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Implementing the Community Health Worker Model within Diabetes Management: Challenges and Lessons Learned from Programs across the U.S.

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Abstract

Introduction/objectives—The Community Health Worker (CHW) model has gained popularity as a method for reaching vulnerable populations with diabetes mellitus (DM), yet little is known about its actual role in program delivery. The purpose of this qualitative study was to examine methods of implementation as well as related challenges and lessons learned.

Methods—Semi-structured interviews were conducted with program managers. Four databases (PubMed, CINAHL, ISI Web of Knowledge, PsycInfo), the CDC's 1998 directory of CHW programs and Google Search Engine and were used to identify CHW programs. Criteria for inclusion were: DM program; used CHW strategy; occurred in United States. Two independent reviewers performed content analyses to identify major themes and findings.

Results—Sixteen programs were assessed, all but three focused on minority populations. Most CHWs were recruited informally; six programs required CHWs to have diabetes. CHW roles and responsibilities varied across programs; educator was the most commonly identified role. Training also varied in terms of both content and intensity. All programs gave CHWs remuneration for their work. Common challenges included difficulties with CHW retention, intervention fidelity and issues related to sustainability. Cultural and gender issues also emerged. Examples of lessons learned included the need for community buy-in and the need to anticipate non-diabetes related issues.

Conclusions—Lessons learned from these programs may be useful to others as they apply the CHW model to diabetes management within their own communities. Further research is needed to elucidate the specific features of this model necessary to positively impact health outcomes.

Diabetes is a morbid and costly disease known to disproportionately affect racial and ethnic minorities.^{1–3} In the United States, community health workers (CHW) are increasingly

called upon to promote health among populations at increased risk for poor health outcomes, including diabetes.⁴⁻⁶ One of the goals of the CHW model is to facilitate access to health care services by enlisting and training lay individuals perceived by community members as willing and able to provide instrumental, emotional, and informational support.⁷ The CHW model is being incorporated into diabetes management strategies in an effort to reach underserved communities with the goal of improving adherence with treatment, reduce complications, and improve health outcomes.

Initial data suggesting success with the CHW model for diabetes management has led to its increasing adoption.^{8, 9} The American Association of Diabetes Educators,¹⁰ the American Public Health Association¹¹ and the Centers for Disease Control and Prevention Division of Diabetes Translation¹² have all endorsed the CHW model. As part of a nationwide diabetes initiative sponsored by the RWJ Foundation, the CHW model was recently identified as a key component of many successful diabetes self-management programs.¹³ However, despite the general support for this model and its increasing popularity among diabetes programs, consensus regarding methods of implementation is lacking and data regarding the effectiveness of this model in terms of diabetes health outcomes is sparse.¹⁴ This study examines how the CHW model is currently being implemented in the context of diabetes management and identifies related challenges and lessons learned.

Methods

Study design

Qualitative semi-structured interviews with program managers were conducted. Published and unpublished programs were identified through a combined literature and internet based search (Figure 1). All study protocols were approved by University of North Carolina-Chapel Hill Institutional Review Board.

Program identification

Four article databases (PubMed, CINAHL, ISI Web of Knowledge, and PsycInfo) were searched through April of 2004 by combining the term *diabetes* with a list of over 55 terms used for CHWs (available upon request) to identify articles describing diabetes programs using a CHW model. Additional articles were identified by hand-searching reference lists of articles found through the databases. The CDC's 1994 and 1998 online directories of CHW programs were then searched to identify unpublished CHW diabetes initiatives in the U.S. This database represents the most comprehensive documentation of CHW programs in the U.S.⁶ Finally, the Google search engine was used to conduct a web-based search combining the term *diabetes* with the terms *lay health advisor*, *promotora*, and *community health worker*. Inclusion criteria required that programs focus on diabetes management, describe a CHW intervention, and have taken place in the United States. In order to be as inclusive as possible, community health workers interventions were defined very broadly as those that incorporated lay individuals identified from the target community and/or committed to serving the needs of the community.¹⁵

For published programs, two independent reviewers used the title and abstract of each reference identified to assess for inclusion criteria. When discrepancies arose or there was insufficient data to determine if a reference should be included, the entire article was reviewed. For unpublished programs, web-based programs descriptions were reviewed and assessed for inclusion criteria; if the web-based description did not provide sufficient information programs were contacted directly to assess eligibility for inclusion.

