Is Anybody Out There? Integrating HIV Services in Rural Regions

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SYNOPSIS

As the HIV epidemic has changed nationally, the parallel change in the Southern states has been a disproportionate increase in HIV infection among people of color and among women. Due to the limited and disjointed health care and social service resources in rural Southern regions, already marginalized groups have difficulty in accessing appropriate care and services to address their HIV infection seamlessly and with continuity. To ameliorate the limitations in the health care infrastructure, the North Carolina Services Integration Project collaborated with North Carolina medical and social service providers and state agencies to create a sustainable and replicable model of integrated care for HIV-positive, geographically dispersed residents.

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While AIDS incidence is decreasing across the United States and the HIV incidence rate has grown stable, the African American and Hispanic populations, women, and residents of the Southeast are disproportionately represented among people with HIV diagnoses.[1–3] For example, in North Carolina (NC), where 50% of the population lives in rural areas,[4] 77% of new HIV and AIDS cases in 2000 were among people identified as African American or Hispanic, while 34% of new HIV cases and 27% of new AIDS cases were among women.[5] The growing epidemic among subpopulations that are socially, financially, and geographically disenfranchised requires a seamless care network to ensure appropriate medical and social services.[6,7]

As in other Southern states with similar distributions of HIV infection, HIV in NC disproportionately affects women and members of racial/ethnic minority groups.[1–3] In addition, rates differ across geographic regions of the state. In the eastern half of the state, a land mass larger than West Virginia or South Carolina, HIV and AIDS incidence rates are greater than those in western NC.[5] Many people with HIV in eastern NC lack reliable transportation systems and have many competing emergent life needs, such as childcare and stable housing. Throughout the 54-county region, the more than 3,000 people living with HIV receive medical care for their HIV infection and complications from infectious disease (ID) clinics of three academic medical centers. Most receive case management services from county health departments or local AIDS service or other community-based organizations. Local agencies often can dedicate only part of their staff's time to case management, thereby limiting the number of clients served and the continuity that can be provided in client care; only some of the more densely populated counties have full-time AIDS-specific service organizations. This dispersion of limited services potentially reduces patients' quality of care in three ways: (*a*) Medical providers lack an understanding of patients' daily needs, activities, and environment. (*b*) Case managers have difficulty accessing clients' medical information because their agencies do not have well-established or positive working relationships with ID clinics or their staffs, thereby limiting their ability to develop comprehensive care plans. (*c*) While some patients have regular contact with their case managers (located in their communities), they cannot readily access medical care due to the distance and time required for travel to ID clinics.

In different areas of health care, integrated care delivery systems have proven beneficial to patients' health and financial resources[7–12] by reducing hospital stays[8] and costs[7,12] and by improving patient and provider satisfaction.[7] However, in largely rural states such as NC, HIV health and social services are fragmented.[13] Furthermore, since providers have grown accustomed to working separately from each other, additional difficulty arises in convincing providers to coordinate care across disciplines and in building regular communication and information-sharing into the standard of care provision. Many providers have never met each other.

PROGRAM DESCRIPTION

To address the needs of disenfranchised populations within a care system of dispersed HIV services, the North Carolina Services Integration Project (NC SIP) led a community-based effort to form an integrated care delivery system for people with HIV who lived in the eastern half of NC. The five-year federally funded project was a collaborative effort among academic medical center ID clinics, case management agencies, and administrators of regional consortia of HIV providers in eastern NC; the NC Department of Health and Human Services AIDS Care Unit; and the HIV/AIDS Bureau, Health Resources and Services Administration, U.S. Department of Health and Human Services. To enhance the quality and extent of care coordination, the NC SIP staff facilitated coordination between HIV clinicians and case managers through multiple modes of enhanced communication. Additionally, providers stored client information within a closed computer network created as part of NC SIP using case management and clinical databases designed to enable confidential and consensual information-sharing for the purpose of enhanced provider decision-making. An additional database of local resources gave providers and clients easy access to local and state HIV resource information.

