




# The Value of Community Health Workers in Diabetes Management in Low-Income Populations: A Qualitative Study

Julie Silverman<sup>1,2</sup> · James Krieger<sup>2,3,4,5</sup> · George Sayre<sup>6</sup> · Karin Nelson<sup>1,2,3,6</sup> 

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## Abstract

To describe community health workers (CHWs) roles in a diabetes self-management intervention. Retrospective qualitative inductive analysis of open text home visit encounter form from Peer Support for Achieving Independence in Diabetes (Peer AID), a randomized controlled trial in which low-income individuals with poorly controlled diabetes received either CHW home visits or usual care. Following visits, CHWs completed encounter forms documenting the health goal of the visit, the self-management strategies discussed and participant concerns. 634 encounter reports were completed for the 145 intervention participants. CHW notes revealed three main obstacles to optimal disease control: gaps in diabetes knowledge and self-management skills; socioeconomic conditions; and the complexity of the healthcare system. CHWs helped participants overcome these obstacles through extensive, hands-on education, connecting participants to community resources, and assistance navigating the medical system. In addition, the CHWs offered uncomplicated accessibility and availability to their clients. CHWs can be a valuable asset for low-income patients with chronic health conditions who may require more support than what can provided in a typical primary care visit.

**Keywords** Community health worker · Qualitative study · Diabetes

## Introduction

There is increasing evidence supporting the use of community health workers (CHWs) to improve health outcomes, reduce disparities and decrease costs. CHWs have been shown to be effective for improving glycemic control among people with poorly controlled diabetes [1] and reducing Medicaid costs through decreasing unnecessary medical

utilization [2, 3]. A wide array of institutions—including the Institute of Medicine,[4–6] Veterans Health Administration [7], and American Public Health Association [8]—recognize the value that CHWs offer and recommend their incorporation into health care delivery.

However, uptake by the U.S. healthcare system has been slow [9, 10]. There is uncertainty about how CHWs would fit into the current primary care model and the health care team would need reconfiguration [11]. Additionally, CHWs do not fit into the traditional (and changing) U.S. payment system. There are questions about training, certification and scope of work [10, 12]. An additional obstacle to incorporation is unfamiliarity with the CHW role. The purpose of this study is to analyze qualitatively the content of CHW visits to illustrate the support skilled CHWs can provide both providers and patients with chronic diseases.

## Methods

We performed a secondary analysis of data from the Peer Support for Achieving Independence in Diabetes (Peer AID) study [13, 14]. Peer AID is an NIH-funded randomized

✉ Karin Nelson  
Karin.Nelson@va.gov

<sup>1</sup> General Internal Medicine Service, VA Puget Sound Healthcare System, 1660 S. Columbian Way, Seattle, WA 98108, USA

<sup>2</sup> Department of Medicine, School of Medicine, University of Washington, Seattle, USA

<sup>3</sup> School of Public Health, University of Washington, Seattle, USA

<sup>4</sup> Public Health - Seattle & King County, Seattle, USA

<sup>5</sup> Present Address: Healthy Food America, Seattle, USA

<sup>6</sup> VA HSR&D Seattle-Denver Center of Innovation for Veteran-Centered and Value-Driven Care, Seattle, USA

controlled trial testing the effectiveness of a home-based diabetes self-management intervention delivered by CHWs. Eligible participants were between 30 and 70 years of age, had poorly controlled type 2 diabetes [defined as hemoglobin A1c (HA1c)  $\geq$  8.0%], were poor (defined as household income  $<$  250% of the federal poverty line) and lived in King County, Washington. They were recruited from a large public hospital, a VA medical center, and a community-health clinic. Compared to usual care, this low-intensity CHW intervention to support diabetes self-management did not significantly improve HA1c; however, the intervention was effective the subgroup of participants whose baseline HA1c  $>$  10% [14]. The institutional review boards of the University of Washington and VA Puget Sound approved the study. Additional details have been previously published [13]. The CHWs were bilingual (English and Spanish) and bicultural employees of Public Health Seattle King County living in the same geographic area as the participants. The CHWs completed 60 h of comprehensive training, including didactic sessions, in-class exercises and field practice. They learned health coaching and motivational interviewing techniques from a professional health coach. The University of Washington and the VA Puget Sound institutional review boards approved the study. Written informed consent was obtained from all participants.

