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The "In-Between People": Participation of Community Health Representatives in Diabetes Prevention and Care in American Indian and Alaska Native Communities

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Respected members of American Indian and Alaska Native communities are a critical resource in helping communities mobilize efforts in diabetes prevention and care. Possessing cultural and historical knowledge and training in health promotion and social support, community health representatives (CHRs) are uniquely equipped to broker the needed relationship between a world shaped by culture and history and the world of conventional scientific knowledge. Grounded in principles of social support and interpersonal communication, as well as an understanding of their community's strengths and history in health protection, CHRs are bridges distinctively positioned to connect these two worlds. With additional training and mentoring in diabetes care and prevention, CHRs, in their self- described roles as "in-between people," can serve both as caring and knowledgeable community members and valuable members of the health care team.

Type 2 diabetes was rare in American Indian and Alaska Native (AI/AN) communities throughout the United States until after World War II, when the prevalence of the disease began to climb (Joe & Young, 1994; Krakoff & Wilson, 1999). In the past 50 years, diabetes has become one of the most common and serious illnesses among people of many AI/AN nations (Narayan, 1997). The age-adjusted prevalence of diagnosed diabetes among AI/ANs older than 20 years is almost three times (10.9%)—and up to four times (15.9%) in the Plains tribes—that for non-Hispanic Whites (3.9%) (Centers for Disease Control and Prevention [CDC], 1998). These rates are based on available Indian Health Services (IHS) data; only about 60% of AI/ANs seek IHS services, so these rates are probably underestimated.

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Type 2 diabetes has emerged not only as an epidemic among AI/AN adults but also among younger people. The appearance of this "middle-aged" disease among youth, now emerging in all North American populations, was first reported as a case series in 1979 among American Indian teenagers (Mazur, Joe, & Young, 1998) and First Nations youth beginning in 1984 (Dean & Moffatt, 1988). From 1988 to 1996, the age-adjusted prevalence of diagnosed diabetes in the 12 IHS service areas increased 54% among those aged 15 to 19 years from 2.9 to 4.5 per 1,000. Among Akimel O'odham youth in this age group, 50.9 per 1,000 have type 2 diabetes, identified by active population screening (Fagot-Campagna et al., 2000); this represents a two- to threefold increase during the past 30 years (Dabalea, Pettit, Jones, & Arslanian, 1999).

Fagot-Campagna and colleagues (2000) observe that type 2 diabetes may be the "first consequence" of the obesity epidemic reported in North American youth from all populations and in all age groups. Currently being reported in countries around the world, including Japan, Libya, Hong Kong, Bangladesh, Australia, and New Zealand, juvenile rates of type 2 diabetes are, like those of adults, associated with rapid industrialization and related societal trends.

Diabetes-related end-stage renal disease (ESRD-DM), requiring outpatient hemodialysis two to three times per week or a kidney transplant, is six times more common among AI/AN adults than among U.S. adults overall (Narva, 1999). From 1990 to 1996, the rate of Native Americans with diabetes who began treatment for ESRD-DM increased 24% to about 580 per 100,000, compared to about 380 per 100,000 people in the overall population with diabetes (CDC, 2000).

The rising trend in type 2 diabetes among AI/AN communities, whose members may perceive it as an "outside" or "unnatural" disorder (Huttlinger, 1995; Joe & Young, 1994; Wing, 1998) or a "white man's sickness" (Garro & Lang, 1994), is a relatively new threat to these communities. National initiatives that address diabetes, particularly in terms of reducing racial and ethnic disparities, are providing some support for locally generated efforts to address the challenges. The Balanced Budget Act of 1997 made possible a number of new programs, including the authorization of IHS grants for the prevention and treatment of diabetes among AI/ANs during a 3-year period (Indian Health Service, 1998). Prevention and treatment initiatives have since been undertaken by 333 tribes, tribal consortia, and urban Indian programs; these initiatives integrate traditional views and practices with conventional health care. Increased federal support, awarded in 2001, will expand these initiatives.