The NC SIP's central philosophy of including all provider voices in formulating the project's workplan and goals enabled the initial integration of HIV services. For example, the idea for the computer network (which was not part of the original grant) emerged during discussions between case managers and ID physicians regarding how to effectively communicate with each other. This approach helped clinicians, case managers, and administrators to build relationships and learn to respect each other's ideas and skills.

Integrated delivery system

Implementation of NC SIP was led primarily by two Agency Coordinators, who were public health professionals with graduate degrees, one in public health and the other in social work. Before joining NC SIP, the Agency Coordinators had worked throughout the HIV community in eastern NC and therefore had trusting relationships with a number of providers and clients. The respect they had already earned in the HIV community was beneficial since the Agency Coordinators' role was to coordinate every aspect of developing the integrated care delivery system, which required relationship-building with and among HIV providers."

Integration of providers and administrators was facilitated by the Agency Coordinators through site visits, meetings, telephone calls, newsletters, a website, electronic communication, trainings, conferences, and group and individual technical assistance. Integration was further enhanced through subject-area workshops on mental health assessment and substance abuse intervention and through development of "caremaps." Caremaps for HIV clinical care, case management, and hospice services were developed by medical and social service providers, who discussed and created practice guidelines for HIV care in NC.

Agency Coordinators designed training workshops to strengthen case managers' skills in areas such as mental health assessment, cultural competence, and stress management. Annual Case Managers' Conferences provided a forum for case managers to learn from and support each other. Collaboration with the NC AIDS Care Unit enabled case managers to receive HIV case management credit hours for attending the trainings.

Initially, the ID clinic physicians planned to increase participation by rural physicians in HIV care through clinical trainings, but attendees were more likely to be nurses and physician assistants. Since the target population of physicians was not participating in the trainings, NC SIP focused its efforts instead on support for the establishment of HIV-specific clinics in rural communities.

Throughout the five-year project period, providers compiled, developed, and distributed caremaps outlining standards for HIV clinical care, case management (including an enhanced component on mental health assessment and referral), and hospice services.[14] The caremap provided both a mode of integration and a tool for clinical and psychosocial care and management. The meetings to develop the caremaps brought professionals together who had not regularly met or discussed standards of care for their unique patient population. Providers not only came together to decide on practice guidelines, but also found in each other a resource and support. The caremaps also helped providers, particularly those in rural areas, understand what basic guidelines to follow and what to expect of care provided by other specialties.

Wide-area network computer system

Agency Coordinators and a Computer Support Specialist worked at length with providers to identify software that met providers' communication and information needs. NC SIP selected a software program that offered electronic mail capability and the ability to integrate case management and clinical databases. Within the closed computer network, patients' medical and case management information could be confidentially accessible to providers caring for shared patients. Providers worked with their clients to ensure each individual's consent to the sharing of information via the computer network.

NC SIP staff trained providers in using computer hardware and software and brought and maintained the network on-line. Throughout the project period, Agency Coordinators continued to hold numerous formal training sessions for case management agencies on using computers and the network system. Agency Coordinators also provided technical assistance onsite and via telephone. Additionally, they developed computerized forms that automatically pulled information from the databases, created a searchable website of information related to NC patient care and services, networked with agencies to encourage them to join the system, and developed informational databases.

User input regarding the type and amount of information the software could store was critical for integration. Because the providers put forth the idea of the computer network and continuously contributed to its improved functionality, they were motivated to learn and use the software and incorporate it into their daily care management activities. Furthermore, the institutional memory created by NC SIP and the virtual HIV community reduced staff turnover and helped new case managers/organizations learn more quickly about how to care for HIV-positive individuals (through the clients' medical records) and about what services were available (from the database of local resources).

PROGRAM EVALUATION

To assess the effect of integration among providers and patients, project evaluators collected data used for quantitative and qualitative evaluations. The combination of data on participation in the integrated delivery system and on changes in provider interaction with qualitative reports from project participants reveals both the tangible and intangible results of integrating care systems in rural areas.