Participants in the intervention group received four home visits, with an optional fifth visit, by a CHW. The CHWs reviewed six required education topics—including signs and symptoms of low and high blood sugar, the relationship between diabetes and food, and how diabetes medications work—with all participants. Depending on the clients' baseline assessment and interests, the CHWs used an additional 17 educational protocols developed for this study. For example, for clients who screened positive for food insecurity, CHWs would help clients apply for SNAP (Supplemental Nutrition Assistance Program) benefits and share other sources of nutrition in the community. At each visit, CHWs asked participants to identify a health goal and discussed potential obstacles to and resources for achieving the goal. After each visit, CHWs completed an encounter form summarizing the session. This form had close-ended items as well as free text options. The encounter form served as a tool for communication with primary care providers (the first two pages were faxed to PCP offices) as well as for documentation of the visit for client management and research fidelity.

### Qualitative Analysis

We performed an inductive content analysis [15] of the text using open coding performed by one author (JS), who iteratively added emergent codes throughout the analysis to reflect quotations that did not adequately fit previously developed codes. Coding continued until thematic saturation

was reached (the point at which subsequent data failed to produce new findings) [16]. Broad themes were identified from the codes and grouped under high-order headings that described distinct activities of the CHWs' role until all relevant themes had been identified. ATLAS.ti [17] qualitative data analysis software was used to organize the coding process.

## Results

Of the 287 Peer AID participants, 145 were randomized to the CHW intervention, resulting in a total of 634 encounter reports (average of 4.4 visits per participant). Three major CHW roles were identified: teaching diabetes fundamental and hands-on, self-management skills; connecting participants to community resources; and helping navigate the medical system. Additionally, the CHWs were easily accessible and enormously supportive, characteristics often lacking in primary care setting.

### Education and Self-Management Support

The CHWs spent significant time identifying and correcting participants' knowledge gaps about diabetes and self-management. Some participants displayed uncertainty about their medication regimen. In response to one participant's confusion, the CHW and participant "organized [the] medicine box together. CHW has a current list of medications.... Client's strategy to fill box in the middle of the week so that one line of am + pm filled boxes remain that will serve as an example for filling up the rest of the week's empty boxes." For another participant, the "client and I wrote what each of his medications are for in the bottle in Spanish to be able to look at before taking." The CHWs also reviewed participants' understanding of their medications and offered education where needed:

Client described taking '2 sugar tablets at 11 am & at 6 pm' to prevent lows and to treat lows. I wasn't clear what she meant until I asked her to show me the 'sugar tablets.' She showed me a bottle of Metformin pills. I explained what Metformin does and that it was great that she was following the PCP's prescription but that they are not called sugar pills and that to treat a low she needs to drink 4 oz. of juice or 1/2 can of soda or 3 hard candies.

CHWs answered participants' questions about their medications. For example, one participant shared, "I'm afraid of weight gain from insulin. Does insulin accelerate food and fat in our systems? So could I get heavier with insulin?" The CHW reviewed the following information:

Yes, because it promotes nutrient storage to the body's cells. So insulin can increase weight up to 10 pounds. That's why it's so important to use the prescribed dosage of insulin (the best/minimum) amount for A1C control. Sometimes people over-eat and then use extra insulin outside of PCP recommendations to cover the blood glucose they just took in, so they are doing 2 things right there that will greatly affect their weight gain. Finding the right balance is what your PCP does and sticking to that plan and talking with your PCP is very important.

Some participants understood their medication regimen but struggled to take their medications as prescribed. One participant was a caregiver for her mother and often forgot to take her own medications. In response,

we problem-solved, and she determined she could bring her medications downstairs and keep them in a special spot - so that she has access to them quickly when she needs them and will not be missed 'on-the-job' with her mother since they will be stored in a location that will make it quick for her to take downstairs.

The CHWs also offered education about food and nutrition. One CHW noticed that a client "makes drinks at home with lots of regular sugar, and she states that someone told her that if she squeezed lemon or lime in it, it would break down the sugar content on it. We talked about trying to use a sugar substitute instead, and she stated that she will just drink plain water instead." Another client had stopped drinking pop "but seems to have substituted orange juice in. I discovered this as I was leaving the appointment and briefly discussed this with her sister... that like pop, orange juice is used to elevate sugars in emergency lows."

