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A Navajo Nation Community Health Representative meets with a client

Community Outreach and Patient Empowerment: *A Collaborative Initiative for Chronic Disease Management in Navajo Nation*

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Introduction

In recent decades, American Indian/Alaska Native (AI/AN) communities have experienced a dramatic epidemic of cardiovascular disease,¹ with rates nearly twice as high as the overall US population.² These alarming trends in heart disease are linked disproportionately to high rates of obesity, high blood pressure, high cholesterol, and diabetes among AI/AN populations.³

Most tribal members are keenly aware that these health disparities are closely linked to the social and economic challenges that their communities face. For instance, in Navajo Nation—the largest federally-recognized tribal nation—over one-third of residents live below the federal poverty line, one-third of the homes lack plumbing, and two-thirds do not have telephone service. Such conditions

have led to lifestyle changes in traditional communities, with a rise in low nutritional value diets and sedentary lifestyles. Many individuals living on the Navajo reservation also struggle to receive regular healthcare services, due to lack of transportation, vast travel distances, and chronic understaffing at health facilities.⁴ Furthermore, patients face barriers to cross-cultural communication with their Indian Health Service (IHS) providers.⁵ Health education is often weak, with a lack of patient educational materials appropriate to AI/AN populations.⁶

It is important to note that most healthcare delivery systems (including the IHS) operate under the assumption that individuals are able to engage in healthcare services and make behavior changes if they are sufficiently knowledgeable and motivated about their health. However, for many AI/AN individuals, barriers to health services and self-management are rooted in larger structural (social, economic, and geographic) challenges that are difficult to overcome, even for the most knowledgeable and motivated.

To help individuals overcome these structural barriers to health, the Navajo Nation Community Health Representative (CHR) Outreach Program employs tribal outreach workers to provide home-based support to high-risk clients, including elders and clients living with uncontrolled chronic diseases. The Navajo Nation is one of more than 250 tribes in the United States that operates a CHR program, supported by federal funding provided through the IHS. Established in 1968 with a mission to improve the general health status of the AI/AN people through direct home health care, community, and patient-centered health promotion, the CHR Program provides an important additional level of support to high-risk individuals who might otherwise not be able to improve their health on their own. A unique strength of this program is that CHRs are members of the communities that they serve. Thus, they are able to understand, advocate, and respond to the needs and wishes of the community in a way that other health providers cannot. All CHRs speak Navajo and are members of the clan network within their communities, and therefore share strong bonds of trust, respect, and culture with their clients.

Despite all of these assets, CHR programs are often underfunded and have limited ability to work closely with provider teams at health facilities. Seeking to strengthen the CHR Program through technical assistance, the Community Outreach and Patient Empowerment (COPE) Program was established as a formal collaboration among the Navajo Nation CHR Program (NNCHR), Navajo Area Indian Health Services (NAIHS), Brigham and Women's Hospital (BWH) and Partners In Health (PIH) in Boston, MA. The COPE Project began as a series of discussions and needs assessments from 2008 to 2009, and was formally established in May of 2010. Initial activities focused on two service units

(healthcare service regions). Based on positive feedback and encouraging preliminary data, the program has expanded to eight units throughout Navajo Nation. As a model of cross-institutional collaboration, the COPE Project highlights how community health workers (CHWs) can effectively integrate into formal healthcare service delivery.

The COPE Program

The objectives of COPE are to provide the CHRs with the training, support and resources necessary to enhance their ability to promote the health of community members living in Navajo Nation and other AI/AN communities; to improve the overall health of high-risk AI/ANs living with poorly-controlled chronic conditions; and to prevent chronic conditions among at-risk individuals in these communities. COPE activities are focused in three areas: CHR training, health promotion materials, and a team-based approach.

CHR training focuses on health promotion and approaches to behavior change such as motivational interviewing and goal setting. Training includes role-play exercises and periodic competency assessments. Health promotion materials for high-risk patients consist of structured, home-based sessions delivered by CHRs over the course of 12 to 18 months. Teaching aids have been developed for low-literacy, non-English speaking populations. COPE's team-based approach allows for increased coordination between clinic- and community-based teams, more effective CHR supervision, and comprehensive evaluation. Models for referral, communication, and CHR documentation within electronic health records are explored at each facility. Here, we describe the program design, implementation challenges, and lessons learned.

