The HIV Care Continuum in Publicly Funded Clinics

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Eliminating racial and ethnic disparities in health outcomes is a national goal. Our research team from UCSF spent more than two years looking at just how this vision could be achieved.[1–3] We learned a number of lessons from people—providers, patients, administrators and policy makers—we encountered along the way. What emerged was a better understanding of just what practical strategies could be adopted to reduce disparities. Much of what needs to happen was occurring at the local clinic level.

We began our work by reviewing the literature on racial/ethnic differences in HIV-related health outcomes (see article by Palacio et al. in this issue[1]). It was not a surprise that disparities could be found across different time points in the epidemic and within situations surrounding prophylactic as well as antiretroviral drugs. It was also clear that more needed to be done to identify potential solutions rather than just further documenting the extent of the problem. This led us to look more closely at strategies that could be used to respond to the problem.

Once we became involved in the details of how programs operated within states, we found that African Americans were much more likely to receive AIDS drugs through Medicaid than ADAP (see Kahn et al. in this issue[2]). A different pattern emerged for Latinos, who were more likely to access AIDS drugs through ADAP. In both cases, quality of care requires linking patients to support services. The policies adopted by states were clearly related to access (see Morin et al. in this issue[3]). States had also developed different strategies for reducing disparities by outreach and educational campaigns or contracts with minority community-based organizations.

Where we perhaps learned the most about ways to reduce disparities came in our visits to local clinics providing care to minority patients. Our research team went to eight HIV specialty clinics, spending one week in each clinic, to gain insight into the challenges of care delivery. Four clinics served primarily African Americans and four served primarily immigrant and first generation Latinos.

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We had the opportunity to observe the clinics in operation and to interview providers and patients of the clinics.

An effective care continuum began in treatment education outreach. It continued through testing and counseling, entry into a medical system, and establishing patient-provider relationships. Effective care further involved determining and committing to courses of treatment, completing ongoing checkups, dealing with an array of psychological and social issues, and engaging in support networks. Movement through this continuum was dependent on individual factors as well as the social, cultural, or policy climate of the location. We found that for those living in poverty, HIV treatment often had a lower priority than securing basic life needs for individuals and families. Within this context, there were multiple barriers and facilitators to treatment and care.

Resistance to testing for HIV was commonly associated with fear of stigmatization, lack of HIV information, or cultural predispositions concerning disease. Outreach efforts tailored messages to the targeted community raising awareness of the presence of HIV within the community. Education efforts focused on the need to know one's status as well as on available treatment, emphasizing that something could be done to help those infected. Providers found that once individuals were tested, there was a critical juncture for moving infected persons into care. Clinic providers spoke of the need to provide an immediate and personal bridge to entering the medical system at the time a test result was given. For instance, at one clinic the physician who would be the primary care provider for a newly infected person would give the test result to begin establishing rapport and to arrange for the first medical appointment. Patients who did not enter care immediately were often lost to follow-up, only to reappear when symptomatic. Clinic staff also spoke of the need to keep providers constant in order to overcome distrust of the medical care system and to correct misinformation.

Clinics and providers needed to step beyond boundaries of primary health care and present comprehensive support services that included links to basic needs of living, mental health services, and substance abuse programs. Deficiencies in care existed when such resources were not available or limited. The ability to provide comprehensive care was closely linked to state policy.[3]

Three of the four states where our clinics were located had a restriction on Medicaid eligibility to persons with an AIDS diagnosis or other disability. While ADAP could provide access to pharmaceuticals for those ineligible for Medicaid, surrounding needs, such as transportation to and from pharmacies and appointments, were often unmet, influencing patient adherence to the treatment plan. Some patients were prevented from accessing ADAP-funded pharmaceuticals because they could not provide the mandatory $5 co-pay per prescription in their state.

All of the clinics and their providers demonstrated a clear commitment to the populations they served. Providers were either culturally matched or culturally sensitive to patients of the clinics. Cultural competence was part of building trust and facilitating communication. Providers worked collaboratively with patients to establish personal support networks involving groups, peers, or family. These networks provided emotional and social support for actively participating in care as well as assistance in treatment decisions.

An inside view of HIV specialty clinics has shaped our thinking about access to and utilization of HIV pharmaceuticals and care. Support services are critical to a patient's ability to benefit from drug access programs. Developing a network of specialty clinics situated within community health centers is an important strategy for reducing disparities. The recruitment and training of African American, Latino, and other racial/ethnic specific HIV-specialty providers is important. Adequate funding for programs that train minority providers is essential. Treatment education outreach programs through community-based groups should be a sustained effort. Finally, the elimination of restrictions on access to Medicaid and the elimination of co-payments for ADAP pharmaceuticals need serious consideration.

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