Teaching How, Not What

The Contributions of Community Health Workers to Diabetes Self-Management

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Purpose

The purpose of this study is to describe ways in which community health workers (CHWs) are used in various clinic and community settings to support diabetes self-management.

Methods

Descriptive quantitative data were collected from logs completed by CHWs. Logs described mode, place, type, duration, and focus of individual contact between the CHW and the patient. Qualitative data were collected from semistructured interviews with patients. Interviews were conducted on site from June to August 2006. Interviewees included a purposeful sample of 47 patients who perceived being helped by CHWs.

Results

CHWs reported providing assistance and teaching or practicing skills as the focus of most of the 1859 individual contacts. The assistance CHWs reported providing was most often in the form of encouragement/motivation. During interviews, patients shared that CHWs were helpful in demonstrating how to incorporate diabetes self-management (DSM) into their daily lives. The information patients shared also provided insight into what they perceived as encouragement/motivation from the CHWs. Quotes from interviews provide specific examples of how support from CHWs was different from that received from family and health care team members.

Conclusions

Both CHWs and patients perceived assistance being provided in similar ways, with consistent emphasis on

encouragement/motivation. Interviews with the patients revealed that a personal connection along with availability and provision of key resources and supports for self-management made the CHW-patient interaction successful for DSM. Examples provide insight into the valuable contributions of CHWs to DSM. This insight should encourage guidelines that make CHWs a routine, standard part of the diabetes care team.

As the prevalence of type 2 diabetes reaches an epidemic proportion, more people face the challenge of learning how to manage the disease properly. People with diabetes must implement diabetes self-management (DSM) in dealing with a disease that can make them feel overwhelmed or frightened. They must also contend with adapting their DSM based on the constraints of daily life.[1] Effective DSM is essential to prevent further complications and to improve the quality of life of those with diabetes. To promote an approach from the perspective of individuals' needs, key Resources and Supports for Self-Management (RSSM) have been identified.[2] These resources include individualized assessment, collaborative goal setting, skills enhancement, follow-up and support, access to resources in daily life, and continuity of quality clinical care.

For successful self-management, these key resources must be used for a lifetime. In particular, research suggests that follow-up and support are critical for chronic disease management. Follow-up may include monitoring of clinical status, encouraging and motivating patients, and facilitating coping skills. Furthermore, the experience of the Diabetes Initiative suggests that this type of support should be available on demand, be proactive in preventing people from slipping through the cracks, and provide a personal connection.[3]

One way to provide this type of support is to use community health workers (CHWs). The literature demonstrates that CHWs are effective in DSM programs.[4] CHWs are trusted and respected community members who serve as a bridge between their peers and the health care system.[5] They are known by many different names and serve in a variety of roles including outreach and patient recruitment, education and skills training, assistance with goal setting, patient social support, case management, and patient follow-up.

In addition to these roles, CHWs strengthen existing community networks.[6,7] As members of the community they serve, they can act as liaisons between health care providers and community members. They educate the provider about community needs and culture while providing patient education in a culturally appropriate way. At the same time, they are using the same language and value system as that of the community. The duties they perform as liaisons add to the continuity of care and allow CHWs to assist health care providers by sharing information about the relevance of interventions.[5]

Culturally relevant interventions may be particularly important for those who have traditionally lacked access to care. In fact, research shows the effectiveness of CHWs in chronic disease management in disadvantaged populations.[8,9] These predominately ethnic and minority populations often face an increased burden of diabetes and its management. For example, ethnic and minority populations are 2 to 5 times more likely to have diabetes and more likely to suffer from complications than non-Hispanic whites.[10,11] Specifically, Hispanics are 1.7 times more likely to have diabetes than non-Hispanic whites[10] and 2 to 3 times more likely to suffer from serious secondary complications.[12,13]

Among Hispanics in the border region, the prevalence of diabetes is nearly 50% higher than the rest of the country.[14] Inadequate access to proper diabetes prevention and control programs and improper quality of care have been identified as some potential reasons for such disparities in diabetes health outcomes.[15] Particularly for Hispanics, language barriers, cultural differences, and administrative obstacles are barriers that place this population at increased risk of underuse of services, poor quality of care, and worse health outcomes than whites.[16]

Use of CHWs has been suggested as a way to reduce health disparities by increasing access and quality of care for underserved populations.[7,17-19] However, the most important duties and the nature of the patient-CHW interaction that make this relationship a success have not been well delineated. The purpose of this study is to describe ways in which CHWs are used in various clinic and community settings to support DSM.

