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Academic Health Center Management of Chronic Diseases through Knowledge Networks: Project ECHO

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Abstract

The authors describe an innovative academic health center (AHC)-led program of health care delivery and clinical education for the management of complex, common, and chronic diseases in underserved areas, using hepatitis C virus (HCV) as a model. The program, based at the University of New Mexico School of Medicine, represents a paradigm shift in thinking and funding for the threefold mission of AHCs, moving from traditional fee-for-service models to

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public health funding of knowledge networks. This program, Project Extension for Community Healthcare Outcomes (ECHO), involves a partnership of academic medicine, public health offices, corrections departments, and rural community clinics dedicated to providing best practices and protocol-driven health care in rural areas. Telemedicine and Internet connections enable specialists in the program to comanage patients with complex diseases, using case-based knowledge networks and learning loops. Project ECHO partners (nurse practitioners, primary care physicians, physician assistants, and pharmacists) present HCV-positive patients during weekly two-hour telemedicine clinics using a standardized, case-based format that includes discussion of history, physical examination, test results, treatment complications, and psychiatric, medical, and substance abuse issues. In these case-based learning clinics, partners rapidly gain deep domain expertise in HCV as they collaborate with university specialists in hepatology, infectious disease, psychiatry, and substance abuse in comanaging their patients. Systematic monitoring of treatment outcomes is an integral aspect of the project. The authors believe this methodology will be generalizable to other complex and chronic conditions in a wide variety of underserved areas to improve disease outcomes, and it offers an opportunity for AHCs to enhance and expand their traditional mission of teaching, patient care, and research.

Healthy People 2010 for the first time identified the elimination of health disparities as a national health goal of the United States.[1] Rural, uninsured, and underserved populations represent three of the most significant sectors of inequality in the U.S. health care system. This inequality is especially prominent in the treatment of chronic, common, and complex diseases that disproportionately contribute to the overall morbidity and mortality in this country.[2] A central contributor to health disparities in underserved areas is a shortage of health care providers with the specialty expertise required to manage chronic disorders, such as diabetes, hepatitis C virus (HCV), cardiovascular disease, and depression, optimally[3] In this article we describe the rationale for an innovative telemedicine program based in an academic health center (AHC) designed to improve patient care by developing and supporting the competence of primary care providers in underserved areas to manage complex disorders. This competence is developed through access to AHC specialists using a unique process of case-based learning known as knowledge networks. These networks integrate the strengths and resources of academically diverse partners in the modern health care sector in a model that is widely applicable for managing diverse national public health challenges. In the University of New Mexico’s Project Extension for Community Health care Outcomes (Project ECHO), we use the treatment of HCV, a complex, chronic condition, as a model for managing other common and complex conditions, such as diabetes, cardiovascular diseases, mental health disorders, and HIV.

New Mexico as a Medically Underserved Area

New Mexico is the fifth-largest state in the country with a predominantly rural and frontier population of 1.83 million people, over half of whom are members of racial and ethnic minorities.[4] The population in many rural parts of the state is widely dispersed, making the availability of specialty care economically nonviable. Forty percent of patients in New Mexico are Hispanic, an ethnic group that has high rates of HCV infection nationally.[4,5] It is conservatively estimated that 32,000 New Mexicans are infected with HCV, and the state leads the nation in deaths from chronic liver disease and cirrhosis[6]

The poverty rate in New Mexico is 17.7% compared with 11.7% nationally. New Mexico also has one of the highest rates of uninsured citizens in the United States. According to 2002 data, 21.3% of New Mexicans lack health insurance, considerably more than the 15.2% national average. Thirty-two percent of Hispanic adults and 29.4% of American Indians in New Mexico lack health care coverage.[7] Uninsured rural inhabitants often receive their primary health care from federally qualified health centers that are paid to provide indigent care through a cost-reimbursement mechanism. Access to infectious disease specialists, gastroenterologists, or hematologists trained in HCV management is extremely limited for both insured and uninsured rural patients in New Mexico. Most of these specialists are concentrated in the one AHC that serves the entire state, the University of New Mexico Health Sciences Center. Although pharmaceutical companies have offered antiviral therapy to indigent patients through patient-assistance programs in rural and frontier areas, lack of primary care expertise in the treatment of HCV and scarce specialty resources have limited patients' ability to take advantage of such programs.