Quantitative evaluation

Participation. Provider participation, all of which was voluntary, and support from a wide variety and high number of providers represented the quality and acceptance of the integration. Nearly all participants in the integrated delivery system utilized the computer network to varying degrees. To evaluate the computerized network, data were collected on users, clients, postings to the Discussion Page, postings to shared client records (to measure interaction), and frequency of provider usage. At the beginning of 2001, the project's final year, more than 150 HIV provider users were based in three academic medical centers, nine ID/HIV clinics, 14 county health departments, more than 50 case management and AIDS services agencies, nine Ryan White HIV Care Consortia (regional HIV providers supported by funding through the Ryan White Comprehensive AIDS Resources and Emergency [CARE] Act), and one local jail. Nearly 7,000 HIV-positive patients were registered in the clinical and/or case management databases.

NC HIV Provider Survey. The NC HIV Provider Survey, an adjunct to the Needs Assessment Interview developed by The Measurement Group,[15] examined HIV providers' level of interaction by catchment area before project initiation and during stabilization of the integrated delivery system and computer network. (Methods are detailed elsewhere.[13]) Surveyed individuals included medical, social service, legal aid, and HIV testing providers. The baseline survey was administered in 1997 (85% response rate), before the project was implemented.[13] The 1999 follow-up included the 119 original randomly selected providers as well as 49 case managers involved in the NC SIP (eight of whom were among those surveyed at baseline), resulting in a total of 160 follow-up responses; 85 survey questionnaires were returned, for a response rate of 53%.

The survey questionnaire listed all of the HIV providers in a participant's region (defined by Ryan White Consortia or, for the larger consortia, by county) and asked four questions to detect, on a 5-point Likert scale, the amount of knowledge about, number of referrals to and from, and level of satisfaction with the listed providers. The Table displays results from Student *t*-tests of the mean responses from baseline and follow-up surveys for all providers and for providers involved in NC SIP. Even when we used unequal variances as a conservative measure for the *t*-tests, results continued to be statistically significant. A comparison between baseline and follow-up surveys of all providers indicates a significant decrease in knowledge, referrals, and satisfaction from 1997 to 1999, potentially explained by unusually high turnover throughout service organizations during this period. On the other hand, in an analysis comparing HIV providers involved or not involved in NC SIP, participating providers were found to have a significant advantage: NC SIP participants reported more knowledge of, referrals to, and satisfaction with other providers in their region. Survey results indicate strengths of both the integrated care delivery system and NC SIP's philosophy of equal collaboration with medical and social service providers, administrators, and government agencies.

Southeast HIV Patient Survey and medical chart abstraction. To allay concerns among clients, providers, and administrators regarding the confidentiality of information stored on the computer network, NC SIP assured all participants that patient information stored in the databases would not be used for research purposes. Therefore, in order to indirectly evaluate significant case-control and pre-post differences in access to care and services among eastern NC HIV patients, data on satisfaction, quality of care, health status, and cost were collected for a sample of patients via annual chart abstractions and two telephone interviews.

Table. NC HIV Provider Survey results: baseline vs. follow-up and participating providers vs. non-participating providers

	All providers: follow-up (1999) vs. baseline (1997)		*1999 survey: participants vs. non-participants*	
Variable	*Difference*	*p-value*[a]	*Difference*	*p-value*[a]
Knowledge of named agency	−0.28	<0.01	0.77	<0.01
Referrals to named agency	−0.27	<0.01	0.45	<0.01
Referrals from named agency	−0.09	0.21	0.22	0.17
Satisfaction with relationship with named agency	−1.91	<0.01	0.54	<0.01

[a] Student *t*-test of differences between means.