The CHWs used a teach-back method to confirm participants' understanding:

I worked with her on documenting her blood glucoses (twice daily) using the Alternate Days/Times Patterned check. After educating on this piece and going over the healthy plate with vegetables covering 1/2 the plate (the second educational piece on this nutrition basic), I asked her how much carbohydrates she has been eating and how much she thought was the right amount to eat. She said half the plate. So I re-clarified that vegetables could cover half the plate and that carbohydrates (like starches) need to be measured referring to her book. We pulled out her measuring cups (using 1/3 c.) to measure out rice and showing that she could eat 2 portions of rice = 2/3 c. + 2 other carbohydrate portions (for 4 maximum) at a meal. I will call her to see how proportioning out her carbohydrates goes.

The CHWs helped participants develop their own skills. For one client residing in a rehabilitation facility, the CHW "accompan[ie]d him on an 'eat-around' at the lunchtime meal to watch initial food item selections, help him request substitutions, then debrief and discuss food selection choices and his comfort in this type of future self-advocacy." In another example, the CHW "gave [the] client a book that has healthy and easy to do meals, and I also asked client if she wanted to, I would be willing to cook with and give her a better idea to get her started. And she was very happy." The CHWs made sure the participants knew how to use their new knowledge for better diabetes management.

### Addressing Socioeconomic Challenges

Despite appropriate education and the desire to manage their diabetes more effectively, participants faced significant socioeconomic obstacles to achieving optimal diabetic control. Food insecurity was a major barrier addressed by CHWs. For one client, they "worked on reducing food insecurity through access to a local community garden in May/June and the DSHS Senior Nutrition Farmer's Market Program." Helping another food-insecure participant, the CHW planned on "mailing DSHS website for food stamp application, checking on income guidelines prior. Checking on free or \$10 cost yoga classes. Mailing out... the website for walking groups." The CHWs helped one client with meal planning on a reduced budget:

When I asked him if he had enough money to purchase the food he'd need until his next meals-on-wheels delivery, he said he wasn't sure but that he'd make it work. This left me doubtful so I asked him if he was willing to figure it out with me on paper. We figured out that he'd need about 14 meals to get through Monday after lunch. So starting Thursday he has 5 meals-on-wheels left and would need money for 9 meals. He decided on what would be the most economical meals to eat that would also be healthy and made a list of purchases: ground beef \$5, whole chicken \$5 (to make 6 meals), cabbage \$3, ham hock \$4, 24 eggs \$7, oatmeal \$5, bread \$3.50, grits \$3, fruit list \$12 = \$47 and he has \$50.00 so he may have to spend less on fruit perhaps. So he planned for 4 breakfasts and 3 lunches.

For participants struggling to afford their medications, the CHWs helped participants apply to various discount prescription drug programs. The CHWs assistance extended beyond food and medication. When a participant received an electricity bill for \$700, the CHW contacted an energy assistance program to get this bill reduced. In another case, the CHW "referred [the participant] to the Office of Civil Rights to explore her rights" when she faced workplace discrimination. For another participant,

the CHW discovered that the patient's wheelchair was too wide for her doorway and contacted the housing authority to get the doorway widened. In another situation, the CHW submitted a weatherization services application to the housing authority to address a leaky roof and mold. CHWs connected participants to valuable resources and helped problem solve some of their socioeconomic challenges.

### Navigating the Healthcare System

The complexity of the healthcare system presented another barrier to optimal glycemic control. CHWs played an important role in navigating the system to get appropriate care. When participants did not understand their PCP's plan, the CHWs would call the medical clinic to clarify the provider's instructions:

I helped client make a call to clinic to ask Care Coordinator about insulin use. Client was confused on how many times he should be using it. Client was only using it once a day, but he needed to use it twice a day. I encouraged client that if he has questions he should always call clinic, and they will be able to help him with questions, or concerns.

Even seemingly small issues, like getting new equipment, could be impediments:

She hasn't been able to check her blood glucose because she didn't know how to refill her monitor with new puncture tips. The instruction booklet she had didn't match the type of Accu-check she has.... I called the... pharmacy who referred me directly to the company. These phone calls took quite a while, but in the end I was able to teach her how to re-fill these tips into her device."

