their fear that their physician would be upset with them if they had not achieved expected results (Quotes 19, 20). A few participants, however, did complain that FHAs do not themselves have diabetes. As one participant noted, “I guess the only problem that I have with REACH is that none of [the FHAs] are diabetic. And I know they say well, we’re not diabetics but we’ve been trained. But then you still don’t know how I feel. . . . Being trained and going through it are two different things.”

A few participants described their participation in REACH as the first time they had not felt alone in dealing with a difficult illness (Table 2, Quote 21). There were a number of participants, however, who, while finding REACH helpful, felt they already had adequate social support. For them, REACH was a source of better information more than of emotional support.

Another source of motivation, and of useful information, was the community of REACH participants. Participants spoke of exchanging information on the experience of living with diabetes, with people with whom they could identify, and on specific strategies to meet self-management goals, information that in the volume, degree of detail, and relevance to their everyday lives was more useful than that received from their physicians (Table 2, Quotes 22, 23).

Many participants had little to say about how their participation in the FHA intervention specifically affected their interactions with their physicians (Table 3). As one participant noted: “There hasn’t been any change in the way I act with my doctor. It’s basically the same, but through the REACH program, you know, we learned a lot of things that I guess you could say the doctor didn’t have time to sit down and explain to us.”

Some participants, however, noted that the new knowledge they gained through the program influenced their expectations of their physicians and their comfort in asking questions and seeking more information and services (Table 3, Quote 25). In these accounts, when participants started asking their physicians more questions, the physicians responded positively, reinforcing and further explaining information learned from REACH (Quotes 24–28). One participant reported that her physician seemed surprised when she realized

that her patient hadn’t known to ask these questions (Quote 27).

The theme of having more confidence—and less fear—about asking questions and making specific requests of doctors was especially pronounced among Latino participants (Quotes 29, 30). Several participants specifically described the strategies they learned through REACH to prepare themselves to ask questions and make requests to their physicians in office visits (Quotes 31, 32).

Discussion

These interviews with African-American and Latino adults who had participated in a CHW-led diabetes self-management program supported a number of prior findings from quantitative studies on deficiencies in patient–doctor interactions.^{1,20–25} Striking themes were a lack of adequate information from healthcare providers for effective diabetes self-management, participants’ low expectations for help from their providers, and participants’ hesitation to make specific requests of their healthcare providers before participating in the intervention. Most of these reported deficiencies in patient–physician interactions emerged only in response to queries about what participants had gained from REACH rather than in response to direct queries about perceived deficiencies. Overall, almost all participants—even those who later discussed in depth information and support they had not received from their healthcare providers—voiced satisfaction with their personal physicians and the care received from their providers.

These interview findings suggest important ways that the FHA intervention improved diabetes self-management and understanding among participants. Although almost all participants accepted the brief nature of clinic visits, they highlighted key contrasts between the quality of their experiences with physicians and their experiences with their FHAs. In particular, participants expressed their appreciation of FHAs’ provision of thorough information, explanations, and demonstrations of specific ways to improve behaviors (teaching “how” and not just “what”); and of receiving sustained positive, nonjudgmental support and encouragement from the FHAs and other peer participants.

Participants reported that their visits with physicians had been constrained by both time and a lack of participant knowledge about how and what to ask their physicians—as well as by their overall low expectations for what they could receive from their physicians. As a result, before REACH, many participants had received fragmented and incomplete information and did not know where to start in managing their diabetes better. With the additional knowledge, information on specific strategies to improve diabetes self-management, training in strategies to improve patient–doctor communication, and confidence gained from REACH, partici-

Table 3. Ways the FHA intervention affected participants' interactions with their physicians

Knowledge gained through REACH about diabetes care increased respondents' expectations of their physicians and their comfort in asking questions and seeking more information