Compounding the obstacles of a predominantly rural population with a high rate of uninsured citizens is a shortage of health care providers. Thirty-two of the 33 counties in New Mexico are listed as medically underserved areas, and 14 of these counties are designated as locations of health professional shortage. Only 20% of New Mexico physicians practice in rural or frontier areas.[7]

HCV: A National Public Health Problem

HCV qualifies as a pandemic, with perhaps 200 million HCV-infected persons worldwide and three million persons chronically infected in the United States alone. Twenty percent of those infected with HCV will develop cirrhosis over the course of two decades, and 4% of these individuals will progress to liver cancer annually. Statistical projections for 2010 through 2019 indicate there may be as many as 193,000 deaths attributed to HCV in the United States, with a total of 1.83 million life-years lost to the disease. The estimated total cost of advanced liver disease due to HCV is $11 billion in direct medical care costs and nearly $54 billion in societal costs due to premature disability and death.[8] Current treatments combining pegylated interferon and ribavirin result in a sustained viral response for 45% to 71% of patients. Effective treatment leads to improvement of liver disease and, in many instances, reversal of cirrhosis.[9] One of the major obstacles to patients receiving treatment for HCV has been the serious and complex side effects of antiviral therapy (e.g., anemia, neutropenia, depression) and the coexistence of psychiatric and substance abuse disorders.[10,11] The complexity of disease management and lack of access to trained specialists, who are typically available only in urban centers, have been substantial limitations to the provision of care to a largely rural population.

HCV is also endemic in the national prison population, and its treatment in prisoners is somewhat controversial.[12] Despite a lack of universal testing in prisons, to date, 1,978 prisoners have tested positive for HCV in the state of New Mexico, and it is expected that 2,400 of the 6,000 prisoners in New Mexico will eventually be diagnosed with HCV. Before the New Mexico Department of Corrections became a partner in Project ECHO, not a single prisoner had been treated for HCV. Project ECHO has offered at least a partial solution to the difficulties in obtaining appropriate and timely treatment for HCV-infected prisoners in New Mexico.

HCV in New Mexico and Project ECHO

We chose HCV as the exemplar in Project ECHO because it exhibits the six characteristics we have identified that make a disease amenable to treatment using knowledge networks:

1. The disease is common.
2. The disease has complex management.
3. Treatment for the disease is evolving.
4. The disease has high societal impact.

5. There are serious outcomes of failing to treat the disease.
6. Improved outcomes can be obtained with disease management.

Common diseases such as HCV, cardiovascular disease, and mental health disorders account for the majority of morbidity and mortality in the United States.[13,14] Improving outcomes for these diseases can thus have a disproportionately great impact on quality and quantity of life in this country.

These common conditions are also complicated to manage, and effective of education, lifestyle modification, and medication regimens beyond the training, time, resources, or experience of most primary care providers.[15] Often, multidisciplinary teams with expertise in specific areas are necessary to competently treat these conditions. The treatment of these diseases is rapidly evolving, with new research constantly dictating changes in disease management, making it nearly impossible for a primary care provider to keep up with the latest developments in one, much less a multitude of, chronic health problems.

These diseases have high societal impact, including loss of productivity at work, early disability and retirement, absenteeism, and excessive use of health care resources, including hospitalizations and pharmaceutical costs. Seventy-five percent of the world's annual medical expenditures of $1 trillion can be attributed to chronic diseases.[16] Failing to treat these conditions early and adequately results in increased morbidity and mortality, as these conditions are the leading causes of death in the world. For example, the Global Burden of Disease Study estimates that in 2020, the five leading causes of death worldwide will be ischemic heart disease, unipolar major depression, traffic accidents, cerebrovascular disease, and chronic obstructive pulmonary disease.[17] Through the use of state-of-the-art technology and best practices for the management of such diseases, substantially improved outcomes in quality of life, cost-effectiveness of care, and survival can be achieved.[18,19]

