

Allies for Quality:

Lay Health Workers' Role in Improving Health Care Quality

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This is the second in a series of four briefs from the evaluation of the California HealthCare Foundation's Allies for Quality Program. Each brief will address one aspect of patient and consumer groups in improving health care quality, highlighting the strategies and concepts arising from the work of the grantees and ultimately identifying ways patient and consumer groups can work to improve health care quality.

Introduction

Historically, all cultures have had systems of natural helpers who provide community members with social support and advice. When these helpers are involved in the field of health, they are often referred to as "lay health workers." In the last half of the twentieth century, the contributions of lay health workers in the United States have received increased attention, recognition, and credibility.

The range of activities and roles of lay health workers is as diverse as their titles: *promotoras de salud*, community health workers, health advocates, ambassadors, peer health educators, community health aides, health intermediaries, and indigenous health workers. Some reject all attempts at labeling. For the purposes of this issue brief, the term "lay health worker" is meant to include all community-based non-professionals linking consumers to the health care system.

In the United States, the primary role of lay health workers is to fill a gap in the health care system that is particularly acute among underserved communities. Many of the factors that contribute to this gap also affect health care quality. From the perspective of the eight patient and consumer

organizations that make up California HealthCare Foundation's Allies for Quality grantees, these factors include the following:

- Difficulty obtaining health services;
- Receiving incomplete health information or treatment;
- Scarcity of culturally relevant and accessible health information;
- Culturally inappropriate or insensitive provider-patient interactions;
- Lack of knowledge about self-care practices; and
- Lack of understanding on the part of providers and the health care system about community health needs.

Lay health workers are uniquely positioned to help fill this gap and provide needed support services, in no small part because they often come from the very communities they serve and share elements of their cultural and linguistic background, economic status, or experience of disease or disability.

Overview

The Allies for Quality grantees are in the unusual and beneficial position of being funded so that their lay health workers can specifically address

issues of health care quality. Of the eight grantees, five have implemented programs built around lay health workers. These are the California Black Health Network, the Community Health Worker/*Promotora* Network, the Center for Disability Issues and the Health Professions at Western University of Health Sciences, the Diabetes Prevention and Control Program, and the Women's Information Network Against Breast Cancer. A snapshot of each group's experience in working with lay health workers is provided later in this brief. More information about the grantees can be found on the California HealthCare Foundation's Web site, www.chcf.org.

Jointly, the work of the Allies for Quality grantees with lay health workers provides an understanding of how recruiting and training these workers to interact with community members, health care professionals, patients, or people with disabilities enables them to make significant contributions to improving health care quality. The following themes, attributes, and goals characterize their work.

Recruiting for Compatibility

All of the five grantees recruited or engaged lay health workers among people familiar with the specific health condition or community that is the grantee's focus. Because these workers often share a deep understanding of beliefs, perceptions, and salient concerns of the populations they work with along with linguistic, cultural, or historical background, they are particularly suited to engage their peers in a culturally appropriate manner. For most groups, this shared base of experience enhances the ability of lay health workers to assess and meet the needs of their various audiences.

Developing Health Care Quality Leaders

All of the five grantees are developing and enhancing leadership skills among their lay health workers using focused, original curricula, training sessions, and various capacity-building opportunities. These curricula impart information about the disease the group is addressing or the environment the community workers are operating in. The training programs teach people how to advocate for health care quality for themselves and their families, then apply their skills to serve a broader community.

Empowering Consumers

One important aspect of the lay health worker approach is the workers' ability to spend a significant amount of time with their audience in individual or small-group settings. Small groups help foster deeper relationships, which can increase consumer trust in the health care system. As the lay health workers use this time to educate and provide emotional support, they are also teaching consumers how to understand their risks for particular health conditions and the appropriate self-help measures; navigate the difficulties of the health care system; make use of community resources; and appreciate their rights and responsibilities as patients.

Bringing Consumers into the System

Whereas the standard medical model holds that consumers seek out health professionals, the lay health worker model sometimes reverses this order. Most of the grantees' lay health workers use churches, schools, medical centers, local organizations, and local networks to offer community members the chance to learn more about the health risks they face and how to use the health care system.