Patients who were HIV-positive, attended one of seven ID clinics (three study sites and four Southeastern NC control sites), and were Medicaid-eligible were asked before project implementation to participate in a telephone survey and have their medical records examined annually for four years. Based on power calculations and budgetary constraints, a target was set of 800 study participants; in the end, 833 patients consented. Baseline population characteristics of the 542 participants (70% response rate) who had both a baseline Southeast HIV Patient Survey and chart abstraction are detailed elsewhere.[13] The follow-up survey was initiated two years after completion of the baseline survey. Additional patients were enrolled to make up for the participants who had died or were lost to follow-up. Ultimately, 229 additional patients were enrolled and 245 participants were re-interviewed. Additionally, from the time of enrollment until the time of the follow-up survey, patients' medical records were reviewed annually by nurses of each ID clinic, enabling linkage of their survey responses to their clinical outcomes and utilization. Merging data from the four years of annual medical record review with the baseline and follow-up Southeast HIV Patient Surveys will provide important data about the effects of integration on patient care.

Qualitative evaluation

Formal and informal feedback from NC SIP participants enabled a qualitative evaluation of the integrated care delivery system and the computer network. The project offered a number of benefits to providers.

Benefit to case managers. Integration provided information never before accessible to case managers in rural areas. Using the software, case managers were able to look up, for example, information on the side effects of HIV medications and on local or state services. The system helped create a common expectation of, or standard of care for, case management services. Case managers also had, for the first time, direct communication access to ID clinicians and social workers and were able to send and check e-mail using laptop computers from any location with a telephone jack.[16] The computer network, workshops, conferences, and the process of caremap development empowered case managers to contribute to their clients' care as much as medical providers did.

Benefit to North Carolina clinicians. ID physicians helped develop the computerized clinical database of the network, which served as an automated medical record. In this way, clinicians ensured that the computer network could interface with existing forms of data collection and medical recordkeeping. Features included automatic graphs detailing patients' HIV-specific medications with CD4+ and viral load counts, which improved clinicians' understanding of what medications were effective in a patient, enhancing their decision-making capabilities. The clinical database interfaced with the case management database to allow sharing of information such as current medications, future appointments, and lab results. For the clinicians, information from the case management database was also available to improve clinical decision-making. Additionally, joint caremapping and training activities reduced the isolation and burden often experienced by rural-based clinicians.

Benefit to HIV/AIDS services administrators. The Agency Coordinators created a billing template that the Ryan White Consortia administrators used to bill the NC AIDS Care Unit, reducing paperwork and time required on a monthly basis for reimbursement. For Medicaid-billable services, the NC SIP software simply had to export information into the already existing Medicaid system so that one computer system could be used for all billing.

Effect on patient care. Patient-level outcomes are more difficult to ascertain in the short term since improving care coordination takes time and integrated care does not have an immediate effect among patients. Quantitative patient outcomes will be evaluated later. For the purposes of program evaluation, though, anecdotal evidence from clinicians, case managers, and patients themselves indicates changes in care already experienced by patients. Some patients knew of the enhanced communication occurring between their care providers. This awareness stemmed not merely from the consent requested of them by their providers to use the computer network to store and share related care information but from interactions with their providers. When case managers, for example, knew immediately after an ID appointment what new medications had been prescribed and when to arrange transportation for the next clinic appointment, clients took notice that the increased provider communication helped their care become more efficiently managed. As well, providers were able to identify and confront patients who had been visiting different ID clinics (resulting in either over-prescribing or mixing of prescriptions).

Value of NC SIP philosophy. The NC SIP philosophy of asking all providers to contribute to the project's workplan and goals empowered NC SIP staff to respond to each provider's concerns and ideas immediately and to take responsibility for NC SIP's effect on providers, patients, and care. While this style of collaboration seems obvious, responsiveness and reliability are difficult to deliver, particularly within a health care system rife with bureaucracy, political distrust, and poor financial management and communication. Providers' interest and motivation increased over the project period as they learned how much they could trust and depend on NC SIP staff.

FUNDING

Funding integration efforts is difficult because clients are not directly served. Because the workplan of the grant changed after initiation of federal funding, NC SIP sought additional financial support from pharmaceutical companies and provider organizations. Also, provider time to attend trainings and learn to use the system was critical. NC SIP offered group trainings, followed by as many individual follow-up trainings as needed. The amount of time that NC SIP staff spent on computer-related tasks to meet the high level of users' need was enormous and largely unanticipated. Most support was in-person, with each of three NC SIP staff members (two Agency Coordinators and the Computer Software Specialist) traveling, conservatively, 2,500 miles per month.

