

What did the Community Health Worker do that was Helpful? Perceptions from Patients with Type 2 Diabetes

Yan CH^{1*}, Rodriquez A², Gerber BS³ and Sharp LK¹

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Abstract

Objective: Evidence supporting the effectiveness of community health worker (CHW) programs in improving type 2 diabetes mellitus (T2DM) outcomes is mixed. This may relate to the different roles or support services CHWs provide across programs. Furthermore, little is known about what activities patients considered most helpful. This summative evaluation reports on patients' perspectives of CHW activities offered as part of a larger randomized controlled trial of a team-based diabetes-management program.

Methods: Following one-year of access to CHW support, 192 racial/ethnic minorities with uncontrolled T2DM completed a summative evaluation assessing how helpful they found the CHWs, on a ten-point scale, along with an open-ended question about specific activities they found most helpful.

Results: Patients' mean age was 57 years, 25% identified as Hispanic, of which 47% preferred Spanish, and 75% were African-American. Perceived helpfulness was similar for both groups (Hispanic 9.2, standard deviation [SD] 1.5 ç•É African-American 9.1, SD 1.9); although the number of CHW visits was higher among Hispanics compared to African-Americans (9.8, SD 5.4 ç•É 5.0, SD 4.7; p<0.001). Conversely, the frequency of CHW visits was similar between Spanish- and English-speaking Hispanics; however, the mean helpfulness rating was higher for Spanish-speakers than for English-speakers (9.6, SD 0.8 ç•É 8.8, SD 1.8; p=0.05). After qualitative coding of the list

in diabetes specific support/education, but also helped them communicate with other team members. An interesting pattern of helpfulness ratings emerged suggesting that frequency of visits related to factors other than perceived helpfulness. Finally, this is among the first reports of engagement within racial/ethnic groups.

management. Ö' T' I, Ö. along with modest reductions in hemoglobin improvement in patients' diabetes knowledge and disease self-

Keywords: Community health worker; Type 2 diabetes mellitus; Underserved; Health disparities; Summative evaluation; Patient preferences; Perspectives

A1c (HbA1c) [12], others found no impact on outcomes [10]. Limitations included a lack of standardized CHW training, inconsistent CHW activities, and differing levels of CHW integration into the healthcare system [1, 14, 15]. This may relate to the fact that the scope of practice, training, and skills involved in serving as a CHW have not been well defined [16]. These variations in CHW intervention approaches limit the ability to understand the underlying pathways that might drive improvement in patients and prevent comparison across different CHW interventions [17].

Three published qualitative studies have explored the pathways through which CHWs might impact T2DM outcomes by asking patients what CHW roles they found most helpful [14, 18, 19]. The first assessed 25 African-American women's experiences with a CHW-delivered peer support program. Participants valued the social and emotional support provided by the CHW, along with the partnership and healthcare liaison CHWs offered [19]. The second purposefully sampled 47 Hispanic adults who noted CHWs provided

Community health workers (CHW) in the United States (US) fill

diabetes and non-diabetes-related needs [14]. The third included 40 of 151 African-Americans and Hispanics who participated in a CHW-led diabetes self-management program. Similar to the other studies, participants reported that CHWs provided them with knowledge and support that built their confidence to communicate with their healthcare providers along with providing non-judgmental assistance to work on their diabetes-related goals [18].

In terms of T2DM and CHW support, patients across studies identified similar roles and activities they found helpful such as motivation, confidence, and support. However, generalizability of the studies is limited due to small samples that were biased towards highly engaged patients. In addition, CHWs were all community-based as opposed to integrated into healthcare teams. Team-based healthcare models with CHW support are increasingly popular; however, patients' perspectives are sorely missing. Understanding the pathways through which CHW roles and activities drive improvements in outcomes is essential in developing cost-effective and sustainable diabetes-management programs [16,18]. Among a sample of racial/ethnic minorities with uncontrolled T2DM, this analysis explored the CHW roles and activities patients identified as helpful. The CHWs support was delivered in the context of a randomized controlled trial of a team-based diabetes-management program.

Data for this report was collected within the context of a larger NIH-funded, randomized crossover trial of a team-based diabetes-management program. The team included a primary care physician, clinical pharmacist, and CHW hired within the healthcare system. All participants received primary care services and clinical pharmacy support for two years with the addition of CHW support randomized to one of those years [20,21]. Full details of the study design and primary outcomes are published elsewhere [22,23]. This report focuses exclusively on the summative evaluation of patients' experiences with the CHWs.