Balancing the Power Dynamic

A major outcome of this work is that by empowering consumers through knowledge and support, lay health workers are taking a groundbreaking step toward balancing the power dynamic between patients and providers, and between patients and their health care system. The lay health workers of the Diabetes Prevention and Control Program's Diabetes Consumer Action Groups Project, for example, disseminate a "health record card" that helps diabetes patients keep a record of their medical tests and examinations, as well as track the health care they are receiving against evidence-based guidelines for diabetes treatment. The Women's Information Network Against Breast Cancer provides patients with access to information and peer support upon diagnosis, distributing kits that include culturally competent patient education books and videos developed in accordance with evidence-based guidelines.

This work helps to transfer some of the control over the process of health care to the consumer. The resulting increase in self-sufficiency enables people to establish a more productive partnership with their providers, including better use of their health care system and community resources, more effective communication with their health care providers, and taking responsibility for their own care.

Lay Health Workers in Action

California Black Health Network

The California Black Health Network (CBHN) uses lay health workers to reach out to African American communities with information and prevention activities for major health problems, along with discussions of patients' rights and responsibilities within the health care system. At its community-based lectures and

workshops on health care quality held in venues such as churches and on college campuses, CBHN recruits potential lay health educators to carry the information to their own communities. Incorporating lay health workers makes it possible for CBHN to reach the community in its "home territory," geographically, intellectually, and spiritually.

The tools used by the lay health workers include a "quality kit" developed by CBHN that contains resources on when to seek care; questions to ask providers; and information sheets on heart disease, hypertension, and diabetes. Each person attending an informational session receives a quality kit.

Community Health Worker/Promotora Network

The Community Health Worker/Promotora Network works to obtain recognition for community health workers and link them in a network where they receive support, build leadership skills, learn from each other, and benefit from the advocacy provided by the organization on their behalf. Network members include both volunteer and paid community health workers. Their main roles are to create connections between Latino communities, health agencies, and community-based organizations by addressing informational, cultural, socioeconomic, and linguistic gaps.

The Community Health Worker/Promotora Network has been particularly successful at building the capacity of lay health workers to point out these gaps to local health agencies and community leaders. The network's members, who primarily serve the state's Spanish-speaking community, are removing cultural and linguistic barriers, increasing the trustworthiness of the institutions they represent, and expanding institutions'

service delivery to include health education and prevention strategies.

The Center for Disability Issues and the Health Professions

The Center for Disability Issues and the Health Professions recruits as “disability educators” people affiliated with Independent Living Centers throughout California. Many are people with disabilities who have first-hand experience interacting with providers as advocates for their own care. The Center has developed a training curriculum called “Health Savvy” which addresses rights to quality health care for people with disabilities. The goals of the educators are to reduce the level of bias experienced by people with disabilities in the health care setting by training them to expect and ask for quality care. Specifically, the educators assist Independent Living Center clients to identify and select health care providers, maximize time with providers, understand the nature and importance of routine preventive screenings, keep an accurate medical history, and effectively communicate health care needs.

Diabetes Prevention and Control Program

The Diabetes Prevention and Control Program’s Diabetes Consumer Action Project is teaching people with diabetes to become “diabetes leaders” who train other diabetes patients to be advocates for their own health care and how to receive evidence-based clinical care. One asset of the Diabetes Prevention and Control and Project approach is the intrinsic motivation of people with a condition to help others with the same condition. This situation has increased the success of a volunteer-dependent program with limited resources.

Women’s Information Network Against Breast Cancer

The Women’s Information Network Against Breast Cancer (WIN ABC) works with volunteers who are breast cancer survivors specially recruited from the medical centers in which WIN ABC works. The volunteers are trained to mentor newly diagnosed patients at each center. These peers receive WIN ABC’s established “Breast Buddy® Breast Care Training Program,” which includes discussions and educational materials on breast health; breast cancer diagnosis and treatment; navigating the health care system through enhanced communication skills and informed decision-making; gaining access to evidence-based quality care; psychosocial support and cultural issues; self-care; and educating, motivating, coaching, and supporting patients to advocate for themselves and partner more effectively with their health care team. WIN ABC has also established breast cancer resource rooms at each medical center.