Other efforts are unfolding as a variety of agencies and organizations strive to address the Initiative to Eliminate Racial and Ethnic Disparities in Health, which was signed by President Clinton in 1998. In this presidential initiative, diabetes was identified as one of six health issues with strong potential for disease and disability prevention. Healthy People 2010, a "road map" set of objectives for improving the health of all persons in the United States through 2010, focuses on eliminating health disparities, including 17 objectives that specifically address diabetes and its complications and two process measures are devoted to the establishment of culturally appropriate and linguistically competent community health programs (U.S. Department of Health and Human Services, 2000).

The importance of social support in chronic disease prevention and diabetes self-care has been documented in recent years (Ford, Tilley, & McDonald, 1998; Wang & Fenske, 1996). Related to this the community health worker model (a social network intervention) is attracting increasing interest among health program planners (Beam & Tessaro, 1994; Love, Gardner, & Legion, 1997; University of Arizona, 1998). Community health workers are "community members who work almost exclusively in community settings and who serve as connectors between health care consumers and providers to promote health among groups that have traditionally lacked access to adequate health care" (Witmer, 2000, p. 1055). In many American Indian communities, community health representatives (CHRs), and in Alaska Native communities, community health aides who serve as physician extenders, fill this role. We discuss the overall role of these tribal workers, hereafter referred to as CHRs, in the context of the theoretical basis for the community health worker (CHW) model and social support theory. These members of the health care team, also respected members in the communities in which they serve, mediate between health care systems and communities to improve the health of the people in their communities.

DEFINITION

Community health workers go by a variety of titles (e.g., community health advisors [CHAs], lay health workers, lay health instructors, peer counselors); here we refer to them as CHWs and specifically, in the case of many AI/AN communities, as CHRs. CHWs are typ-

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ically respected and trusted community network members, responsive to others' needs (Heaney & Israel, 1997), and able to serve as "bridges" (Love et al., 1997, p. 510) and "culture brokers" (McElroy & Jezewski, 2000, p. 193) between community residents and health care delivery systems. The CHW model of change is designed to strengthen already existing community network ties and enhance the total network by enlisting persons perceived by community members as willing and able to provide advice, emotional support, and tangible aid (Israel, 1985).

HISTORY

All cultures in the world have a lay health care system (Leninger, 1991) and there have probably always been people who were natural helpers, community members whom neighbors turned to for social support and advice, as well as specific skills such as midwifery and treatment of illness. In the United States, formal participation of trained workers in this role has been documented since the 1950s (University of Arizona, 1998), but internationally they have been utilized more widely.

CDC's database of CHA, or CHW, programs currently number 200 and represent about 10,000 community workers. The National Community Health Advisor Study, which was conducted in 1996 and 1997, estimated that there are actually more than 600 such programs and at least 12,500 such workers throughout the United States, of whom one fourth serve as volunteers (University of Arizona, 1998).

CHRs IN AI/AN COMMUNITIES

The largest and likely the oldest system to formally use the skills of community workers was established in 1968, when IHS adopted the fledgling Community Health Representative program from the Office of Economic Opportunity. The program was designed to bridge gaps between people and resources and to integrate basic medical knowledge about disease prevention and care with local knowledge (Landen, 1992; Mayer, Brown, & Kelly, 1998; Yellow Bird, 1998). Designed to "integrate the unique helping of tribal life with the practices of health promotion and disease prevention" (Indian Health Service, 1991, p. 12), tribal CHR programs employ tribal members able to foster cross-cultural understanding through their shared tribal language and experiences. They support them with guidance and health care and education training.

In 1988, the Indian Health Care Improvement Act Amendment recognized the unique skills of these workers mandating that "the CHR Program endeavors to provide quality outreach health care services and health promotion/disease prevention services to American Indians and Alaska Natives within their communities." CHR services are managed and carried out by tribal governments, embodying the precepts and goals of Indian self-determination (Indian Health Service, 1991, 1999a).

Currently, about 1,400 CHRs serve in more than 250 tribes in more than 400 rural communities. "Deeply involved in promoting health and preventing disease within their own communities, CHRs provide early intervention and case findings that result in patients receiving care earlier in the course of their illnesses," observes the Indian Health Service. Serving long hours and often on a 24-hour basis, CHRs promote access for their people to and from the health care system, support delivery of and continuity of care and culturally relevant education, and provide social support.