Project ECHO addresses the aforementioned six core characteristics of diseases amenable to treatment via knowledge networks through four major avenues. The first of these avenues is the use of telemedicine to maximize scarce specialty health care resources. The Institute of Medicine's definition of telemedicine is one of the most widely accepted: "the use of electronic information and communication technologies to provide and support health care when distance separates the participants."[20] The broadness of this definition is particularly applicable to Project ECHO, which incorporates several modalities of distance learning, including audio and video teleconferencing, Internet-based assessment tools, best practices, online presentations, and telephone, fax, and e-mail communications. What renders the use of telemedicine in Project ECHO innovative and relatively unique is that learning technology is geared toward ensuring providers are as well informed as possible, rather than telemedicine's traditional focus exclusively on treating the patient. Thus, in contrast to forms of telemedicine that are direct treatment modalities, the use of information technologies in Project ECHO facilitates and supports the provision of care.[21] It is this shift in the fulcrum of telemedicine that gives power and scope to the program's learning loops and knowledge networks.

The second avenue to treating diseases through knowledge networks is the use of a disease-management model combined with the employment of best practices. The third avenue is case-based learning with longitudinal comanagement of patients by primary care providers and specialists from the University of New Mexico Health Sciences Center and the New Mexico State Health Department. The fourth is the coordination of Project ECHO through a centralized Health Insurance Portability and Accountability Act (HIPAA)-compliant database that allows outcomes to be monitored for continuous quality assurance and improvement.

The primary goal of Project ECHO is to demonstrate how a partnership of academic medicine, public health, corrections, and community health centers can foster the capacity of rural physician partners to provide safe and effective treatment for HCV infection in any population, consistent with the accepted standard of care. Current Project ECHO partners include University of New Mexico Health Sciences Center Department of Internal Medicine, eight prisons in the New Mexico Corrections Department, the Indian Health Service hospitals in Santa Fe, the New Mexico State Health Department, federally qualified health centers (Health Centers of Northern New Mexico—two clinics), Presbyterian Medical Services, First Choice Clinics (three clinics), Hidalgo Medical Services, La Casa Family Health, Ben Archer Clinics, La Clinica De Familia), and other health care providers (Pojoaque Primary Care, El Pueblo Community Health, and Memorial Medical Center Family Practice Residency program.) Such a partnership is uniquely suited to address the barriers to treating HCV in medically underserved populations through the use of interactive audio and video clinics called knowledge networks. A secondary goal of Project ECHO is to use the treatment of HCV as a pilot to demonstrate the capacity of an AHC-led partnership that could use public health funding to manage any number of complex diseases in underserved rural and urban populations.

Operation of Project ECHO

Operationally, project partners are recruited through statewide health care conferences, presentations, and partner contacts. Once a partner joins the network, members of the HCV team visit the site to conduct a one-day hands-on training workshop. State-of-the-art technology for data sharing and collaboration and audio/video teleconferencing is essential to Project ECHO's mission of reaching out to underserved rural clinics and prison populations. The current videoconferencing network structure is illustrated in Figure 1. Telemedicine experts assist partners with installation of the HCV Care Manager, a specifically designed software program developed by the Liver Research Institute, Denver, Colorado, in collaboration with Project ECHO (Figure 2). Partners then spend one to two days at the University of New Mexico Hepatitis C clinic shadowing the core Project ECHO team to experience the dynamics of an HCV clinic.

After completing this initial orientation and training, partners—who currently include pharmacists, nurse practitioners, primary care physicians, and physician assistants— begin presenting HCV positive patients during weekly two-hour telemedicine clinics using a standardized, case-based format that includes discussion of treatment complications and psychiatric, medical, and substance abuse issues. During these clinics, partners collaborate with specialists from gastroenterology, infectious disease, psychiatry, substance abuse, and pharmacology, as well as with other network providers in learning loops.

Learning loops are case-based educational experiences in which community providers learn through three main routes: (1) longitudinal comanagement of patients with specialists, (2) other primary care providers on the network via shared case-management decision making, and (3) short didactic presentations on relevant topics, such as vaccination for hepatitis A and B and diagnosis of depression. These learning loops create deep domain knowledge about the area in question—here HCV—among rural providers, enabling them to provide the highest-quality treatment for their patients. Ethical and legal issues, such as licensing and credentialing, related to the comanagement of patients through the use of telemedicine have been major obstacles to wider utilization of telehealth.[22] Project ECHO specialists only collaborate with health care providers within the state of New Mexico and so do not confront issues with practicing in other states. Further, the novel use of telemedicine in Project ECHO means that academic specialists serve as consultants to other health care professionals, who remain the primary providers of care for underserved patients.