- And so by me going to the REACH, when I go to see my doctor, . . . they told me and what I read, you know, what they taught me at the meetings and then I go to her and tell her the same thing. And then she says right, you have to do it that way. . . . And so I'm telling her and then she's explaining it to me too. So that's what I'm learning with her. Well, I'm not learning with her. I'm learning with REACH and then she's . . . further explaining it to me. (Quote 24)
- Before I started REACH, I thought my doctor was just supposed to give me my medicines and that was that. I didn't expect any more than that, and I didn't feel I should take her time asking a lot of questions. I also thought I knew what I needed to know about my diabetes. . . . I now realize how much I didn't know at all. I learned how to do what I need to do: specific ways to cook healthy food, what I should be eating, and be active. I wasn't even taking my medicines the way that I should have. Now I feel more comfortable talking with my doctor and asking all that I think that I need to know. I know more so I can ask more. I'm not so afraid." (translated from Spanish) (Quote 25)
- And I have to follow through with exposing myself to the REACH program to people who are asking something of me that I can give . . . I don't feel like before it was never asked of me. And then I didn't know how to—well, I didn't know how to go further than that. If a doctor wasn't able to honestly give me what I thought I was looking for and maybe I didn't even know what I was looking for. If the doctor didn't give it to me, then I didn't know to pursue it. (Quote 26)

Participants after REACH requested test results from physicians

- After I started REACH . . . I can now go and ask my doctor you know, . . . where is my LDL level and you know, which one is controlling the other one? Because I didn't know this until I went to REACH that your doctor can tell you certain things about your blood level. If you exercise enough to control this. I didn't know that, that by them taking your blood they can tell you how much you exercise. I didn't know that until I went to REACH. I was shocked. And when I went to my doctor and I asked her these questions, she went on and told me. I was shocked and I started laughing. She asked me well, what's the problem? She said you could have asked me this if you wanted to know. I said I didn't know that you knew this. She said yes. (Quote 27)
- You, know. I think if you don't know any better, you feel it's adequate. Up until I found out about the A1c from the REACH project, then I went to her and told her that well, I've been going to my A1c classes and what is my A1c number. Oh, okay. So she got up and went to the computer and gave me a printout. Anything else you need to know? And I said right now, as far as I know, that is fine. And she said, "Okay, I'll give you whatever else you need." (Quote 28)

Participants had more confidence to be more assertive in asking questions and making specific requests of their doctors during office visits

- My relationship with my doctor is better because now I have more confidence. . . . Before I just went and they checked me and gave me papers and that was it. I didn't say anything to my doctor, but in REACH they told me I have to ask questions and make requests, like to ask him to check my feet or to tell me how much I weight, so now I ask. I have to go there with a clear mind and ask the doctor everything. . . . [My FHA] helped me see that when you ask questions, nothing bad happens . . . they don't send you to the police or take you to the "immi" [INS]. (translated from Spanish) (Quote 29)
- [My FHA] explained that we have to ask the doctor questions all about what we . . . so we don't have any doubt . . . the FHA advised us to write down everything that we want to ask before the visit and when we go we have to ask the things on our list. . . . I am trying to ask what I need to but sometimes one doesn't have such confidence no matter how much you know you should do something . . . you know when one comes from a country [Mexico] where when you go to a doctor or public hospital you understand that the doctor is doing you a favor to even see you. (translated from Spanish) (Quote 30)

Respondents emphasized the helpfulness of specific techniques they learned through REACH, such as writing down all their questions before they went to the doctor

- After the [REACH] program, they said to me, you have to do it . . . write down your questions, and I write down my questions and when I go I ask them to the doctor. Aren't you going to check my feet? . . . I know now that it is my right to have the doctor listen to me . . . [As I learned through REACH] sometimes one doesn't know how to ask questions, like I didn't know what the A1c was, and now I know that I have to ask about my ABCs [A1c, blood pressure, cholesterol level]. I didn't know anything about that. Now I ask, "So how were my tests? What was it?" Sometimes they still don't tell you the specific numbers unless you ask. (translated from Spanish) (Quote 31)
- [At the REACH classes] we went through activities where it was explained how people had . . . when they went back to the doctor, they brought these things up to them . . . it was something like preparing you for how to bring up things with your physician if you didn't know . . . it was examples. . . . And it was just there for us, all we had to do was just copy from them, I guess . . . And if there was something that we didn't fully know how to do, we could look back at those examples that we'd been given through the classes and you could decide how you wanted to present it to your physician (translated from Spanish). (Quote 32)

pants better knew what questions to ask their doctor, how to approach asking these questions, and how to evaluate whether they were receiving the necessary tests and services. The current findings reinforced ways that greater patient assertiveness may positively influence physician communication, as physicians often assume that if patients want information, they will ask for it.^{18,19,23} These effects, along with a patient's lack of

knowledge and a provider's time constraints, may compound each other—the doctor might ask the patient if they have any questions, and if the patient, not knowing what to ask, responds "no," then the doctor may feel that they have adequately addressed the need to respond to the patient's questions.