The emblem of the CHR program reflects a view of CHRs as "front-line caregivers" committed to providing a high standard of health care and service to their people. It features an eagle feather standing for courage to overcome barriers, a circle representing the unity of tribes in striving to create better lives for all AI/AN people, inner triangles illustrating council fires in which tribal members discuss their problems and plan together to resolve them, and outer triangles representing all AI/AN tribes in the United States (see Figure 1).

The CHR program reported almost 2.3 million client contacts in 1998, most of which occurred in community (34%) and home (30%) settings. The two leading detailed activities were case management (22%) and health education (20%). Many of the efforts reported by CHRs were channeled toward health promotion and disease prevention (19%) and diabetes care and education (14%) (Indian Health Service, 1999b). Reports by coordinators of the Special Diabetes Grants (made possible by the Balanced Budget Act of 1997) indicate that many projects included participation of CHRs in their plans to prevent and treat diabetes. Training of community advocates in diabetes care and prevention, including CHRs, for implementation of interventions is a strategy that is being utilized in at least half of the com-

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FIGURE 1
Emblem of the Community Health Representative Program

munity grant programs (Acton, Valdez, Hosey, Vanderwagon, & Smith, 1999).

EFFECTIVENESS OF CHWs

The use of CHWs in health intervention programs has been associated with improved health care access, prenatal care, pregnancy and birth outcomes, client health status, and health- and screening-related behaviors, as well as reduced health care costs (Brownstein, 1998). A 6-month self-management program for patients with chronic disease who used lay health instructors resulted in improved health behaviors, improved health status, and fewer hospitalizations compared with usual care (Lorig et al., 1999).

CHWs have been shown to be helpful in diabetes care as well. Diabetic patients in Saint Louis, Missouri, who accepted a home health aide to support their self-care efforts for 18 months (N = 44) showed improvements in glycemic control and attendance at eye and diabetes clinic visits and decreased emergency room visits, compared to a control group (Hopper, Miller, Birge, & Swift, 1984). Hispanic populations who used community workers were more likely to complete diabetes education programs, according to two studies (Brown & Harris, 1995; Corkery et al., 1997). Spanish-speaking persons (N = 109) using peer educators demonstrated improvements in diabetes education and self-care (Lorig & Gonzalez, 2001). African American patients with diabetes randomized to an integrated CHW and nurse case manager group had greater declines after 2 years in hemoglobin A1c values, cholesterol, triglycerides, and diastolic blood pressure than a routine-care group or those led solely by community workers or nurse case managers (Gary et al., 2000). The work of CHRs in accomplishing the diabetes program goals of American Indians (Gilliland et al., 1998) and community health aides in Alaska Native communities (Mayer et al., 1998) has also been noted.

THEORETICAL CONCEPTS SUPPORTING THE CHW AND CHR MODELS

Theoretical support for the use of the CHW/CHR model is based on social support and social influence.

Social Support

Social support, "the comfort, assistance, and/or information one receives through contacts from one's social network" (Wallston, Alagna, DeVellis, & DeVillis, 1984), typically involves conveying empathy for the difficulties of adaptation while providing a private setting for repeating and clarifying instructions (Elder, Guadalupe, & Harris, 1999). Social influence, a key construct in the fields of health communication and health promotion, includes recognition of the influence of a person's and a community's peer network in making health decisions (Eng, Parker, & Harlan, 1997; Eng & Young, 1992; Love et al., 1997).

The behavioral categories of social support, according to House (1981), are emotional (e.g., listening, caring, empathy, trust), instrumental (e.g., tangible aid through resources, transportation), informational (e.g., advice, suggestions, referrals, education), and appraisal (e.g., affirmation and feedback) (see Figure 2).

This construct of social support provides a conceptual framework for the CHW model (Barnes & Fairbanks, 1997; Eng et al., 1997; Eng & Young, 1992; Heaney & Israel, 1997; University of Arizona, 1998) (see Figure 2). CHWs may also be involved in mobilizing community resources to address the health and social well-being of their people (Berkley-Patton, Fawcett, Paine-Andrews, & Johns, 1997) and may be instrumental in supporting preventive services (Love et al., 1997).