Benefits of Project ECHO for Providers

Health care providers in underserved areas face a number of unique professional difficulties, including personal isolation and professional stagnation, excessive workload, and lack of access to consultation and continuing medical education (CME). These problems have led to accelerated burnout and rapid turnover, which prevent the development of longitudinal patient–physician relationships and continuity of care among underserved populations.[23] One of the primary benefits of a partnership with an AHC is the potential to improve the recruitment and retention of physicians and other health care providers with personal or professional investments in rural medicine by helping to alleviate the aforementioned stresses.

Project ECHO addresses many of the problems encountered by rural and corrections health care providers. Participants in the network are offered free CME credits. Providers who manage 20 patients through a year of antiviral therapy are eligible to obtain certification demonstrating their expertise in the area of HCV treatment. Participation in weekly telemedicine clinics reduces peer isolation and fosters professional development. Project ECHO strives to restore the balance of education and clinical work that characterizes residency training by using case-based, patient-centered learning that has been shown to be far more effective in building essential clinical knowledge and skills than traditional lecture- or conference-based didactic CME.[24,25] Similar efforts in other rural areas have shown high rates of provider satisfaction.[26]

One of the most important barriers confronting a primary care provider attempting to manage complex diseases like hepatitis C, HIV, or diabetes is the exponential growth of scientific information, which has generated an professionals. The knowledge networks of Project ECHO deliver patient-specific knowledge on demand, thus bridging this gap to deliver the highest quality of patient care (Figure 3).[27] Indeed, every health care professional practices in an “underserved area” of knowledge outside his or her own expertise and, thus, could benefit from participation in knowledge networks.[28]

Preliminary data from provider satisfaction surveys indicate that many of these goals are being achieved. Twenty-nine providers completed a questionnaire covering their participation during the period August 2004 to June 2005. Ninety-six percent reported enhanced knowledge about management and treatment of HCV patients, and 92% believed they had obtained competence in caring for HCV patients. Reinforcing the target outcomes of Project ECHO to reduce rural provider isolation and to enhance access to specialty services, 84% cited access to expertise in behavioral and mental health care resources as helpful in caring for HCV patients. Seventy-one percent mentioned collegial discussion with peers as a major benefit of participation. Twenty-nine providers completed a survey at the 2006 annual Project ECHO meeting regarding the benefits they received from participation in the network. On a five-point Likert scale (1 strongly disagree, 5 strongly agree), the average response to the statement “I have access to Project ECHO specialists and their expertise whenever needed” was 4.8. The practical importance of an integrated approach to health care was shown in the average response of 4.5 given to the statement, “Collaboration among agencies is a benefit to my clinic.” Finally, survey respondents were invited to qualitatively describe their reasons for participation in Project ECHO. The single most important reason mentioned was, “To provide appropriate care for hepatitis C patients at their primary care location and to access subspecialty service for patients who would not otherwise have that service.”

Benefits of Project ECHO for Patients

Numerous studies have shown that specialist treatment of complex, chronic conditions, such as HIV, diabetes, and depression, is superior to that of primary care providers, chiefly because of domain knowledge and experience.[18,29,30] The Project ECHO model enables primary care providers, in collaboration with specialists, to develop a similar level of treatment competence in a chosen content area. This increased competence reduces medical errors (e.g., failure to vaccinate HCV-positive patients for hepatitis A and B), avoids unnecessary testing (e.g., the HCV RIBA assay), reduces the morbidity and mortality of untreated disease (e.g., cirrhosis and hepatocellular cancer), mitigates the cost of future interventions (e.g., liver transplantation), and may reduce treatment-related complications (e.g., anemia and depression). The project does not supplant but supplements the traditional strengths of the primary care physician–patient relationship. The model empowers primary providers to offer safer and more comprehensive care for complicated disorders that previously would have been managed through specialty referral, with the resulting long wait times, increased cost, and fragmentation of care.

