Patient Perceptions of a Community-Based Care Coordination System

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Community health workers (CHWs) work with health professionals to improve health outcomes by facilitating community-based health education and increase access and continuity to health services within a community. Uninsured, low-income participants of a community-based program, Project Access Dallas, participated in focus group sessions for determining participants' perceptions of CHW effectiveness and participants' abilities to independently manage their health needs. Of the 95 adults invited, 24 (25.3%) attended. Participants reported that CHWs are an invaluable asset in learning how to navigate the health care system, obtaining appointments and being better able to care for themselves with CHW emotional/psychological support. Results suggest that CHWs in a case management model improved patient comprehension of health issues, patient navigation through a health care system, and patients' abilities to independently manage health issues. Implementation of CHWs within a case management model appears to be an effective mechanism for providing health services to underserved populations.

Keywords: community health workers; community empowerment; uninsured

Empowering individuals to identify and implement plans for addressing their own needs is an essential aspect of community health. Through "critical consciousness," people in a community can be empowered to take control of their lives and contribute to transforming and improving the community's health (Barnes & Fairbanks, 1997). Attempts to increase community involvement in health system services and activities have resulted in innovative case management programs such as the use of CHWs (Lemak, Johnson, & Goodrick, 2004). Community individuals can receive continuum of care and improved overall quality of care in the delivery of primary care and preventive services with CHWs acting as liaisons (Witmer, Seifer, Finocchio, Leslie, & O'Neil, 1995).

Novel interventions reveal the value of training local community members to work with health professionals to achieve improved health outcomes (Department of Health and Human Services [DHHS], 1994). Those who have traditionally lacked health care access benefit from the connections that CHWs (also known as lay health promoters [LHPs]), and, in Spanish, promotoras de salud) can provide (Witmer et al., 1995). CHW programs are based on "natural helping," and build on a community's existing social network and social relationships (Israel, 1985). Natural helping strategies can successfully develop networks or incorporate existent networks into interventions designed to improve community and individual health (Eng & Young, 1992). Recent trends in health care support a greater reliance on lay helping (Service & Salber, 1979), which can reduce differences between professionals' intentions and clients' expectations (Eng, Hatch, & Callan, 1985),

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facilitate problem identification and resolution (Cottrell, 1976), and transfer responsibility from medical professionals to appropriate community groups (Gottlieb, 1985).

Community health worker interventions have also been endorsed by the Centers for Disease Control and Prevention (CDC) as an essential strategy for eliminating health disparities (CDC, 2006). Because CHWs typically share a common language, religious beliefs, and/or social and ethnic characteristics with those in the community where they reside, they can serve as cultural brokers for underserved, hard-to-access populations (Brownstein, Cheal, Ackermann, Bassford, & Campos-Outcalt, 1992; Lam et al., 2003). Research has begun to examine the relative cost effectiveness of CHWs and their success in cancer screening, blood pressure control, preventing infectious diseases, and diabetes management; however, the use of CHWs remains a growing area for medical care practice and research in the United States (Berman, Gwatkin, & Burger, 1987; Hiatt et al., 2001; Rashid, Taiwo, Barraza-Roppe, & Lemus, 2004).

Project Access Dallas (PAD) is a community initiated and administered collaboration between health care providers, hospitals, the faith community, businesses, and public health entities. Established in 2002, PAD provides access to care for the "working poor" who are ineligible for existing, publicly-funded health care in Dallas County. CHWs provide essential care coordination functions within PAD, including numerous services related to navigation of health care services, health promotion, and disease prevention. The focus of this qualitative study was to examine program participants' perspectives on the efficacy of using CHWs in a case management model, and to gain an understanding of how PAD was valued by members of the community. The study examined two questions: (a) What is the effect of a community care coordination system on PAD participants' abilities to independently navigate and manage their health and the healthcare system, and (b) how effective is the PAD care coordination system in providing health education, making referrals to social and healthcare services, and ensuring adherence to screening, medication, and medical appointments?