Key informant interviews

Interviews were conducted through June 2005. At least five attempts were made to contact the program manager or other representative of each program identified; calls were made at different times of day and on different days. Once a program representative was contacted, informed consent was obtained to conduct a telephone-based semi-structured interview with the program manager. Interviews lasted approximately 45 minutes. The content and structure of the interview paralleled that of the National Community Health Advisor study, a survey published in 1998 by Rosenthal and colleagues to explore and define how community health workers view their work and their field.⁶ The interview included questions on CHW roles, responsibilities, recruitment, training, as well as challenges and lessons learned. The interview was audio-recorded and transcribed verbatim.

Data analysis

Two independent reviewers read a representative transcript, generated a set of codes and corresponding code book, and coded all of the transcripts using the codebook, and then met for consensus until 100% consensus was achieved. Disagreements were decided by a third author. Atlas TI software was used for data management. Based on questions from the interviews, deductive techniques were used to code programmatic elements regarding roles, responsibilities, recruitment and training. Inductive techniques were used to assess challenges and lessons learned, allowing themes to emerge through the coding process.^{16, 17} Challenges and lessons learned were analyzed broadly within a socio-ecologic framework¹⁸; themes were categorized at the community level, the health system/institutional level and at the level of the individual CHW.

Results

A systematic search of the published and unpublished literature identified 324 references (Figure 1). Two hundred and ninety-six references were excluded from consideration because they failed to meet inclusion criteria or were repeats. Twenty-three programs met inclusion criteria. Of these 23 programs, 7 program managers could not be reached despite multiple attempts; 6 of those unable to be reached were identified through the internet-based search. All program managers successfully contacted agreed to an interview. The following results represent data from the 16 programs interviewed.

Program characteristics

The program managers indicated that, CHWs interact with community members most frequently in community venues, followed by telephone contacts, contacts in the clinic and finally in participants' homes; most reported some combination of two or more (Table 1).

Most programs focused on Latino or African American populations. Although all programs were interested in both intervention delivery and evaluation to varying degrees, 10 programs were primarily designed as research projects and 6 programs were conducted as demonstration or service projects. The majority of CHWs worked for their program as full-time employees, some worked part time or hourly and some received stipends only.

Roles and responsibilities

Five primary CHW roles within diabetes management programs were identified through the coding process: educator, case manager, role model/mentor, advocate, and program facilitator (Table 2). Educator was the most commonly identified role: *“The primary role of the [CHW] is to educate the community about the epidemic of diabetes and to educate those who have diabetes about how to manage their diabetes appropriately.”*

However, the educator role was not endorsed unanimously. For example, one program manager felt that CHWs should not be charged with the task of teaching diabetes management classes. *“I don’t want the community workers working for me giving health advice. Um, because I have had problems with that in the early days and because of the focus groups where our subjects told us that they didn’t want that. They didn’t want lay advisors telling them how to take care of their diabetes. They wanted professionals... That’s how they said it to me, ‘I don’t want my health care provider to be my next door neighbor.’”* Case manager was identified as a main role by half of programs; each of the remaining CHW roles was identified by one third of program managers or fewer.

Primary responsibilities mirrored the primary roles. Many CHWs were engaged in some type of teaching capacity. Over half of the programs expected their CHWs to provide self-management guidance, facilitate medical follow-up and help identify resources. Half described social support as a main CHW responsibility. Just under a third of the programs have CHWs engaged in some sort of medical management, including reviewing medications and monitoring for diabetes complications.

Recruitment criteria and methods

Program managers described ten categories of recruitment criteria for the position of CHW (Table 2). The most common criterion identified was that the CHW voice a strong community commitment. For example, *“We were looking for people who really had the commitment to work in the community, to do this kind of outreach in the community. [We asked] ‘are you looking to give back to your community?’ kind of looking for their motivation and not necessarily their skills.”* Programs used several methods to recruit CHWs. The most common method, used by half of programs, was through personal community contacts, followed closely by personal contacts in the clinic.

Training topics and methods

Six main training topics were identified (Table 2). All programs reported that their CHWs received training on diabetes and self-management. Seven of sixteen programs reported providing CHWs health-related technical skills training, ranging from monitoring blood glucose levels and blood pressure to dealing with diabetic emergencies. For example, *“We*

train them to be able to take blood pressure and they get certified by the Department of Health and Mental Hygiene. They learn other techniques too, they don't draw blood but they do learn how to train the people to take their own blood and to do a blood glucose on a glucometer. After a period of time, we talk to them a little bit about the drugs." Despite the importance of provision of social support in the CHW model, only one quarter of programs provided CHWs with training on interpersonal skills such as communication skills and conflict resolution.

Training intensity varied widely across programs, ranging from 8 hours plus some field work to over 240 hours. The most commonly reported method of training was the use of hands-on exercises followed by interactive discussion and practice teaching/role playing.