Since the first Project ECHO HCV telemedicine clinic was held in June of 2003, 137 clinics have been conducted, with a total of 1,234 case presentations of patients enrolled in the HCV disease-management program. In 2005 alone there were 1,581 patient visits for HCV disease management at Project ECHO partner sites. Currently, there are 173 patients on interferon and ribavirin treatment for HCV in New Mexico via Project ECHO. This number is substantial given that most large university HCV programs typically have approximately 50 patients on treatment at one time, given the complexities of the treatment process. In addition, 2,683 hours of CME credit have been issued and 390 hours of on-site staff and provider training have been offered during the last two years at no cost to participants. Through indigent drug-replacement programs, pharmaceutical firms have donated more than three million dollars of no-cost pharmaceuticals for patients in Project ECHO.

We believe that the successes of Project ECHO thus far include significantly improved outcomes in patient care. The numbers of case presentations and teleconference hours represent substantial progress in the treatment of HCV in New Mexico, precisely because participants are providing high-quality and accessible care to hundreds of HCV-positive patients who would otherwise not receive treatment. Our initial goals were to construct a network enabling two major populations—those in the criminal justice system and those in underserved rural and urban areas—to receive state-of-the-art HCV medical management with antiviral therapy, and, concomitant with this outreach, to demonstrate the efficacy of telemedicine for the treatment of chronic disease in a variety of underserved areas. We feel that conducting near-weekly teleconferences with each of these groups in a three-year time period and obtaining free pharmaceutical, laboratory, medical, and behavioral health care for patients enrolled in Project ECHO are evidence of having accomplished our target goals. The teleconference model has been so successful that the Project ECHO team recently instituted separate clinics for HIV–HCV coinfection and substance abuse disorders. On July 1, 2006, additional Project ECHO clinics have started for substance abuse disorders, rheumatology consultation, gestational diabetes, and management of mental health disorders throughout New Mexico. Future patient-care goals are to expand access to these diverse specialty networks to any provider in New Mexico wishing to participate.

Barriers to Project ECHO

Project ECHO incorporates many of the principles, practices, and policies recommended by the Agency for Health care Research and Quality (AHRQ) and other government panels and professional organizations to meet the challenges of 21st-century health care delivery, particularly the problem of health disparities.[31]

The single greatest barrier to the success of Project ECHO was obtaining funding and constructing infrastructure to treat this prevalent and serious infectious disease in one of the most underserved and impoverished states in the country. Without treatment, 8,000 patients in New Mexico will develop cirrhosis, eventuating in several thousand deaths.[6]

Acquiring stable funding and infrastructure to provide disease management for HCV infection and other complex conditions can only be achieved through the collaboration of public health, government, academic, and private sectors in the United States. AHCs, with their triple mission of research, education, and clinical care, are the ideal and perhaps only entity with the technical sophistication, administrative experience, and professional ethos to lead such a collaborative initiative. The most effective interventions to improve health care delivery to rural areas are those that support the education of primary care physicians, increase the flow of providers to rural areas, strengthen and support rural health care institutions with the latest clinical research, and integrate rural health care into larger regional systems.[32,33] Endeavors like Project ECHO have the potential to help achieve the above objectives in almost any setting, including the rural United States or the developing world.[23]

Project ECHO was set up initially on a federal grant from the AHRQ. We subsequently proposed a public health model to operate Project ECHO, and we received key funding from the New Mexico State Legislature to address this health care disparity and achieve continuity of specialty care for the uninsured. Another indication of the success of Project ECHO and its collaborative model has been the acquisition of stable and recurring funding from pharmaceutical companies and the University of New Mexico. In March 2006, the New Mexico State Legislature provided permanent recurring funding for the project.

Project ECHO and the Mission of AHCs

Integral to the value of this paradigm shift in the treatment of chronic, complex diseases is the enabling of AHCs to fulfill their historic threefold mission of clinical care, education, and research, as well as honor an increasingly recognized obligation to protect and improve public health.[34,35] We have already outlined the potential clinical and public health implications of knowledge networks, but they also have significance for education and research.

Psychiatry, family medicine, and internal medicine residents as well as medical students regularly participate in HCV clinics, seeing firsthand the benefits of telemedicine and knowledge networks. They participate in discussions, review cases with faculty, and learn about detailed disease management.

Collaborations such as Project ECHO are ideal venues for the pursuit of clinical research in the fields of epidemiology, health care delivery, best practices, evidence-based medicine, and health care cost-effectiveness, the results of which have real-world applicability.