▶ PROGRAM FEATURES

The Project Access Dallas Community Care Coordination System

The PAD program implemented a Community Care Coordination system (Care Coordination) using CHWs to provide culturally competent case management to meet the needs of patients who encounter social and economic barriers while trying to access and navigate health care services. The CHWs coordinate both referrals and access to care for patients, and provide support services such as transportation, translation services, health education, home visits, appointment compliance reminders, and encouragement to follow health prescriptions. They also serve as a link for patients to other service organizations within their community.

Care Coordination Components

Using a modified health risk assessment (HRA) survey tool, Project Access Dallas' Care Coordination program consists of three major components: (a) identifying social concerns, (b) identifying patients with or at risk of developing Type 2 diabetes, and (c) identifying patients suffering from depression. Patients are assigned to either Care Coordination or Self-Care by CHW's based on their ability to navigate the health care system and their identified social and medical needs. Patients assigned to Care Coordination tend to have more complex and chronic health problems, whereas those assigned to Self-Care generally have less serious illnesses and are able to manage their own health needs.

Caseloads

The CHWs are responsible for a caseload of between 20-40 patients with whom they make a minimum number of monthly face-to-face contacts with each

TABLE 1
Examples of Focus Group Questions

Area Evaluated	Group
Individual Health Empowerment	
Is it important to you what is happening with your health? Why?	Diabetes
Do you ever not take your medications? What are reasons for not taking your medications as prescribed?	Depression
Did PAD help you learn about how to solve difficulties you have encountered in receiving medical care? How?	Social Services
Has PAD made any changes in your life? How?	Social Services
Health Education Services	
Have you ever received information about how to take care of yourself through PAD?	Diabetes
Do you understand how to take your medications?	Diabetes
Has PAD helped you understand your health condition?	Depression
PAD Healthcare System	
What did you like most about the services you received through PAD? What was the worst thing about the services?	Diabetes Social Services Depression
Have you had trouble getting an appointment? What kind?	Depression Social Services
Has PAD helped you with any other difficulties you are having besides health problems? How?	Social Services

Note: PAD = Project Access Dallas.

patient. They develop a Care Coordination Plan (Plan) with each of their assigned patients for addressing their clinical needs (e.g., cancer screenings, diabetic check-ups, or mental health treatments) and personal health self-management goals. Personal goals teach self-sufficiency and independence by prompting the patients to identify step-by-step methods to meet any challenges or barriers they are facing.

In addition to managing a caseload, CHW's staff a patient helpline to assist Self-Care patients with any questions or concerns that they may have. This ensures that all patients have access to the Care Coordination system, regardless of their level of care assignment.

A board-certified internal medicine physician and a clinical psychologist meet monthly with the CHWs to discuss general cases, with a specific focus on those with diabetes and mental illness.

► METHOD

An exploratory study was conducted from May to July 2004 using focus-group methodology. Six focus groups were planned, stratified by patient preferred language (English or Spanish) and the three major care coordination components (social concerns, Type 2 diabetes, and depression; Kitzinger, 1995). The approach sought to achieve content and language homogeneity within each group, while using a semi-structured interview guide to investigate feelings of individual empowerment, adequacy of PAD health education services, and overall satisfaction with the PAD healthcare system (see Table 1; Morgan, 1997).

Inclusion/Exclusion Criteria

Patients were eligible for the study if they were (a) adults over 18 years of age, (b) PAD participants receiving Care Coordination services, (c) able to communicate either in English (English Language [EL]) or Spanish (Spanish Language [SL]), and (d) mentally oriented. The PAD enrollment database was used for identifying potential subjects. Eligible patients ($N = 95$) were contacted by telephone (three attempts) and invited to participate in one of the two-hour sessions, and reminder notices were mailed prior to their scheduled session (Krueger & Casey, 2000; Powell & Single, 1996). Among those contacted ($n = 70$), 15.7% ($n = 11$) refused to participate and 34.7 % ($n = 24$) eventually participated in one of the groups.