Social support has been influential among African American adults striving to control their blood pressure (Ford et al., 1998) and among overall populations striving to eat healthy diets (Kelsey, Earp, & Kirkley, 1997). This support factor has also been found to be valuable in predicting diabetes self-care among older adults (Wang & Fenske, 1996) and in encouraging participation in an AI/AN diabetes education program (Griffin,

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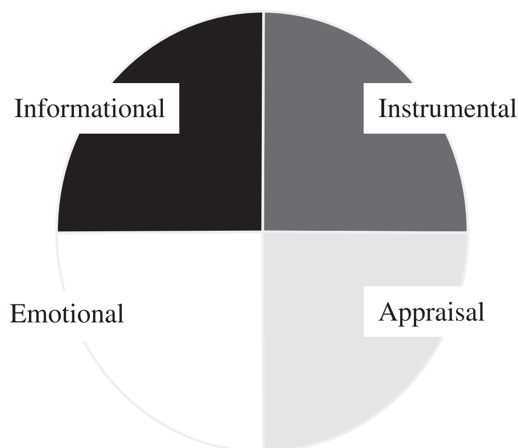
Gilliland, Perez, & Carter, 1999). In a diabetes intervention trial among Pima Indians, social support influenced glucose control "in ways that extend beyond our current paradigm of diabetes management" (Gregg & Narayan, 1998, p. 875; Narayan et al., 1998).

In studying social support as a predictive variable, researchers have identified some problems of scientific rigor in terms of measurement, including difficulty distinguishing between the recipient's social skills and their perception of social support (Cohen, Sherrod, & Clark, 1986; Tillotson & Smith, 1996), the inherent kinship and support based on cultural values in some communities (Berkman, 1984), and the influence of varying stages of illness and stress (Wallston et al., 1984). In addition to concerns about measurement, Wallston et al. (1984) have raised the possibility that too much social support may be harmful in some interventions, contributing to dependency and low self-esteem.

FIGURE 2
Social Support Theory as a Foundation for Community Health Advisor Model



Social Influence and Relational Communication

The role of social influence on behaviors, extending beyond the realm of social support theory, must also be considered when evaluating the effect of CHW intervention strategies (Wallston et al., 1984). Self-efficacy is one's judgment of capability to accomplish a certain level of performance and is identified as a determinant of behavior change and maintenance linked to the behavior categories of social support, particularly appraisal (see Figure 2). Self-efficacy is a concept found in social cognitive theory (Bandura, 1977, 1986), and it has recently been added to the health belief model (Glanz, Lewis, & Rimer, 1997). The subjective norms of the theory of reasoned action (an individual's attitude toward an action, expectations concerning the attributes of the action, and the influence of people the individual respects) also provide predictive variables for adopting adaptive health behaviors (Fishbein & Ajzen, 1975).

Research into aspects of relational communication between health care providers and patients offers thought-provoking data to consider in maximizing the influence of CHWs for diabetes care and prevention. In one study of interpersonal communication between doctors and patients, the physicians' attributes of receptivity (openness), immediacy (warmth, familiarity), composure, formality (professionalism), and similarity (in origin, ethnicity, culture, and economic challenges) were significantly associated with patient satisfaction with their care, but only similarity between patients and their providers was significantly related to patient adoption of recommended health care behaviors (Burgoon et al., 1987). Although this study involved physicians, the similarity of CHWs to their clients may uniquely position them to communicate effectively with community members and influence adoption of healthy behaviors.