Methods

Study Setting

The Diabetes Initiative of the Robert Wood Johnson Foundation is a national program whose mission is to

improve the quality of life of people with diabetes by demonstrating the feasibility in real-world settings of self-management systems and building community supports for diabetes care.[20] This article includes findings from program sites serving predominantly low-income Hispanic populations in which CHWs were integral to their DSM programs.

- *Campesinos Sin Fronteras (Somerton, Arizona).* Within the DSM program at this community-based organization, CHW duties include leading self-management classes and support groups in the community, referring patients, checking on patients at least once a week, and conducting outreach activities for migrant farm workers throughout the community. The population served is primarily Mexican/Mexican American.
- *Gateway Community Health Center Incorporated (Laredo, Texas).* At this federally qualified health center, CHWs are embedded into the DSM program, where their duties include leading 10-week self-management and 10-week support classes at the clinic as well as patient follow-up via telephone. They serve Webb County, where the population is more than 95% Hispanic and more than one third live below the federal poverty line.
- *Holyoke Health Center Incorporated (Holyoke, Massachusetts).* CHWs in the DSM program at Holyoke's federally qualified health center work mainly in the clinical setting to identify, motivate, and engage patients with type 2 diabetes who have not seen their primary care physician in the previous 4 months. They also facilitate a variety of classes and provide ongoing follow-up and support. Their patient population is 89% Latino/Puerto Rican, and 100% live at or below the federal poverty level.
- *La Clínica de la Raza Fruitvale Health Project (Oakland, California).* In the DSM program at this federally qualified health center, CHWs lead orientation and education classes, support groups, and walking clubs. They also have weekly contact with the patients and provide ongoing support. Approximately 85% of the patient population lives at or below 150% of the federal poverty level, and most are uninsured or enrolled in MediCal.

Data Collection

The National Program Office (NPO) of the Diabetes Initiative at Washington University in St Louis, Missouri, collected descriptive quantitative data to capture the CHWs' reports of what they do. The CHW worker logs (Figure 1) were used to document all individual services provided over a 2-week period. These were completed quarterly over a 1-year period starting in July 2005 at each site. The time frame was chosen to control for any seasonal differences in the data. CHWs completed them, and the data collected included information on mode, place, type, duration, and focus of contact. Type of contact included face to face, telephone, e-mail, and mail. Frequencies were calculated to show the mode, place, type, and focus of contact. Among the CHWs who reported providing assistance, frequencies were calculated to determine what types of assistance were provided. The mean and standard deviation for duration of contact were calculated. Analyses were conducted in SPSS version 14.

Qualitative data were collected from 47 Hispanic adults (12 men and 35 women) with type 2 diabetes to understand the patient perception of what occurred in the CHW interaction and what was perceived as helpful to the patient. The purpose of these interviews was not to assess the effectiveness of CHWs but, assuming they are effective, to identify some of the specific reasons for this. Accordingly, local project coordinators at each site identified and recruited a minimum of 10 patients who had had positive experiences with a CHW (a purposeful sample). Specific recruitment methods varied by site. In some cases, coordinators recruited 12 to 15 patients to account for possible attrition due to illness, transportation problems, or other scheduling conflicts. All recruited patients who kept their appointments were interviewed. Patients were given a $20 gift at the end of the interview for their participation.

At each site, a team consisting of a trained interviewer assisted by a local liaison conducted the interview. A trained interviewer from the NPO conducted the in-depth interviews from June through August 2006 over a span of 3 days at each program site. The interviewer was a second-year master's in public health student trained in research and evaluation methods and health disparities research. She had prior experience with qualitative data collection and coding, recruiting low-income minority adults in community settings to participate in research, and administering face-to-face study protocols. She was also proficient in Spanish. The local liaison was not involved in delivering services to the person being interviewed.