Knowledge networks offer AHCs a unique opportunity to assume leadership in partnerships with a focused synergy on major public health problems, thus continuing to justify and warrant traditional state and federal mechanisms of funding and support as well as attracting new community, industry, and managed care resources.[36]

Evaluation

Like all innovations, a knowledge network must be constantly evaluated and improved in response to feedback. We survey participants regarding their experience and have incorporated feedback into the timing and length of sessions, case presentation format, disease-management protocols, procedures for accessing indigent care, pharmaceutical drug-replacement programs, efficacy and ease of use of technology, and content of short didactic presentations. Other survey instruments are used to assess the efficacy of knowledge networks and learning loops. A biannual meeting of all providers serves to share best practices among rural sites. Over time, as outcomes become available, we will compare them with alternate care models to assess further the function of the Project ECHO model.

We hope the methodology of Project ECHO can be generalized to many common, complex, and chronic conditions in a wide variety of underserved and developing areas to effectively improve disease outcomes. This project can be a model for the interaction of AHCs with the diverse communities they serve, providing educational, research, and clinical expertise to primary care providers in locations distant from the AHC in both geography and resources.

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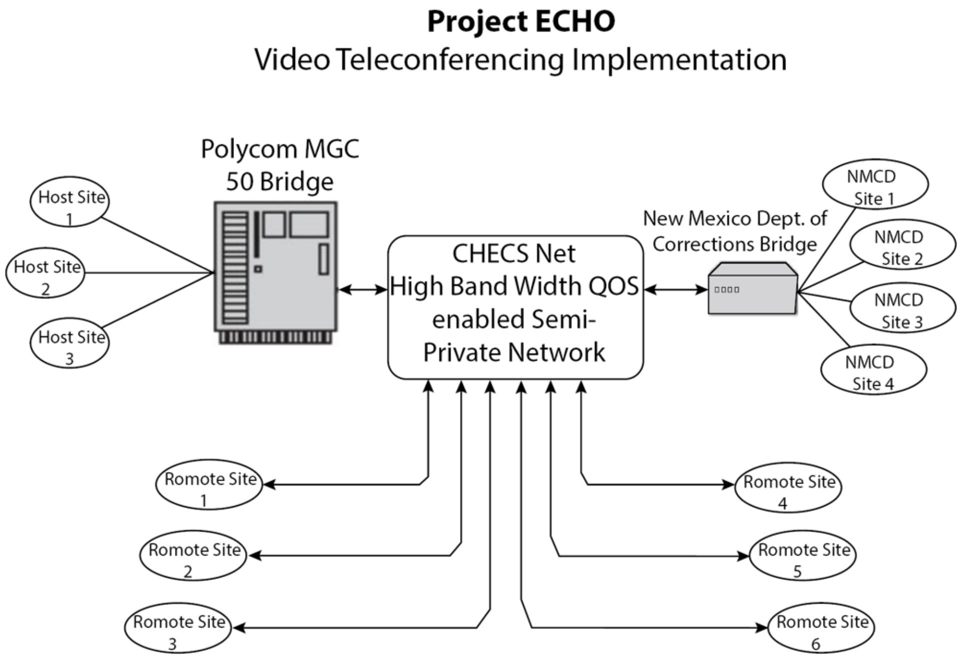
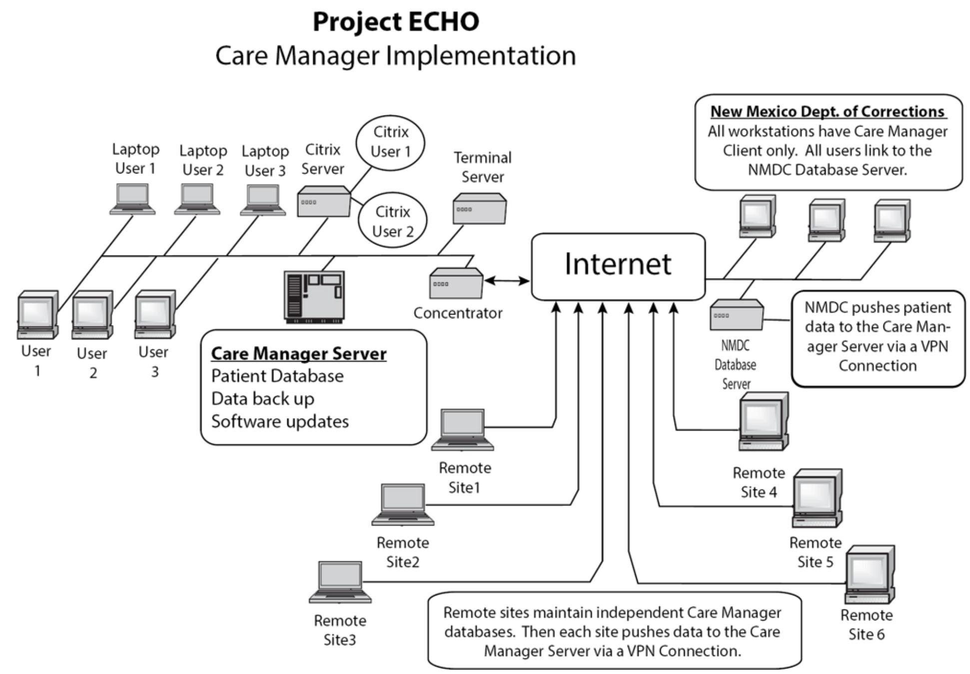


