

Journal Supplement

Rationale

Despite the conclusive evidence that receipt of HIV care and antiretroviral treatment has a dramatic impact on improving health and prolonging life, the CDC estimates that approximately 1/3 of persons living with HIV in the United States who know their HIV seropositive status do not receive HIV medical care. The first step in the process of care is making contact with the health care system – entry into care. After that, people need to become engaged in the process of health care, such that they remain in care over time. Research suggests that clients who are retained in care and adherent to antiretroviral treatment have decreased morbidity and mortality. If 1/3 of people living with HIV have not yet taken that first step, we can only imagine how many people are not yet fully engaged in the HIV health care and treatment.

This issue is of enormous importance to the U.S. Congress, and to federal agencies that oversee HIV prevention, care and treatment. Congress, in the most recent reauthorization of the RWCA, emphasized the importance of reaching out to those not in care and strengthening processes to engage and retain them in care. Many of those who are not in care are newly diagnosed with HIV. Thus, this is central issue for the CDC, which has developed initiatives to promote routine HIV testing and link people with care. By reaching people earlier in their HIV disease and linking them with care, it is hoped that there will be decreased transmission of HIV and better health and quality of life for those infected.

Many individuals touch the health care system at some point in time, but drop out of care and return only when seriously ill. Thus, engagement and retention in care is a major priority for HRSA, which launched the targeted Outreach Initiative (Outreach Initiative) in 2001 to “engage people in HIV care, turn sporadic users of care into regular users, and promote retention in care.” This journal supplement will address the impact of these interventions on engagement and retention in HIV care, including the individuals and community factors that impact access to care and how care-seeking behavior changes over time.

Data Sources and Sample

Ten programs based in Seattle WA, Portland OR, Los Angeles CA, Detroit MI (2), Boston MA, New York City, Providence RI, Washington DC, and Miami FL participated in the Outreach Initiative and recruited participants for their interventions and the study from October, 2003 through June, 2004. Each of the programs targeted different populations, including low income men of color who have sex with men, recently incarcerated individuals, adolescents, the homeless, women, and substance users. Two programs were clinic-based, targeting new patients or those with multiple missed appointments. The other eight programs were housed in community-based organizations and either worked with clinics or case managers to find their patients who had dropped out of care, or with prisons, homeless shelters, drop-in programs, needle exchange

programs and drug treatment centers to recruit sporadic users of care into their interventions and the study.

Data was collected longitudinally over a period of 18 months for all study enrollees, except those who enrolled in the last 6 months of the study, most of whom will have 12 months of data. All 10 programs contributed data to a multi-site evaluation center. The sample size for the quantitative study is 1136 HIV positive individuals. Components of the quantitative database include:

- Client interviews: socio-demographic information, mental health (need and service use), substance use (past and current), health care utilization (self-report), experience with health care providers, support service needs and unmet needs, practical barriers to care, HIV-related stigma, health beliefs, and health-related quality of life.
- Chart review data: CD4 and viral load values and dates, HIV primary care visits.
- Outreach/intervention encounter data: date, location, duration, type of staff, type of encounter, content of encounter.

In addition, 6 of the programs collected qualitative data from front-line staff about their experiences working to engage and retain people in care; and clients about the process of engagement in care, and the role of the outreach interventions in this process.

All qualitative data has been merged and coded. Baseline quantitative data is complete, and follow-up data collection will continue through April 30, 2006 with the final data submissions to the multi-site evaluation center scheduled for May 31, 2006.