The interviews began with an introduction of the project and an explanation of the purpose of the interview. The interviewer reassured each patient that CHWs were not being evaluated and that the impact of CHWs was well noted. Patients were also assured that the interview team would not share their individual comments with their local

CHW Initials: _____ Client ID: _____ Date: _____

Mode of contact

- ☐ Face to Face
- ☐ Phone
- ☐ E-mail
- ☐ Mail
- ☐ Other (Please specify) _____

Place

- ☐ Home
- ☐ Community
- ☐ Clinic
- ☐ Other (Please specify) _____

Type of contact

- ☐ CHW Initiated
- ☐ Client Initiated
- ☐ Medical Visit

Duration of contact

__:__ hours:minutes

Focus of contact:

- ☐ Teaching or practicing skills (check the type of skill)
  - ☐ healthy eating
  - ☐ healthy coping
  - ☐ physical activity
  - ☐ problem solving
  - ☐ monitoring
  - ☐ reducing risks
  - ☐ taking medication
- ☐ Providing assistance
  - ☐ helping to set a goal
  - ☐ giving health information (education)
  - ☐ emotional support (for an acute problem or stressor)
  - ☐ encouragement or motivation
  - ☐ personal needs (e.g., transportation, translation, filling out forms, etc)
- ☐ Making a referral
  - ☐ for social services (e.g., housing, food, employment, etc)
  - ☐ for health services
- ☐ Recruiting participants, inviting them to participate in programs, etc
- ☐ Monitoring and follow-up on participant progress (e.g., check-in, general updates, etc)
- ☐ Making client aware of rights, services available, etc (advocacy)
- ☐ Other (Please specify) _____

Figure 1. Individual visits community health worker log.