Figure 1.

Project ECHO video teleconferencing implementation. Project ECHO is based at the University of New Mexico, Albuquerque, NM, and was implemented in June 2003.



New Mexico Dept. of Corrections
All workstations have Care Manager Client only. All users link to the NMDC Database Server.

Care Manager Server
Patient Database
Data back up
Software updates

NMDC pushes patient data to the Care Manager Server via a VPN Connection

Remote sites maintain independent Care Manager databases. Then each site pushes data to the Care Manager Server via a VPN Connection.

Figure 2.

Project ECHO care manager implementation. Project ECHO is based at the University of New Mexico, Albuquerque, NM, and was implemented in June 2003.

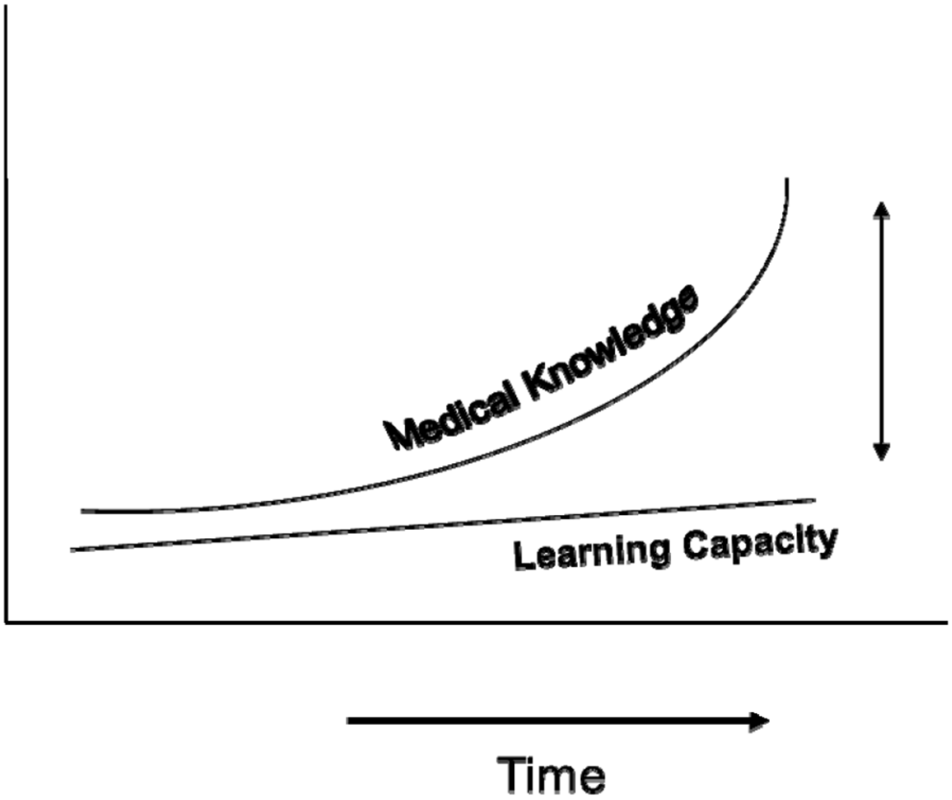


Figure 3.
The role of expanding knowledge in caring for underserved populations.