Because no SL patients with depression were identified and too few EL patients with social concerns were available, four focus groups were conducted: two groups for Type 2 diabetes (one EL, $N = 4$ and one SL, $N = 9$); one group for depression (EL, $N = 4$); and one social concern group (SL, $N = 7$). The focus groups were moderated by two investigators (English and Spanish speakers), with one serving as a lead moderator and the other monitoring for time and clarification. The sessions were held at the community clinic familiar to all participants. Sessions were tape-recorded, transcribed verbatim, and interpreted. No patient identifiers were included, human subjects' approval was received from the Institutional Review Board, and informed consent was obtained from all participants. Financial compensation, meals, and child care were provided during the sessions. Demographic information was available from the PAD database for only 18 of the 25 participants (Table 2), and a total of 88 pages of transcribed narrative data were collected.

Data Analysis

Data were transcribed and translated by an independent translator. Two investigators and a research assistant independently analyzed the data. Data were categorized into themes within each of the focus group areas evaluated, whether individual health empowerment, health education services, or PAD health care system. Themes were identified through consensus between the two investigators, based on broad and relevant topics they identified in the narrative transcripts (Krueger & Casey, 2000; Morgan, 1997). This process was repeated several times to further identify themes or categories across all the data.

▶ RESULTS

The analysis identified four primary themes: (a) education, (b) financial constraints, (c) communication and respect, and (d) access to medication and transportation (see Table 3).

Education

Exercise and nutrition. Education was the most discussed theme among all groups. All participants from both diabetes groups shared the importance of understanding what was happening to their health. They stated that receiving education about their diabetes improved their capability to manage their health and maintain control over their diabetes. The majority felt it was important to know and understand what was

TABLE 2
Characteristics of the Participants

Characteristics of the Population (n = 18)	Percentage (n)
Age, Mean	44 (Standard Deviation 15.9)
Gender	
Female	78.9 (15)
Male	15.8 (3)
Ethnicity	
Hispanic	74 (14)
Caucasian	11 (2)
African American	11 (2)
Education	
None	11 (2)
Completed 8th Grade	53 (10)
Completed 12th Grade	21 (4)
> 12th Grade	5 (1)
Other	5 (1)
Marital Status	
Married	33.3 (6)
Single	22.2 (4)
Separated	16.7 (3)
Divorced	11.1 (2)
Widowed	11.1 (2)
Unknown	5.6 (1)
Employed	55.6 (10)
Monthly Income, Median	$1,200
Household Size, Mean	4.5 (Standard Deviation 3.1)

happening to their health for two main reasons. First, their knowledge about their health allowed them to work toward preventing further complications. One participant said,

> You know, I think when you have this kind of disease, we like to learn more, because sometimes you feel like eating something and you say, "Ah, okay, I'm going to eat it," 'cause we don't know. If we have a class to tell us what is going to be the result, maybe we stop.

Second, many participants expressed the desire to take care of themselves for their families' sakes. One noted that understanding her own health was important so that she could be healthy enough to care for her family members. She said,

> I have found that I have to try to stay healthy, because I'm taking care of my mother and my stepfather. We live in separate homes, but when my health is bad, I'm feeling down, there is no one to help them.

TABLE 3
Results of the Focus Group Sessions

Focus Group Area Evaluated		*Major Findings According to the Areas Evaluated*
Diabetes Mellitus	Individual Health Empowerment	Assistance and information allows people to better care for themselves and feel confident of the care received.
		Knowing, learning, and understanding what is happening to their bodies gives people more control.
		Prevention (receiving certain tests) regularly is important.
		As age increases, the number of health problems to face increases as well.
	Health Education Services	Consistency in informing patients of available classes.
		Mixed answers about the physician's willingness to take the time to educate the patients.
		More education on specific self management (how to eat properly, take medication, how to live with the disease, and how to accept the disease) is needed.
		Moral support is received but financial help is needed.
		Depression, lack of confidence, forgetfulness, side effects, and perception of lack of medicine's effectiveness are reasons for not taking them consistently.
		Transportation classes are needed.
	PAD Health Care System	Gratitude. PAD sees and treats patients without discriminations.
		Feel cared for and respected.
		Cost of medications is reasonable.
		Accessibility to medical attention (i.e., diabetic checkups, course education, affordability of care) and medications.
		Impact of body and soul.
		Lack of language barrier problems because of translators (CHWs).
		Social workers (CHWs) help in navigating the system.
Mental Health	Individual Health Empowerment	Difficulty in managing too many medications.
		Feel that they have health problems not mental health problems.
		Need more emphasis on physical rather than mental health.
	Health Education Services	Need consistency in procedures and guidelines.
		Consistently offered group education classes.
	PAD Health Care System	Problems in establishing communication with the case worker.
		Problems in obtaining referrals to specialists.
		Problems in keeping set appointments with doctors because of distance.
		Courtesy and respect is received.
		Receiving otherwise unaffordable services (samples, eyewear, and specialty exams).
	Individual Health Empowerment	Confidence received from support of health workers in facing their problems and working with the doctors.
		Transportation help.
		Improvement in health because of better communication with providers via CHWs.
		Support, caring, and loving services from CHWs and doctors (they can trust them).
		Emotional and psychological support.
		Improved family relations.
		Affordability of appointments and treatments no longer afraid to visit physicians or receive appropriate care.