Key Issues

Any attempt to develop a lay health worker program must come to grips with some fundamental issues. Chief among these are the challenges involved in monitoring performance, obtaining recognition, and developing an effective training model. The experience of the Allies for Quality grantees illustrates the importance of addressing such factors in designing lay health worker services.

Developing and maintaining a system for following up with both the workers themselves and the community members who attend the educational sessions is crucial to determine how well the program is succeeding. Unless this process is integrated into the framework of the program, it can easily be overlooked. Greater

support for such a system would help to reinforce the lessons that lay health workers are trying to teach, as well as track the impact they are having on the intended community.

Many professional health providers and communities do not fully understand the special knowledge and skills of lay health workers, or the role they can play in expanding access to quality care. Lay health worker programs must commit to obtaining recognition for the value that these workers bring and supporting their integration into provider and community settings.

Options include certification programs administered by local agencies and educational centers, as well as promoting the abilities of lay health workers to community groups and decision makers within the health care system and encouraging them to include these workers in program planning.

Consistent training is also a key component of working with and preparing lay health workers. It teaches them to deliver appropriate educational messages that motivate patients and community members to take care of their health and engage in ensuring access to quality health care in accordance with evidence-based guidelines. Each of the grantee groups either developed or drew upon training programs to orient and equip their lay health workers. While each group's training incorporated health information and tools specific to the disease or condition they addressed, the following topics were common to each group's training program:

- Patients' rights and responsibilities;
- Advocating and taking action;
- Communication skills to improve consumer-provider relationships; and
- Taking responsibility for one's own health.

Finally, efficient train-the-trainer models can maximize the scarce resources of main program staff and reduce the time required to train lay health workers, particularly in statewide programs that must contend with California's large geographic size and diverse population.

Lessons Learned

Using lay health workers to disseminate culturally competent education and information and address issues of quality of care has been a successful strategy among the Allies for Quality. The following lessons are drawn from their work:

- Lay health workers quickly gain trust and effectively communicate with their audience because they share key experiences with the community members they serve.
- As intermediaries between their communities and health care systems, lay health workers are often an effective resource for culturally relevant and accessible health education and health care quality information as well as a point of access to health care.
- Lay health workers' position within their communities and health care systems gives them the ability both to make quality issues relevant to their community and help change the health care delivery system to be more responsive to community needs.
- Lay health workers can be a cost-effective extension of the health care system.

Allies for Quality have shown that lay health workers can successfully engage significant numbers of consumers in increasing knowledge and reducing barriers to health care quality. With the benefit of greater recognition and support for their efforts to assist hard-to-reach clients, lay health workers can increase both access and quality for many consumers.

Funding Lay Health Workers

The use of lay health workers offers a cost-effective alternative to employing health care professionals as conduits of education, emotional support, and intervention activities. The health care delivery system and other organizations that benefit from these services need to consider how to fund their work.

Although the funding the Allies for Quality received helped them develop and refine the lay health worker component of their programs, not all of the grantees had sufficient resources to provide stipends or paid positions for these workers. Instead, they relied on the volunteer services of people who, because of their relationship to the intended population they dealt with, were interested in improving the quality of their own care and that of others in similar situations.

Programs that must rely on volunteer services in this way are less stable and more difficult to sustain over time. Volunteers pursue other interests, new volunteers must be recruited and trained more frequently than paid staff, and program continuity suffers. For a lay health worker program to be most effective, sufficient investment is needed in crucial infrastructure elements, including leadership development, training, evaluation, and stipends to support these workers.

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ABOUT THE PROJECT

Allies for Quality: Patient and Consumer Groups Improving Health Care was developed by the California HealthCare Foundation (CHCF) to support and encourage patient and consumer groups' involvement in health care quality issues. CHCF is an independent philanthropy committed to improving California's health care delivery and financing systems. More information about the grantees is available at www.chcf.org.

The Allies for Quality Grantees include:

- California Black Health Network
- The Diabetes Prevention and Control Program
- The Center for Disabilities and the Health Professions
- Community Health Councils, Inc.
- The Community Health Worker/*Promotora* Network
- The Sickle Cell Disease Foundation
- Women's Health Leadership
- The Women's Information Network Against Breast Cancer

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