CHWs' "insider," or emic, understanding of their community's cultural strengths and values provides them with the background needed to choose effective health communication approaches. Internalization is a communication strategy that influences a person to adopt actions based on their consistency with their existing personal and cultural values. Of the triad of communication strategies deemed persuasive in promoting behaviors: 1) compliance-gaining, 2) identification (with admired people), and 3) internalization, the latter is the most powerful (Arnold & Bowers, 1984). This strategy is the means for identifying meaningful, culturally based images and messages in health care programs, such as the stories and prayers written by Georgia Perez, a former CHR, for the 'S trong in Body and Spirit!" program by the Native American Diabetes Project in New Mexico (Carter, Perez, & Gilliland, 1999) and adapted by various tribes using the American Dia-

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betes Association's "Awakening the Spirit!" Program for Native Americans (Perez, 1998). Other examples of internalization are the culturally specific storytelling components within many AI/AN diabetes programs (Acton et al., 1999; Gilliland et al., 1998; Hagey, 1984; Marlow, Melkus, & Bosma, 1998; Mayer et al., 1998) and programs that support traditional indigenous practices, including physical activity and food restoration and preparation (Cook & Hurley, 1998; Duran & Duran, 1999; Leonard, Leonard, & Wilson, 1988; Olson, 1999; Roubideaux, 1999).

Finally, CHR functions may provide more time for one-to-one contact during home visits and drives to health centers, particularly in rural communities. This "drive time" can create the space for skilled CHRs to not only tell stories relevant to health promotion and support but to listen to people's own stories and explore with them the meaning of their health and health challenges in the context of shared cultural values and social relationships. Listening allows communicators to identify "what is close to people's hearts" (Labonte & Robertson, 1996, p. 441).

The constructs of social support and social influence, as well as certain interpersonal skills and traits, are reflected in the core roles, competencies, and qualities of CHWs. The Community Health Advisor Study identified 7 core roles of CHAs, or CHWs, and 15 competencies (skills and qualities) for the position (see Figure 3). This list should strike a familiar chord with all professionals who work in communities because of their alliance with principles of community organization and participatory action research, which involves a spirit of colearning (Minkler, 2000) and invites the direct participation of people affected by problems (such as diabetes) in all aspects of program planning and research design (Stringer, 1996). The key elements of participatory action research, which include giving back, having respect and love for other human beings, building trust, and having a sense of social justice (Smith, Wilms, & Johnson, 1997), are reflected in this list of skills and competencies.

These values and skills are also illustrated in a poem, "I Want to Help My People," written by Lakota and Dakota CHRs from the Aberdeen area (see Figure 4). "A poem is the shortest emotional distance between two points," said Robert Frost (Richardson, 1999, p. 521), and in sharing their poem, these CHRs have transformed their personal experiences into a public form to help others understand their work and commitment (Eisner, 1997).

FIGURE 3
Community Health Advisor Core Roles, Skills, and Competencies

---- Roles -----

- Cultural mediation between communities and health service systems
- Informal counseling and social support
- Provision of culturally relevant health education
- Advocacy for individual and community needs
- Assurance that people get the services they need
- Building of individual and community capacity to promote health
- Provision of direct services

--- Competencies: *Skills* ----

- Communication
- Knowledge
- Capacity building
- Interpersonal
- Service coordination
- Teaching
- Advocacy
- Organizational

--- Competencies: Qualities ---

- Relationship with community being served
- Desire to help community
- Empathy
- Persistence
- Creativity and resourcefulness
- Personal strength and courage
- Respect

SOURCE: Adapted from the University of Arizona (1998).

DISCUSSION

Interventions that fail to address the root causes of the increasing incidence of diabetes within an ecological context are unlikely to have sustained impact. Moreover, "the direction of change for chronic disease prevention can only come from within each community, by that community, and for that community" (Mayer et al., 1998, p. 143). To effectively address the growing threat of diabetes to AI/AN peoples, approaches must anchor efforts within local social, cultural, and spiritual knowledge and control while using the latest strides that public health and social science disciplines offer in terms of assessment, planning, and evaluation. This hybrid approach has brought the experience and wisdom of many people to bear on issues such as alcohol and drug prevention (Duran & Duran, 1999) and, increasingly, diabetes prevention (Carter et al., 1999; Mayer et al., 1998; Roubideaux, 1999). And, like

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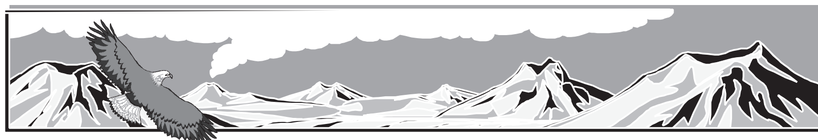
FIGURE 4
"I Want to Help My People": A Poem by Lakota and Dakota Sioux Community Health Representatives (CHRs)



"I Want to Help my People"

A Poem by Lakota & Dakota Sioux Community Health Representatives

"I am a representative of my community."
"I am a representative for health."
"I believe in my Creator."
"I see it as a calling."
"This is what I'm supposed to do."
"I want to help my people."