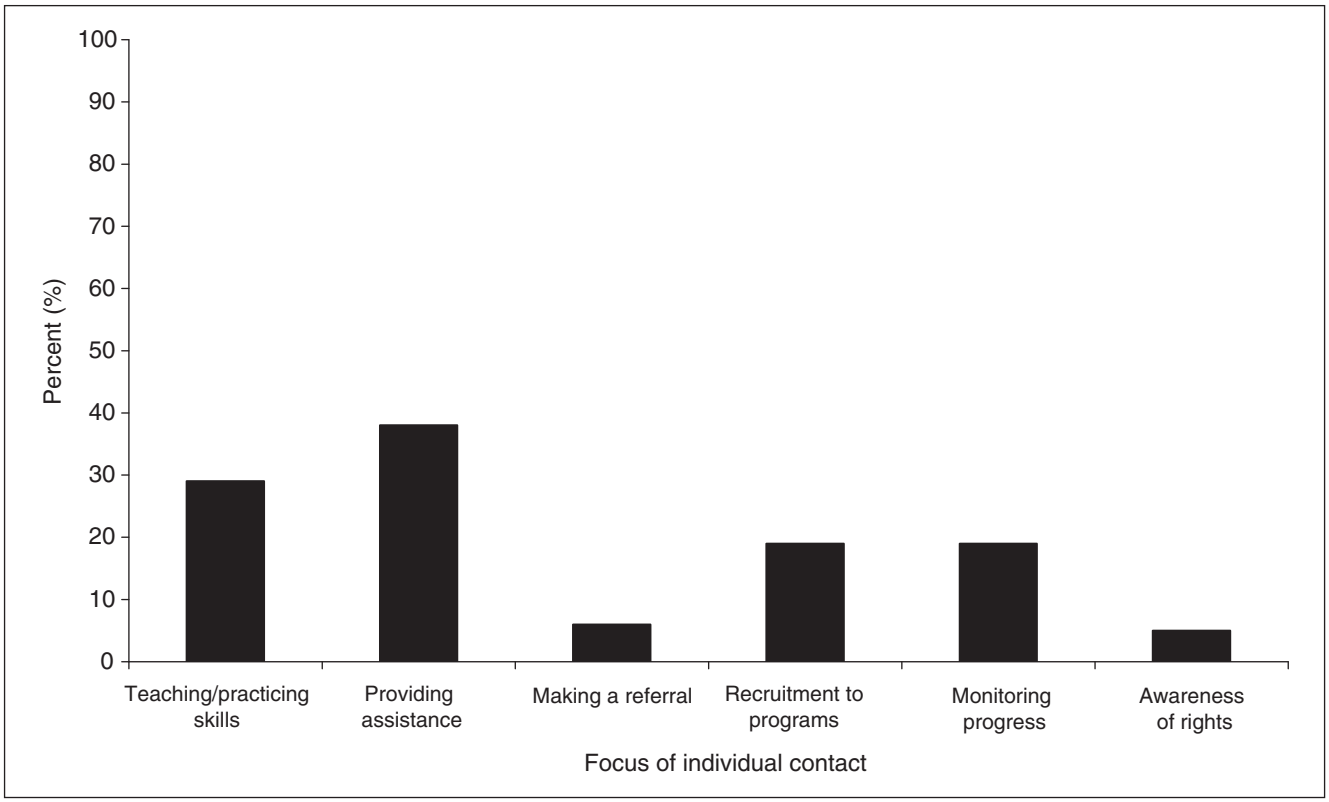

Figure 2. Focus of individual contacts between the community health worker and patients in diabetes self-management programs.

program staff. With permission from the patients, interviews were recorded. For confidentiality reasons, no identifying information other than names was collected from the patients.

The interviewer asked the following questions in English or Spanish according to the patients' preferences:

1. How has the CHW been helpful to you?
2. How does the CHW help you in ways that are different from what your physician, nurse, or dietician does?
3. What does the CHW do that is different from what family or friends do?
4. Can you tell about 1 specific instance when the CHW was especially helpful to you?
5. Can you think of how the CHW has been helpful to you in your diabetes self-management?
6. Is there anything else that you would like to share with us?

The interviewer probed for specific examples and/or more information as appropriate. The local liaison helped with translation and clarification when necessary.

All recorded interviews were translated and coded using the in vivo restatement method, a process that involves deriving themes from the patients' words, grouping like themes, and providing supporting quotes.

Results

The CHWs' logs identified 1859 individual contacts with patients. CHWs reported using the telephone 82% of the time, making it the most common mode of individual contact. This was followed by face-to-face contact, which was the chosen mode 15% of the time. The place of contact closely followed these trends. For example, the home was identified by CHWs as the place of contact 59% of the time, whereas contact occurred in the community and the clinic 8% and 7% of the time, respectively.

Although most contacts (89%) were initiated by CHWs, about 6% of individual contacts were patient initiated. The median time CHWs reported per individual contact was approximately 6 minutes, with a range from half a minute to 180 minutes.

CHWs reported providing assistance 38% of the time as the focus of the individual contact and teaching or practicing a skill 29% of the time. CHWs also reported