(continued)

TABLE 3 (continued)

Focus Group Area Evaluated		Major Findings According to the Areas Evaluated
Social Services	Health Education Services	Providing positive, immediate, trustworthy, supporting, and kind assistance not previously provided from other providers.
		Improved health through nutrition education.
		Education on emotions management.
	PAD Health Care System	Afraid of being charged for received services.
		Dissatisfaction of receiving test results in a timely manner.
		Need extended support for emergencies cases.
		Support and help from PAD people (i.e., CHWs are available to talk to when needed).

Note: PAD = Project Access Dallas; CHW = community health worker.

Although all participants with diabetes reported receiving helpful information about their disease and caring for themselves, they tended to want even more education about diet and exercise. They wanted specific instructions about what kinds of exercises they could do to help manage their health and disease, as well as more specific information about nutrition. They expressed a need for more detailed instructions about what to eat, what to substitute for their cravings, what to avoid, and the consequences of eating something they had been told not to eat. Although a preference for a more convenient location for diabetes education classes was a concern for one participant, all of them felt that more efforts were needed to systematically inform them of educational opportunities related to their disease and principles of self care.

Specific instruction about complications. Most participants reported receiving either from the CHW or their physician some level of education regarding their health and the health practices in which they should be engaged. The EL participants in particular felt that they still needed more instruction about avoiding future complications and problems, as well as for improving their quality of life. Although they were being told to do many things, such as taking care of their feet, they felt they needed more guidance about specifically how to perform these tasks. They also wanted to know exactly what can happen to their eyes and lower limbs, for example, if they do not care for themselves as instructed. In contrast, the SL participants felt that the program was providing them abundant guidance in taking care of themselves, liking themselves, eating the right foods, taking their medication, and living with diabetes. Indeed, one SL participant felt so motivated

and confident in her education that she educated her daughter about the disease with the hope of preventing adult onset diabetes.

General health. Many participants mentioned that with increasing age they are finding that their health problems are increasing as well. Thus, the subjects volunteered that they are becoming more interested in knowing, learning, and understanding their health problems to have more control over their bodies. The diabetes SL group was very proactive regarding their health and in actively seeking more information from the PAD Program.

Among those in the depression group, responses were mixed about whether PAD was helping them to understand and manage their health problems. Some participants felt that they suffered more from general health problems and even questioned whether they were depressed. They confessed feeling frustrated with the care coordination system, because they felt that their identification as depressed patients caused the CHWs to focus more on their mental health and less on their general health.

Financial Constraints

The cost of medications was seen as a major barrier to medication compliance, especially among the Diabetes EL group, with participants admitting skipping their medications because of cost. In the Diabetes SL group, reasons for not taking medications included forgetfulness, inability to obtain medication, as well as financial problems. However, most patients took their medications regularly because they reported feeling the immediate consequences of skipping a dose. As one participant noted,

. . . But, as I say, I'll pay as long as they're helping me, it's okay, I'll pay for them. But my doctor gave me the name brand, and they are helping me, so I keep buying these, even if the price is high.

Participants from the Depression group also reported financial issues and limitations on prescription refills as problems in following their prescribed medication schedule, despite a low copay rate. However, there was general consensus among the focus group participants that the dollar amount they paid for their medications was reasonable.