Study findings build on prior evaluations of CHW interventions to provide insights into specific ways that

CHW interventions can effectively complement and enhance formal diabetes health care. As postulated in earlier studies,^{12–15,43} FHAs provided a low-cost way to provide more time-intensive and community-based diabetes self-management training and support. In addition, FHAs served as important bridges between participants and the healthcare system, helping coach participants on more effective communication and areas to discuss with their healthcare providers. Because they came from similar backgrounds, there was less social distance between FHAs and participants, helping create trust and comfort in order to work effectively together to improve diabetes-specific behaviors. As important as the FHAs' one-on-one interactions with participants was the group support and information exchange among participants at the group sessions. Indeed, a good part of the benefits of interventions such as REACH may lie in creating a community that provides sustained emotional support and encouragement and a venue for sharing information about how to manage diabetes.

The findings also reinforce those of two prior studies on factors explaining the success of CHWs in promoting healthy behaviors and self-management. In one study¹⁶ a survey was conducted of Latino women participants in a CHW-led chronic disease screening program, who emphasized the importance of the nonjudgmental support and encouragement provided by the CHW in reducing barriers to health care and motivating their enhanced self-care. In semi-structured interviews¹⁷ with participants in CHW programs supporting diabetes self-management, participants noted the value of having CHWs explain how to do something rather than just telling them what to do, as well as the ongoing follow-up and support provided by CHWs.

An important strength of this study is that, by being embedded within a larger CBPR process of developing, implementing, and evaluating the CHW intervention, not only were the study questions developed with community input, thereby targeting questions of key interest to the participating community organizations and members, but findings will be used to continue to improve and refine the ongoing CHW intervention. The key findings reported in this paper have been shared with REACH participants, FHAs, REACH Detroit Partnership Steering Committee members, health system staff and leaders, and community members through several community and health systems. In addition, the findings are being incorporated into the initial and booster trainings for FHAs to further strengthen their skills in those areas identified as most helpful to participants.

Moreover, findings about the need for flexible, ongoing support and the additional benefits of interactions with people who are themselves living with diabetes are being used to inform a peer leader training program for adults with diabetes who successfully com-

plete REACH and are willing to serve as volunteer peer mentors, providing support in conjunction with the FHAs and leading informal, small, drop-in weekly groups. Finally, study findings of the ways that FHAs can best complement formal healthcare visits will guide efforts to increase coordination and communication among FHAs and healthcare providers.

These findings must be interpreted in the face of several limitations. First, findings are based on a small group of inner-city African-American and Latino adults with diabetes who had access to regular healthcare. Lack of access to healthcare is a notable source of racial and ethnic disparities that was not addressed in this study. Second, as with any study based on self-report, the results are subject to social desirability bias. Although participants were assured of confidentiality and did not request the names of their healthcare providers, participants' reluctance to report critical opinions may have contributed to the somewhat paradoxical findings that participants reported high levels of satisfaction with their providers while also describing substantial deficiencies in their care and interactions. Third, all interviews were with participants who had either finished or were participating in the FHA intervention. Thus, their reports of their relationships with healthcare providers before their participation in REACH were subject to recall bias and influence from their participation in the intervention. Moreover, participants who agreed to be interviewed may have been more engaged in the program and have held more favorable views of the intervention than those who declined to be interviewed.

Conclusion

Participants in the FHA intervention delineated deficiencies in both their own prior diabetes knowledge and their interactions with physicians. The deficiencies participants cited in their prior knowledge, motivation, and diabetes self-management support have been identified in multiple studies as key to clinical outcomes. Moreover, such low expectations of and unassertiveness in requesting information and test results from providers contribute to racial and ethnic disparities in chronic disease care.¹ Study findings suggest a number of ways that community health worker programs that provide both one-on-one support and group self-management training sessions may be effective in promoting more effective diabetes care and patient–doctor relationships among Latino and African-American adults with diabetes. Through these mechanisms, such interventions may help to mitigate racial and ethnic disparities in diabetes care and outcomes.

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