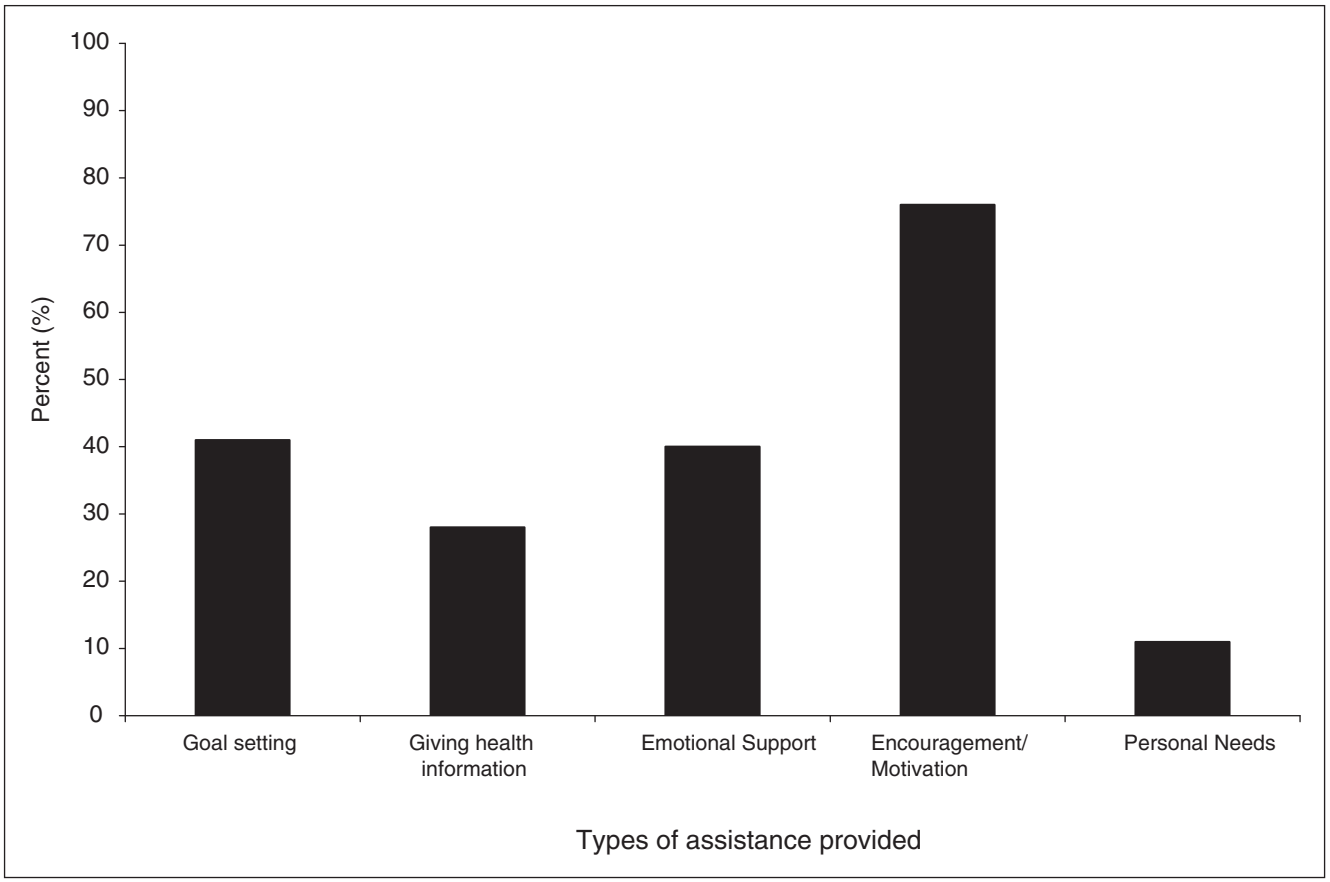

Figure 3. Type of assistance provided by community health workers to patients in the diabetes self-management programs.

that they recruited participants to take advantage of program offerings, monitored their progress, and made them aware of their rights (see Figure 2). Other services included helping patients with scheduling/rescheduling appointments, distributing newsletters or promotional flyers, giving out incentives, and so forth.

The skills CHWs reported teaching most often included those related to healthy eating, physical activity, and blood glucose monitoring. CHWs also reported helping participants develop problem-solving and healthy coping skills.

In terms of providing assistance, CHWs reported providing concrete assistance such as helping with goal setting, giving health information, providing emotional support for an acute problem or stressor, helping with transportation, filling out forms, and similar personal needs. The most common type of assistance provided was encouragement and/or motivation (76%), as reported by CHWs (see Figure 3). The mechanism by which encouragement and motivation were provided to the patients is less clear from the CHW logs, but as discussed next, salient themes from the qualitative analysis explained what the patients perceived as encouragement and motivation.

Turning to the qualitative data, analysis of interviews revealed several themes that were apparent across several sites. Many of the themes from the patient interviews coincided with categories identified by CHWs. The patients' comments suggested that it was the CHW explaining how to do something as opposed to telling them what to do that helped them with their DSM. In the following examples, patients explained the skills and education they learned, and one patient offered an example of how this is different from what the physician or nurse does. Note the specificity in patient-reported assistance (italics added).

> They [CHWs] taught me a lot about *how to control my diabetes*, *how to eat healthy*, and *how to do my exercise*.
>
> She [CHW] helps me to decrease how much I eat and *to measure the portions*.

> Nurses, they only give you a brochure, and they tell you here is what you can eat and what you cannot eat, but they don't tell you that *you should only eat half or a portion of this*, just that, *how to measure* what you should eat. That is the difference of what the [CHW] does to what the doctor or nurse does.
>
> I didn't know *how to check my blood sugar,* and they [CHWs] showed me. Also *how to calibrate the machine*.

Problem solving was another area in which patients reported receiving appreciable help from the CHWs.

> If I ask them [CHWs] about something, they help me resolve anything; for example, *if my sugar level rises, I talk to them*, I ask them what can I do, and then they help me; or many times my sugar lowers, and I talk to them, and they tell me to do this.

CHWs identified providing assistance for patients, and patients felt they were helped by the assistance that was provided. This included assistance with personal needs, as in the following example:

> She [CHW] helps me fill out papers and where to call for a free book about diabetes with a lot of instructions.