When a participant had difficulty accessing a low-income dental clinic, the CHW did not simply supply the client with the dental clinic phone number; instead, she replied: "I understand—the system has a definition of homeless that you fit in order to qualify for services—even if you don't see yourself as homeless. Let's call together and figure out how their system works." When a participant expressed the desire to cut down on alcohol use, the CHW connected him to clinic resources that he otherwise would not likely have accessed. In some cases, the CHWs accompanied participants to their medical appointments to offer emotional support and encouragement, or in some cases much-needed translation: "A nurse was trying to explain (post-operative instructions) to him in English. Since I was there I was able to translate the newest recommendation."

### Availability and Support

One of the most valuable roles the CHWs played was being available for participants with time and support. The CHWs communicated with their clients much more frequently than the 4 or 5 scheduled home visits. In response to a participant's goal to increase exercise, CHW noted "I will call him once a week to check on his progress and if needed offer to meet him at a walking group." For another participant, the CHW planned to "check in with him 2 times per week to provide support, especially around the commitment he made to check blood glucose on the alternate pattern." The CHWs continued to promote self-management techniques outside of their routine visits. A participant was nervous about accessing the food bank for the first time: "She needs support in feeling comfortable with the food bank, so as part of her Nutritional Goal and ensuring she eats 5 or more servings of fruits and vegetables, she will meet me at the El Centro Food Bank and discover how it works." On encountering a client with little support who was feeling weak, the CHW offered to "check in with client re: chore worker hours. If chore worker not made available, CHW will shop for client once before the next visit in 2 months."

### Discussion

In this study, we found that CHWs played four key roles: identifying and addressing gaps in participant knowledge of diabetes and self-management skills; identifying socioeconomic obstacles to diabetes self-care and connecting clients to appropriate community resources; helping participants navigate the healthcare system; and providing time and support. These roles may typically fall outside of the scope and time of a primary care practice.

The knowledge and behavioral gaps observed in this study were impressive. While it is not surprising that people with poorly controlled diabetes did not have a good grasp of their condition, these participants had a PCP and were engaged and motivated enough to volunteer for this study. In fact, they were frequent utilizers of the health care system, with 5.7 mean visits in the previous 12 months [13]. One might expect that these engaged patients would have a reasonable understanding of diabetes. That such knowledge gaps existed among this group highlights that education provided in the primary care setting may not be adequate. The requisite information and training for successful diabetes management may not be able to be imparted in a typical PCP appointment. By analyzing the content of CHW visits, we describe some advantages of this model of self-management support. CHWs have time to spend with clients, allowing them to provide in-depth and hands on training. The value of teaching a person how to read food labels and

purchase healthy and affordable foods while walking through an actual grocery store is immeasurable and something that cannot be replicated in a traditional primary care setting.

CHWs can see participants in their homes. The CHWs saw what foods were in the refrigerator; they saw the patient's leaky roof; they saw the lack of sidewalks and opportunities for physical activity in the neighborhood. Patients do not necessarily share these issues with their PCPs but these issues are important to health management. Without knowledge that their patients do not have access to fresh produce or that their neighborhood is unsafe to walk in, PCPs may recommend medical plans that are impractical for their patient.

### Strengths and Limitations

Strengths of the study include the in-depth analysis of the rich information collected by experienced CHWs in the field. They also provide information about the lived experience and challenges faced by low income persons with diabetes. The encounter forms analyzed in the study were designed as a communication tool between CHWs and health care teams, a way to document and ensure protocol fidelity, and a case management tool for the CHWs and their supervisor. As such, the forms were not developed with qualitative analysis in mind, and the data was not uniformly collected; it was up to the CHW as to what information they chose to record. The data analyzed were not direct quotes from study participants. Rather, they were the CHWs' summary of each visit. What the CHWs documented is their interpretation of the visit, which is highly subjective. An additional limitation is the use of only one coder to review and code the encounter forms. Because only two CHWs were used, there are limitations to the generalizability of the study.

### Public Health Implications

CHWs can play an important role in the healthcare system, particularly for low-income patients, and could be one potential mechanism to improve the health of populations [8]. By seeing patients in the community and assuming roles that go beyond those typically played by members of conventional primary care teams, CHWs have a fuller understanding of these patients' lives and difficulties. Sharing their insights with the health care team can help the providers understand why their patients are struggling with managing their diabetes and other chronic medical conditions.

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### Compliance with Ethical Standards

**Conflict of interest** The authors have no financial conflict of interest to report.

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