Briefly, enrolled patients were required to have established primary care for at least one-year within the urban, academic medical center where the research was being conducted. Recruitment within the larger trial was conducted by experienced research assistants at patients' regularly scheduled clinic visits. Data for the current report was collected at the end of the year that patients worked with a CHW as part of the data collection in the larger study. The University of Illinois at Chicago Institutional Review Board approved all research.

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Four women, two African-American and two bilingual native Spanish-speaking Latinas, served as full-time CHWs. CHWs were US citizens, had a bachelor's degree, and were experienced working in communities involved in the research. They had experienced the stress of caring for families with limited resources, dealing with discrimination, and many other barriers that patients similarly face

Unemployed	1 (2.9)	22 (14.0)	23 (12.0)
Retired	7 (20.0)	21 (13.4)	28 (14.6)
Disabled and unable to work	18 (51.4)	78 (49.7)	96 (50.0)
Marital Status, n (%)			
Single, never married	19 (54.3)	60 (38.2)	79 (41.2)
Married or living with partner	8 (22.9)	50 (31.9)	58 (30.2)
Widowed, separated, or divorced	8 (22.9)	47 (29.9)	57 (29.7)
Insurance, n (%)			
HMO/PPO	5 (14.7)	29 (18.5)	34 (17.8)
Medicare	8 (23.5)	27 (17.2)	35 (18.3)
Public Aid/Medicaid	17 (50.0)	97 (61.8)	114 (59.7)
Uninsured	4 (11.8)	4 (2.6)	8 (4.2)
Self-rated health status, n (%)			
Excellent/ Very good	3 (8.6)	8 (5.1)	11 (5.7)
Good	16 (45.7)	48 (30.6)	64 (33.3)
Fair	15 (42.9)	80 (51.0)	95 (49.5)
Poor	1 (2.9)	21 (13.4)	22 (11.5)
†Numbers are less than 100% due to refuse to answer or missing data *Statistically significant at p<0.05 (Fisher's exact test)			

Table 1: Baseline patient characteristics and demographics (N= 192).

them on diet and nutrition, such as recommending healthier recipes, food portion sizes or reading food labels. These resulted in weight loss for at least one patient who noted “with her [CHW] help, I lost 12 lbs, and she helped me focus [by having] me write down everything I ate.”

Several patients mentioned that the CHW supported them in adhering to their medication regimens, such as setting an alarm on their smartphones, putting together a medication schedule for them, or calling them to check if they took their medications. Other patients appreciated when the CHW clarified which medications to take at what time or discussed their medication-related concerns.

Theme

The third most common CHW role was facilitating communication with the healthcare team. This included the CHW speaking up in support of patients at their pharmacist visits (n=10) or physician visits (n=16), and helping patients build their self-efficacy to engage in aspects of their care (n=52). For example, one patient stated that the CHW “helped me take notes at the pharmacy appointment” and another patient found it helpful that the CHW would “help me talk to the pharmacy about my medications when I had problems.”

ended question. Several patients commented on the emotional support they received in response to experiencing the death of a loved one or other stressful life events while working with the CHW. Others described that having a trusting, nonjudgmental, and accepting advocate was a new experience that contributed to a renewed feeling of worth and self-confidence. Some mentioned they felt supported and encouraged to attend their health provider appointments when the CHW accompanied them. It is important to note that 45% of the patients did not mention social support. Perhaps some patients had sufficient social support or simply did not mention it because other activities were more valued. However, one must also consider that some individuals may be less able to use social support provided by a CHW along with the possibility that CHWs may not effectively provide social support to everyone. The "fit" between the patient and the CHW may be important, although not often discussed outside of racial/ethnic or language concordance.

It is important to note that the CHW model did not work for everyone in the study. This is reflected by 35 (18%) patients not completing a single visit with their CHW. Of these patients, 34 (97%) were African-American. The reason is unclear. However, this may potentially be related to the language barrier experienced by Hispanic patients who benefited the most from and relied on the CHW to assist in interpretations with their providers. In addition, it is noteworthy that over half of those without CHW contact were disabled or unable to work suggesting that this group may be experiencing some unrecognized barrier in need of closer examination. Understanding why certain patients do not engage in CHW-led diabetes management programs may suggest novel approaches designed to address specific patient's needs.

This study involved a single urban, academic medical center that served predominantly lower income, minority patients. This limits generalizability of results. The number of CHW encounters varied across patients and may have influenced their experiences with their CHW in ways not captured. Furthermore, responses to the open-ended question may have been impacted by recall bias or varying levels of motivation to respond. There is potential for selection bias as only patients who returned for data collection in the large study completed the survey. Despite these limitations, this study provides support that many patients find CHW helpful in management of their diabetes. Unique to other studies, CHWs were integrated into a healthcare team. This is important as evidence demonstrates that CHWs' patient care

contribution to patient health outcomes

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