Consistent with CHW logs, encouragement/motivation was mentioned repeatedly in interviews across all sites. From the logs, the details of how encouragement and motivation were provided are unclear, but the patient responses shared some insight on what was valuable to them.

> She [CHW] has come, like when I am very down, she comes to talk to me, or when I talk to them by phone.
>
> She's [CHW] never saying you can't do this. She's never putting me down or nothing, she's always pumps you up. . . . She's always cheering you up, she never saying you don't look good; no, she's always in the cheer up mood . . . she never lets us down, she don't pressure us or anything.
>
> She's [CHW] always calling me to see if I'm doing alright and if I needed any help or anything.
>
> [CHW] calls to see how I am, how I feel when I wake up, if I am taking my meds and all that.

Some areas that emerged in patient interviews that were not addressed by CHW logs include accessibility and confidence building. One patient also discussed how this was different from what she received from family and physicians and how it helped her with DSM.

> They [CHWs] are always available for us to listen; sometimes the family doesn't, they say not to pay attention to the disease or they just brush it off. So for me, they have helped me a lot.
>
> The confidence they [CHWs] give us, with the doctors, it is much more difficult.
>
> They [CHWs] are very kind, very attentive, always available for whatever questions we have.

Coupled with attentiveness and availability was openness to individual's problems and perspectives.

> I can express myself, my problems with her [CHW], and . . . right away she'll find a way to help my problem, and if I talk to family . . . they don't pump me up, they don't help me out, they might let me down a little bit.

Discussion

The experience of the Diabetes Initiative sites is consistent with the literature; CHWs make important and substantive contributions to teaching key skills, helping with problem solving and with motivation and ongoing follow-up and support. They also play a unique role as liaisons between the community and health care world in supporting DSM. The interviews go further in revealing how the nature of the CHW-patient relationship itself is important in successful DSM. The amount of encouragement/motivation provided suggests that it is the ongoing follow-up and support as well as the personal CHW-patient relationship that facilitate a successful DSM relationship.

Patients and CHWs identified concrete ways in which the CHW was helpful, and patients discussed how this help and support were different from what they received from their health care team, friends, and family. Among the issues addressed, the CHWs taught or helped patients practice a variety of skills necessary for the successful self-management of diabetes. Remarks from patients suggested that CHWs are successful in assisting with DSM because they take an extra step in explaining the specifics of how patients can put their self-management skills into practice. The CHWs were not simply providing checklists of things to do; they were providing explanations and encouragement for incorporating appropriate self-management behaviors into patients' daily lives. Importantly, they were available to spend as much time as needed attending to a patient's concerns.

Furthermore, themes uniformly emerged that indicated CHWs were monitoring patient status and encouraging self-management through ongoing follow-up and support. In addition, CHWs were essential in facilitating coping skills when needed. From patients' remarks, this support was often proactive, readily accessible, and personalized. They also suggest that this support was different from the

support received from family and friends. In fact, patients suggested that family and friends did not always listen or take their problems seriously. Finally, patients believed that they developed more confidence to manage their diabetes as a result of CHW encouragement.

In short, CHWs were perceived as more accessible, helpful in explaining how to carry out self-management, and attentive than health professionals, family, and friends. These factors provided added value to health care as CHWs help patients build the knowledge and develop skills to better manage their diabetes. Detailed examples provided insight into the valuable contributions of CHWs. This insight could help delineate specific duties of CHWs in future DSM interventions.

The emergence of similar themes from the logs (CHW perspectives) and from interviews (patient perspectives) suggests the validity of these descriptive observations. Log data indicate that CHWs are consistent across time in their perception of the services they deliver. Interview data indicate patients were able to give very specific examples of skills learned, assistance provided, and the unique contribution of CHWs to their diabetes self-management. The study should be replicated to determine to what extent this happens in a variety of settings and populations.

Some may tend to view CHWs as making incidental or nonessential contributions to diabetes management. However, assisting in actual implementation of key management skills and ongoing follow-up and support are critical for a chronic disease such as diabetes.[2,3] Along with research showing their benefits,[4] this study has shown how CHWs make substantial contributions in these key Resources and Supports for Self-Management. Furthermore, their patients perceive these contributions as providing help in DSM that is not otherwise available. Clearly, the role of the CHW can be an important and perhaps unique part of the diabetes care team.

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