Program Design

The design and implementation of COPE activities has been informed by iterative feedback from stakeholders - including program leaders, CHRs, supervisors, providers, educators, and clients - to ensure that the program design truly meets the needs of CHRs and their communities.

CHR Training

A strong understanding of core health worker competencies is essential to CHRs' effectiveness as public health leaders in their communities. In Navajo Nation, CHRs are trained as Certified Nursing Assistants and First Responders; many are working toward a Certificate in Public Health. CHRs receive monthly training on specific health topics, such as diabetes, blood pressure, nutrition, and medication adherence, taught whenever possible by bilingual providers and educators to ensure that CHRs can explain complex medical concepts in English and Navajo. Training lasts approximately two hours and includes in-

teractive exercises such as role-play. CHRs also complete competency assessments before and after each session, and receive their graded assessments with an answer key. CHRs who do not pass receive additional training until they obtain a passing grade. CHRs also receive reinforcement training on frequently-missed questions as well as trainer feedback.

However, CHRs in COPE expressed the need for additional training on health issues commonly affecting their community, such as diabetes, high blood pressure, cancer, dementia, and caregiver support. Likewise, providers voiced the concern that education provided to patients by outreach workers, such as CHRs, should be harmonized across clinic- and community-based health educators.

Training in behavior change develops the counseling skills of CHRs in the areas of patient goal setting, harm reduction, and motivational interviewing (MI). MI is a cornerstone of COPE's training to CHRs, as this counseling method has been shown to effectively bring about behavior change among clients across a broad spectrum of chronic health conditions. MI focuses on "meeting the client where they are," using non-judgmental dialogue (such as open-ended questions, affirmations, and reflections) to elicit the client's own feelings about their health rather than telling the client what they should do. COPE is currently using a "Train the Trainer" model to build local capacity in MI and health promotion topics among Navajo-speaking CHR trainers. In this model, all MI trainings are led by Navajo trainers and framed within the Navajo cultural perspective. This culturally-attuned system includes such techniques as acknowledging traditional customs that are consistent with MI (e.g. listening to a client quietly, respecting an elder's opinion), practicing MI role-plays in Navajo, and exploring challenges that might be unique in the Navajo context (e.g. how to do open-ended questions and reflections in the Navajo language).

Health Promotion Materials

The COPE program features a series of modules that together form a longitudinal curriculum to coach patients in making healthy changes and accessing healthcare services. Each module is developed closely with IHS experts to be consistent with standard of care practices. Responding to CHR feedback, patient teaching materials are formatted as printed flipcharts and are designed as "conversation guides." Each flipchart utilizes MI and goal-setting techniques and incorporates visual imagery and Navajo terminology to maximize comprehension among Navajo-speaking clients.

Team-based Approach

Strengthening linkages between the clinic care team and CHRs is essential to maximizing the impact of com-

munity-based activities, and provides a cohesive experience for the patient. Each Service Unit identifies a "COPE liaison," a point-person for coordinating clinical and training efforts. Each site has found different solutions to facilitate increased dialogue between CHRs and providers, such as case management meetings; documentation of CHR visits on electronic health records; team meetings and informal lunches; and physician-CHR home visits.

The referral process requires close communication between clinic-based providers (here defined broadly as physicians, nurse practitioners, pharmacists, nurses, health technicians, case managers and other health professionals who care for patients at the clinics), CHRs, and patients. Criteria for patient referral are not rigid: any patient living with an uncontrolled chronic health condition may be selected by their provider, public health nurse, or CHR. Both clinic providers and CHRs are encouraged to explain the program and obtain the patient's verbal consent to participate in COPE. Patients may alternatively decline home visits or accept CHR visits without participating in COPE. The clinic provider is asked to provide a summary of relevant clinical information, including a list of medical concerns, medications, appointments, and recent laboratory data. CHRs are encouraged to perform an initial intake that elicits information from the patient's perspective on their own health and socioeconomic issues, and identifies health changes that the patient and CHR would work on together, such as diet, exercise, medication adherence, and getting to appointments.