Challenges and Lessons Learned

Several challenges and lessons learned were identified through the coding process. The following paragraphs describe themes at the community level, the health system/institutional level and at the level of the individual CHW; illustrative quotes are provided.

Community level themes

Community buy-in—Themes emerged related to the need for support from the community and early community involvement, particularly in the planning stages. All of these culminated in a recognition of the need for community buy-in. For example: *"But, the crucial part was getting the community involved from the start, from the very beginning of the process to make sure they knew that this was just not another one of those projects that was coming to town, was going to kind of throw some money around, and you know pull out a whole lot of information, gather some data on it and write a publication. Because they made it clear that is not what they wanted and if that was what we were going to do, then they were not going to participate, because that had happened so many times before."*

Also, several managers described the necessity of being visible in the community. For example: *"I think the thing that I would probably say, especially if you're starting a project, do not underestimate the time you have to spend in the community"*

Issues related to gender and culture—Managers reported issues related to gender and or culture, particularly the need for matching CHWs with participants based on these characteristics. For example: *"In dealing with different ethnicities, you have to bridge certain cultural, uhm, problems. For instance, my [female] staff member of Hispanic descent has difficulty speaking to male of their ethnicity and any ethnicity about the sexual dysfunctions that can occur with diabetes."*

Health System/Institution level themes

Training non-traditional learners—Program managers talked about difficulties in training "lay" individuals who often lacked formal education beyond high school and who rarely had a background in health. They described a requisite shift from traditional didactic methods of teaching/training, referred to by some as the "medical model", to more interactive methods, including observational learning and participatory techniques. For

example: *“The difficulty is that you have, the students, the CHWs, the trainees, is they come from different walks of life and they have different levels of education, and our experience is that you can’t just sit them down in a classroom and with a textbook and teach them, and expect them to be able to take a test. They have to learn by touch and feel. And they have to learn by experience.”*

Balance between the need for documentation and CHW burden—Program managers expressed concerns about the need for documentation, tracking implementation and outcomes, and the resulting burden those requirements placed on the CHWs. For example: *“What we found is that a lot of advisors do what they do, but they don’t necessarily like to write...”* Also: *“And the [CHWs] really felt like they needed to be less burdened.”*

Anticipating non-diabetes issues—Program managers noted that the CHWs were often confronted with issues unrelated to diabetes and felt that anticipating and preparing CHWs for such issues would be helpful. For example: *“...because yeah we can say that this is why we’re here, we’re doing heart disease and diabetes prevention, but within all of that, you know people’s lives still go on. You know, there are births that are occurring, there are deaths that are occurring, people losing jobs or people getting jobs or all this stuff is happening and when a CHW goes into someone’s home, they have no idea what they’re going to face. So they have to be willing to listen, to whatever the case may be and to be a support to point them in the direction that’s necessary for them at that time.”*

Retention difficulties—Most of the program managers reported difficulties related to retention of CHWs. *“Out of the eight that we originally had, um, within a year or two, four of them no longer did it. They got busy doing other things, got involved with other things, so they didn’t stay with us.”* Sometimes this was due to competing priorities in the CHWs lives. For example: *“There was one of them that just recently resigned, probably 2 months ago, but you know, resigned because he had some family issues, you know had a child who died and all this stuff. Another one of our males actually passed away himself. And then another one, he resigned early on in the project.”*

Other times it was due to the low paying nature of the CHW position. For example: *“So that we lost a couple people just because they found higher paying jobs. For example, one of our CHWs actually took a job driving a truck, because that paid more than you know, what we could pay.”*

Sustainability issues—Most of the sustainability concerns were related to funding the CHW position. For example: *“But I think a lot of the challenges are going to be around how much to pay, funding... our big problem was that we could not get the institution to maintain this. They were looking to cut back on the diabetes clinic.”*

Individual CHW level themes

Autonomy versus intervention fidelity—Program managers discussed trying to strike the balance between allowing for CHW creativity and autonomy while maintaining intervention fidelity and dissemination of accurate health information. For example: *“...he*

was doing his own little suggestions to the class to people that were there based on his own experience, he had learned in the military to run the bleachers as a form of exercise, and so here was telling these little old seventy-year old ladies to go down to the high school and run the bleachers and that would get their diabetes under control.”