The fact that the cost of appointments and treatment became affordable because of participants' involvement in PAD also helped the participants manage their health. One participant said, "They offer a lot of services that otherwise we could not afford." Another added, "So, at the beginning, you are a little afraid. I got a little sick and I didn't go back to the doctor because I thought it was too much."

After enrollment in the PAD program, participants said that they were no longer afraid to visit the physician to receive the appropriate care. As one observed, "This program helped me; they only charged me thirty dollars. So, for me, is like [sic] they didn't charge me anything, you know." Another was receiving large hospital bills she could not afford to pay and had stopped going to the doctor. However, she began going to the doctor again once she was informed that the bills were covered through PAD. As she noted,

CT Scan, [sic] and it even seemed impossible to me that they would do it, because I was very sick. I was very sick, and when they did it, I thanked God, and thanked God that we are in the project.

Communication and Respect

Communication and respect were powerful themes among all focus group participants. Communication was further broken down into the following two sub-themes: communication between participants and physicians, and communication between participants and CHWs. Patients in the Diabetes EL group reported high levels of satisfaction with the help and education they received, as well as the time their physicians took to help them. Several noted that their physician explained skillfully how and why to take the medication, as well as the consequences for not taking the medication. Another noted that her physician readily provided an appointment with a fellow physician if there was a scheduling conflict.

In contrast, others were not so happy—particularly with the physicians. One participant reported, "Physicians won't take the time; they just run you in

and run you out." With regard to communication with their physicians, participants were asked whether they understood how to take their medications after discussing the reasons for noncompliance. One participant said the doctor did not adequately explain how or why to take the medications. Others felt that their status as a PAD patient was a hindrance in obtaining treatment from several doctors who were not willing to see them and would send them elsewhere.

Some of the participants from the Depression EL focus group felt a lack of respect from both the CHWs and others they had come into contact with while trying to navigate the PAD healthcare system. When discussing the effectiveness of care coordination in providing patients with access to appointments and contacts with physicians as well as CHWs, they voiced concerns about establishing communication with their CHW and in obtaining referrals to specialists. One participant noted, "I had trouble getting referrals to physicians. My doctor's office says they faxed them the paperwork; Project Access Dallas says well, no, we don't have the paperwork. Sometimes takes [sic] three or four months before I finally get an appointment."

However, many of the participants felt they were able to maintain their dignity in the midst of seeking help. In addition to the tangible benefits of the program, subjects also felt they received intangible benefits such as friendship and attention. Participants from the Diabetes SL focus group felt confident in the care they received because not only did they receive support and care for their illness, but they also received moral support from both the CHWs and the physicians. The physicians pushed them to keep to the needed regimen and by doing so "kept better tabs" on them. They reported being in good communication with their CHWs and felt able to talk with them as needed.

In general, participant contact with CHWs proved to be an invaluable asset in learning how to navigate the health care system and in obtaining appointments. One participant said, "I don't have any trouble reaching [CHW manager]; she returns my calls if I call her." Another noted, "When I first came here, I was dying physically and from my soul too. And the CHW and physician helped me in every sense of the word." Other representative comments were, "They don't treat you like you are begging . . . and that is very important. You don't feel like you're coming crawling on your knees," and

I walk in the door and she knows who I am. She makes me feel like I have insurance, like I am one of the people who have a hundred thousand dollar job and can afford her services, and she does not treat me like I'm underclass.

Finally, participants from the Social Services SL group felt their physical health improved in part because of the PAD Program providing interpreters for their doctor visits. This allowed the patients to communicate with the physician about their conditions more effectively and in greater depth than they had been able to without interpreters, and consequently allowed for better, more effective treatment.

Access to Medications and Transportation

The final concern expressed by the participants was related to medications and transportation. Although one participant from the Depression EL group mentioned having too many medications to manage as a main reason for nonadherence, another reported no problems with receiving or taking medications. Participants from the Diabetes SL group pointed out a problem with gaining access to glucose monitor strips. They also noted a need for the PAD staff to teach people how to use public transportation if they do not have their own transportation and are unfamiliar with the public transportation services. For the most part, however, participants stated that they contact their CHW if they have any questions not directly related to their disease, such as appointments or transportation.