"My own life has to have balance or nobody will believe me."
"I'm not better than anybody else."
"I ask for forgiveness."
"I have to have a clean frame of mind."
"I pray to say the right things."
"I want to help my people."

"It's this idea of helping people."
"People trust me."
"They come to me in need."
"I'm there for everyone."
"We're the "in-between" people."
"I want to help my people."

"The eagle sees everything that's going on."
"Our ears are always open."
"Like bees, we're busy, trying to make things right."
"Sometimes we see things that make us sad."
"I can be fierce like a bear …trying to protect."
"I want to help my people."

"We have feelings, too."
"I wish they knew how much we care."
"I say, `We're here for you but please meet us halfway'."
"Some people thank us from the heart."
"Our elders -- they understand."
"I want to help my people."

"From the job came a concern for my people."
"I didn't know my people were so sickly with diabetes."
"People on dialysis talk to me -- `If I had only known….'"
"We've got to think about our children and grandchildren."
"We need prevention here."
"I want to help my people."

"We try again and again – then there's a little change."
"She gets outside and starts moving around."
"Just yesterday, he got off insulin and onto a pill."
"We did it! She switched to diet pop!"
"That's rewarding…rewarding….rewarding…"
"I want to help my people."

"We should tell our youth, "No, diabetes doesn't have to happen to you."
We know how to prevent these long-term illnesses.
Let's commit again to our traditional ways of living,
A life of balance, of people walking together on the same path.
Coming together in a good way.
"I want to help my people."

"I think of all the things I want for my community."
"I think of the animals that fly, swim - that survive…"
"I want our people to stand and be proud like the eagle."
"I think of the patience of the turtle."
"I remember of the strength of the buffalo."
"I want to help my people."

NOTE: Dedicated to Eugene Parker, a veteran CHR who put the needs of his community before his own. Used with permission.

other chronic disease challenges, diabetes prevention and self-care is less dependent on "high-tech" medical interventions than it is on "high-talk" interventions that include outreach, consistent follow-up, preventive care, education of community and family members, and mobilization for community-level action (Love et al., 1997).

All health professionals and community healers, leaders, and members are needed to arrest the mounting challenge of diabetes in AI/AN communities. CHRs are uniquely qualified to carry out culturally relevant communication and health promotion approaches necessary to address diabetes within an ecological context because they are in a position to respect and honor local

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knowledge, speak their tribal language, build trust for health care delivery systems, support people in making informed and adaptive health choices consistent with their personal and cultural values, and help mobilize their communities to promote participation in planning and delivery of interventions and identification of additional resources.

An academic appreciation for the theoretical constructs grounding the CHW model may be helpful in building interventions based on social support, social influence, self-efficacy, and health communications consistent with cultural values.

CHW approaches have recently received heightened attention from health program planners, but this model is not new—it represents an ancient method of communal care and health protection and, since 1968, a formal system of cultural mediation and health promotion in AI/AN nations. One of the goals of the model, to strengthen existing ties, is consistent with values integral to many AI/AN communities. Building on their ability to draw from wisdom and experience in the history and culture of their peoples, as well as to apply specialized knowledge in diabetes prevention and care supported by regular training, CHRs can serve as "vital links" (Landen, 1992), "bridges," and "culture brokers" (Love et al., 1997, p. 510; McElroy & Jezewski, 2000, p. 193) between community residents and health care delivery systems. Described by CHRs themselves as "the in-between" people (see Figure 4, 3rd stanza), perhaps someday these "unsung heroes" (Yellow Bird, 1998) will be honored for their roles in reducing the threat of diabetes to their people.

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