Passion and other intangible qualities—Managers discussed making efforts to find the “right” person for the job of CHW. This theme was often alluded to and included reference to intangible traits. For example: *“Once you get into the details of the situation, then you realize how hard you have to work. And the promotores have to work very hard. They have to be very passionate at what they do”.*

Also: *“Of course there were some that were better than others, and a lot of time that didn’t have to do with knowledge, but just personal style. So when we hired people we were looking for some people who could connect with people and have that style”.*

Sometimes it was not possible to identify those traits ahead of time. For example: *“So we’ve had some fall out, people who get down the road and they go, you know, I just I can’t spend the time to do this or it’s just not me or it’s just not, you know. Or we say, this just isn’t you.”*

Discussion

This study used semi-structured interviews with program managers to assess implementation of the Community Health Worker (CHW) model as well as challenges and lessons learned from 16 diabetes management programs across the United States. Qualitative analysis of interview data demonstrated marked variation in CHWs roles, responsibilities and training across programs. Program managers identified multiple challenges and lessons learned based upon their experience implementing the CHW model within diabetes programs; themes emerged at the level of the community, the health system/institution, and the individual CHW.

In general, the roles CHWs are asked to fulfill, the corresponding responsibilities and the consequent training varied widely between programs; no one role or set of responsibilities was unanimously endorsed upon by all programs. Currently, there is no consensus regarding the most appropriate and effective role or set of roles for the diabetes CHW. Definitions of the diabetes CHW’s roles and responsibilities are evolving as experience in the community builds and will by necessity vary depending on the needs of the community and the capacity of the organizations supporting the CHWs. Historically, the roles of the CHW have existed on a continuum from a more informal “natural helper” role to a paraprofessional role, where the CHW extends the service delivery system performing tasks normally carried out by practitioners.¹⁹ In the case of the diabetes CHW, it is unclear whether CHWs are equally effective at, for example, teaching diabetes education in the community, reviewing medications and discussing adherence, ensuring follow-up with providers and providing social support. Without an agreed upon role or set of roles, the diabetes CHW may be doomed by overly high expectations and lack of clear focus.^{14, 20} Limited understanding of

the CHW role by other health service professionals could also result in tension between CHW and other members of the health care team.⁶

Several important challenges and lessons learned were identified in this study that could inform future use of this model within diabetes management programs, and perhaps within the broader arena of chronic disease management. Recognition of the need for creative approaches to CHW education given the limited educational background of many CHWs was mentioned by the majority of programs. Programs voiced concerns that burdening CHWs with “academic” requirements, paperwork and classroom training requirements could be detrimental to sustaining their involvement in the program. Supporting this finding, a recent survey of CHW training and certification programs demonstrated that hands-on training actually improved CHW retention.²¹

High turnover of CHWs was also an identified challenge. Given the low pay and high job demands it is not surprising that, despite a high level of commitment to the community on the part of most CHWs, programs frequently experienced difficulties with retention. Programs often spent a great deal of time, energy and resources training individuals only to have them leave the program after a short period of time. This was particularly problematic since the complexity inherent in diabetes management often necessitated very intensive training, incorporating topics ranging from anatomy and disease processes to principles of behavior change to computer skills and information tracking/management. There is no clear evidence for what level of training a CHW needs in order to be most effective within a diabetes management program. If CHW roles were more clearly defined, training could be better structured and evaluated. Subsequent studies could then assess whether efforts to decrease the burden placed upon CHWs and to minimize the need for intense training leads to a reduction in CHW turnover and overall program costs while continuing to promote improved health outcomes.

Issues related to intervention fidelity were also identified. Program managers described several instances where CHWs, although well-intentioned, may have provided misguided or inaccurate information. In an effort to pre-empt this issue, programs appointed health professionals to be available to CHWs for questions. This system, however, relies upon CHWs’ judgment as to whether or not they are faced with a situation they feel unequipped to handle given their knowledge and training. As “natural helpers,” empowered by training and positioned in the community as a lay “health expert,” the CHW could feel they *should* know the answer and may not want to appear as though they do not. The extent to which this is a problem depends partly on the content and context of the question; in the context of diabetes management, misinformation has the potential to lead to serious medical consequences. As such, efforts should be made to ensure intervention fidelity, accuracy of information and quality control. Further, the scope of information about which a CHW is responsible deserves serious consideration in order to avoid putting the CHW into situations in which they are over their head.