▶ DISCUSSION

Findings from this study suggest that the PAD Community Care Coordination system and the use of Community Health Workers help patients understand issues about their health and how to navigate a health care system. The findings also suggest that CHWs help patients learn how to independently manage some of their health issues, whereas supporting self-efficacy and independence. PAD community health workers had an impact on the service delivery, but they also provided ad hoc assistance, emotional support, and tangible help. These study results demonstrate the wide variety of functions of CHWs in the PAD Community Care Coordination system. Furthermore, they emphasize and support the effectiveness of using CHWs in facilitating access to health care, increasing the use of preventive services within communities, improving quality of care, and reducing the cost of care (Community Voices, 2006).

Participants expressed a strong need for communication of health education and services available through the PAD program, but they also expressed a very strong desire for communicating with other PAD patients. Thus, communication was seen as an essential function of the CHWs. This finding is consistent with the overall goal of strengthening networks through working with "natural helpers," that it is seen in many community-based programs (Israel, 1985).

Maintaining dignity was important across the groups. It was important for the participants not to feel like a charity case or substandard citizen because they needed assistance.

The cost of copayments and medications was considered reasonable, which promoted participants' feelings of empowerment and independence in being responsible for their own healthcare. Understanding participants' health needs and limitations while respecting their interests and cultural values appears critical to the success of the PAD Program. The education and self-respect the participants gained from the program possibly contributed to their long-term abilities to care for their health. In spite of complaints and identified areas needing improvement, participants perceived the program positively.

Limitations of the study include the number of participants who attended the focus group sessions. Incorrect or outdated personal contact information was the main reason for not being able to establish contact with a number of potential participants. Additionally, patients from the Depression group refused to participate and an insufficient number of EL patients with social concerns were able to attend. In general, participants placed in the English speaking groups were harder to make contact with and were less likely to show up after agreeing to participate in a focus group session.

Interestingly, the group with depression expressed concern about receiving services "only" for their mental health as well as not being able to establish communication with CHWs and navigating the health system. Further research is needed to determine whether these concerns affected their overall views of their participation in the program, and whether or not their frustration with their classification affected the efficacy of the CHW intervention. Further research would also be needed to determine if this groups' generally negative attitude toward the program is a sequelae to their depression. An additional area of interest for future research is to identify the reasons for the differences between the Spanish and English Diabetes Groups in their perceptions about the instruction they received regarding potential complications from diabetes. This would address the question of whether ethnic differences account for the variation or if the variation was because of inconsistency in the services offered.

A number of the participants noted that the focus group session was like group therapy because of the chance to have someone hear their opinions, as well as being able to listen to others' experiences. This was a

common theme across all focus groups—participants spoke of how they enjoyed being together. They wanted to share information and learn from each other. Participants appeared energized by the focus sessions. All of the participants were grateful for the services they received from PAD. They experienced a level of respect and care that they had never received from other health care facilities. Further studies will benefit of having a control group without the CHWs intervention to compare effectiveness of individual health empowerment and health education services.

▶ CONCLUSION

The implementation of community health workers within a case management model appears to be an effective mechanism for the appropriate access to health care services. The community members served by the CHW model place a high value on the influence of this model on their health and well-being. One important subtheme in the category of communication and respect was that participants were also very receptive to communicating and learning from each other. This is significant because if patients are able to provide additional resources and support to each other, the effects of the PAD Program will be far more enduring and far-reaching than originally anticipated. By coming into contact with CHWs, patients were able to become their own CHW to a certain degree. Empowering patients to become independent and to trust one another can become an important public health tool for underserved patient populations.

▶ RECOMMENDATIONS

Programs implementing the CHW case management model should incorporate group educational meetings for patients into their programs. The implementation of group educational meetings has the potential to improve efficiency in the dissemination of health education, improve patient empowerment over their health, and improve patient satisfaction. Future studies should examine both the long-term effects of a PAD Program intervention on participant independence and health, and also the efficacy of using patient focus groups in a more structured way.

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