The initial annual budget was $200,000, with 4% annual increases. Two public health professionals served as the Agency Coordinators, each with an initial annual salary of $34,000 that was commensurate with their education (a master's degree in public health or social work), training, and field experience. The Computer Software Specialist, who assisted with hardware and software installation, training, and maintenance, was a bachelor's level staff member whose annual salary was approximately $24,000. A part-time Systems Administrator, trained in computer science, ensured the integrity and functionality of the computer network; approximately $34,000 of the budget covered 50% FTE of this salary. The remaining $74,000 of the annual budget paid for staff benefits, travel costs (i.e., mileage, food, lodging), training and conference expenses (manuals, speakers), computer software and hardware maintenance (software upgrades, hardware re-installation), network maintenance, and costs related to providing direct and indirect technical assistance and information (telephone charges including the cost of conference calls, newsletters, caremaps, regional provider meetings). In-kind services of project staff and cost-sharing with provider organizations, medical institutions and pharmaceutical companies enabled the project to provide additional assistance and to incorporate more providers beyond those allowed by the base budget due to unanticipated costs and interest.

CONTINUATION AND EXPANSION

NC SIP considered numerous options for funding beyond the five-year grant, including funding by a consortium of payers and decision-makers (providers, administrators, clients, and pharmaceutical companies) or a fee-for-service plan. A consortium whose members might change annually and be subject to political tensions posed continual risk to sustainability. Collection of annual fees for a region-wide system would also be difficult; furthermore, agencies with already low budgets would be unable to enter or remain in a fee-for-service system because it is unlikely that funds could be shifted for the agencies to participate in the system. Also, even though NC SIP constantly collaborated with the NC AIDS Care Unit throughout the project period to ensure the awareness and contributions of state administrators, constraints at the government level could also lead to annual disagreements or financial problems, periodically altering the Unit's support of the system.

Thus, NC SIP planned to create an endowment to sustain and expand the system, relying initially on grants from foundations and other donors. In this way, NC SIP continued, as much as possible, to be removed from any one institution's demands and remain a powerful voice for lone HIV providers in rural areas. NC SIP also planned to expand the integrated delivery system and computer network to western NC and share the model of integrated care delivery with other rural regions and poor countries facing similar obstacles in providing comprehensive care.

CONCLUSIONS

Due to the need for effortless modes of care coordination to address the variety of comorbidities and needs among disenfranchised people living with HIV, systems of care across vast geographic distances require innovative models to meld the care that medical and social service providers offer. NC SIP, through its ability to address providers' needs immediately and bring their ideas to fruition, developed a model of integrated care delivery that providers were excited about and in which they voluntary participated. The integrated delivery system combined a personal touch (through the Agency Coordinators) with multiple modes of efficient communication. Integration not only resulted in enhanced care coordination; it also benefited providers' and administrators' skills, care coordination, and support systems. (They were able to rely on a larger provider community for care management advice and to reduce their isolation by sharing experiences.) NC SIP created a standard of care for HIV providers in eastern NC, while constantly working with the HIV community to improve this standard.

Preparation of this article was supported in part by the HIV/AIDS Bureau's Special Projects of National Significance Domestic Assistance Project Grant Number 93-928 from the Health Resources and Services Administration, Department of Health and Human Services. The manuscript's contents are solely the responsibility of the authors and do not necessarily represent the official view of the funding agency. The authors would like to thank the NC SIP team: Mat Despard, MSW, Jeanine Driscoll, PhD, Jennifer Flythe, Frank Lombard, LCSW, Priscilla Miller, MPH, Kimberly Scott, and Liyun Yu, PhD. They also thank Alison Heald, MD, Joe Eron, MD, Jeff Engel, MD, and Groupware Technologies, Inc.

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