Integration of the CHW model into the framework of chronic care management

Much of the variability and some of the barriers identified in this study relate to the lack of a clearly defined role or set of roles for the diabetes CHW. For this purpose, we propose

placing the CHW model explicitly within the framework of the Chronic Care Model (CCM)²² (Figure 2). Developed by Wagner and colleagues to promote high quality patient-centered, the CCM is based on the premise that effective disease management programs are delivered in partnership with health systems and communities.^{23, 24} Although the model has been successfully applied to diabetes management interventions,²⁵ integration of the community component is often challenging; few studies describe implementation of the full model.^{26, 27} As trusted members of their communities, CHWs could play a pivotal role within the Chronic Care Model, serving to bridge its multiple components and facilitate the development of sustainable and culturally appropriate diabetes management interventions.^{28, 29} Considering the CHW within the broader chronic care model provides a context for understanding newly emerging issues identified by this study and also for designing conceptual and practical approaches to improving CHW interventions. For example, it may be that in the context of diabetes management, acting as a central link is the most necessary and effective role for the CHW. A review of CHWs almost two decades ago suggested that CHW training should be less focused on acquiring specific program skills and more focused on efforts to preserve the CHW's identification with their community, arguing that the central role of the CHW is to reflect and advocate for the needs, problems and feeling of his own community.³⁰

Limitations

Due to the source of information in this study, program managers, the health system perspective is disproportionately represented. This study does not directly include perspectives of Community Health Workers or of representatives from those communities served. The perspective of health practitioners was also not examined directly. Insights from these groups are essential and will need to be explored in order to integrate the CHW into the broader Chronic Care Model in a way that is acceptable to and meets the needs of all parties involved. Also, there are numerous service and research programs using the CHW model for diabetes management and this study is not all-inclusive. However, extensive efforts were made to identify and interview as many programs as possible and as a result this study includes a representative mix of programs- regionally, demographically, academically or otherwise.

Implications

Currently, the CHW model is being implemented in many community settings in response to the great need for accessible diabetes management strategies. However, evidence regarding the most effective way to implement this model and the best CHW roles/responsibilities is limited. Future research should explore effective ways to address the challenges identified in this study. For example, ensuring accuracy of health information may require finding creative ways to increase the involvement of health professionals alongside CHWs. Rigorous evaluation of CHW interventions are needed to ensure that limited resources are allocated wisely. Despite the challenges identified, the CHW model has the potential to link multiple components within the Chronic Care Model, thereby facilitating implementation of proven diabetes management strategies in diverse community settings.

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Figure 1.
 Program identification strategy

Figure 2.

Integration of the Community Health Worker Model into the Chronic Care Model

* Adapted from Wagner et al.²²

Table 1

Program Characteristics (N=16)

	Frequency (%)
LHA location *	
Clinic	6 (37.5)
Community	12 (75.0)
Home	6 (37.5)
Telephone	8 (50.0)
Target population	
Latino	7 (44%)
African American	5 (31%)
White	2 (13%)
Alaska Native	1 (6%)
Mixed population	1 (6%)
Payment	
Full time	9 (56%)
Part time/hourly	4 (25%)
Stipend only	3 (19%)
Stated goals	
Primarily research	10 (63%)
Primarily service	6 (37%)

* Program Manager could answer "yes" to more than one option

Table 2

Community Health Worker's Roles, Responsibilities, Recruitment and Training (N=16) *

		N (%)
CHW roles	Educator	11 (69%)
	Case manager	8 (50%)
	Role model/mentor	5 (31%)
	Advocate	5 (31%)
	Program facilitator	5 (31%)
CHW responsibilities	Teach classes/lead group	11 (69%)
	Self-management guidance (one-on-one)	9 (56%)
	Facilitate follow up/identify resources	9 (56%)
	Social support	8 (50%)
	Medical management	5 (31%)
	Facilitate program	4 (25%)
	Administrative	2 (13%)
Recruitment criteria	Strong community connection	8 (50%)
	Resides in target community	8 (50%)
	Good interpersonal skills	7 (44%)
	Willingness to learn	6 (38%)
	Education/literacy	6 (38%)
	Has diabetes	6 (38%)
	Ethnicity	5 (31%)
	Gender	2 (13%)
	Has transportation	2 (13%)
	Race	1 (6%)
Recruitment methods	Interpersonal contact/community	8 (50%)
	Interpersonal contact/clinic	5 (31%)
	Trained existing paraprofessionals	4 (25%)
	Clinic ads	3 (19%)
	Media ads	3 (19%)
Training topics	Diabetes information and self mgmt	16 (100%)
	Behavioral change skills	8 (50%)
	Technical health skills	7 (44%)
	Research and administrative	6 (38%)
	Resources and referrals	5 (31%)
	Interpersonal skills	4 (25%)
Training methods	Hands on exercises	10 (63%)
	Didactic lecture	7 (44%)
	Practice teaching/role playing	6 (38%)

		N (%)
	Interactive discussion	6 (38%)
	Informal one-on-one	2 (13%)

* Programs could identify more than one