Supportive supervision is also essential for CHRs to function optimally, especially in light of their broad scope of work and time demands. COPE supports these areas by providing training on management skills to CHRs' supervisors, and encouraging each site to collectively identify program evaluation indicators. In addition, annual retreats for the CHRs are held to strengthen team building, analyze quality improvement and COPE progress, as well as nourish CHRs' own mental and physical health as caregivers and "front-line" responders.

Program Evaluation

Annual surveys and focus groups with key stakeholders assess program performance and identify areas for improvement. Qualitative data have been instrumental in helping COPE to identify activities or health topics with limited uptake. For instance, we found that CHRs were uncomfortable talking about alcohol abuse, because they felt that they did not have sufficient knowledge about alcohol use and might offend their clients by breaching this topic. In response, we carried out CHR refresher trainings emphasizing role-plays until CHRs became more comfortable opening the conversation with their clients. The alcohol module was also modified for easier use, providing more

information on treatment options, which allowed CHRs to encourage patients to talk with their providers about any options that interested them. We also track enrollment and attrition among COPE participants, as well as clinical outcomes. To date, more than 525 clients have been enrolled in COPE. Preliminary data from the first 43 clients enrolled in COPE have shown an average drop of one percent in the hemoglobin A1c and an average drop of 10 mg/dl in cholesterol, indicating above average improvements in control of diabetes and high cholesterol. A comprehensive analysis of clinical outcomes, health service utilization and cost is currently underway.

Lessons learned

Integrating community outreach into formal health-care services is challenging for many reasons. First, health care workers often face inherent structural impediments to collaboration: clinic-based providers and outreach workers are located in different places with minimal time to engage in new activities or approaches; responsibilities and competencies of community health workers are often poorly defined and not understood by clinic providers; and historical precedence and organizational structures make collaboration between tribal and federal institutions challenging. We have found it is essential to understand perspectives of stakeholders at all levels, from leadership to providers to outreach workers, and to design an intervention that meets the needs of these partners.

Another challenge is bringing about a cultural shift in how providers approach improving their area's health system. Initially, providers in both AI/AN and non-AI/AN communities may be surprised to know that community health workers exist and that they are at work in the homes of their patients. Validating the efforts of outreach workers and empowering CHRs to deliver high-quality services is an essential function of COPE, requiring proactive work over time.

Another important aspect of this intervention has been the adaptation of the program to the specific cultural needs and desires of the community. The COPE Project built upon the strengths of the Navajo community: the authority and respect of CHRs within their communities, the power of communicating in Navajo (both to train CHRs and to teach clients), and the dedication of many IHS providers to serve marginalized communities. In addition, COPE also sought to overcome some of the barriers faced by some of the most vulnerable members of the Navajo community. The profound geographic distances and lack of basic resources such as telephones, healthy food and utilities faced by many households requires a patient-centered approach in which CHRs pro-actively check on patients, relay information back to providers, and work with clients to make realistic health behavior changes that are



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achievable within their home environment. To this end, we worked to facilitate communication between CHRs and clinical providers, trained CHRs on behavior change (MI instead of simply instructing patients on what to do), and developed culturally-sensitive teaching materials that were appropriate for the population, including individuals who did not speak English and had limited health literacy.

Finally, any attempt at improving the health of marginalized populations must adopt a patient-centered approach to care. This means shifting the locus of intervention from the clinic walls to the home, where patients living in poverty often make behavioral decisions prioritizing household survival over self-care. As community members themselves, community health workers are uniquely capable of empowering patients through individualized coaching and education, providing social support and help navigating access to health care services.

Conclusion

COPE is a collaboration between an academic institution (BWH), tribal entity (NNCHR) and regional IHS that has enhanced existing activities and built bridges to better serve the Navajo community. The CHRs have been empowered to take ownership of this program, which has resulted in a system that is sensitive to the needs of their community. Given the ongoing challenges of poverty, limited healthcare resources, and limited professional human resources in rural tribal settings, COPE provides a promising model for expanding the role and impact of CHRs when integrated into team-based care. **CI**