

# Linking HIV-Seropositive Youth with Health Care: Evaluation of an Intervention

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## ABSTRACT

The purpose of this study was to evaluate the use of a statewide human immunodeficiency virus (HIV) surveillance system to link infected adolescents with care. Eligible participants were HIV-seropositive youths who were reported to the Department of Health from 1985 to 1998 in a state with mandatory, name-linked reporting of HIV and acquired immunodeficiency syndrome (AIDS) cases. Standard public health disease surveillance and intervention strategies were used to link participants with HIV/AIDS case management services. Enrollment in case management services was assessed before and after the intervention was implemented in 1993. The proportion of participants receiving case management services increased from 33% to 51% ( $p = 0.058$ ) after the intervention was implemented. Although enrollment in case management did not vary significantly with participants' demographic and transmission characteristics, people of color were less likely than Caucasians to be located and interviewed. In conclusion, the system of name linked reporting of HIV/AIDS cases was used successfully to increase case management by 55% above baseline levels.

## INTRODUCTION

PREVIOUS RESEARCH has raised concern about premature morbidity and mortality among human immunodeficiency virus (HIV)-seropositive youths resulting from delays in diagnosis and treatment. A statewide census of 117 nonhemophiliac youths diagnosed with HIV infection from 1985 to 1992 found their median cumulative survival to be only 8 years after testing.<sup>1</sup> As in other localities,<sup>2</sup> these young patients were found to be severely immunocompromised by the time they reached medical care. Although most of the cohort had received medical care in the previous year, only one third reported having "an HIV case manager"; and another 30% identified "case coordination" as an unmet need.<sup>3</sup> HIV infection during ado-

lescence typically occurs against a backdrop of serious psychosocial problems that can impede access to care. Case managers can assist HIV-positive youths by providing information and support, assessing needs, and facilitating care plans.<sup>4</sup>

The perceived need for improved case coordination led to the development of an intervention in 1993 to link infected adolescents with case management through the preexisting system of mandatory name-linked reporting of HIV cases to the State Department of Health (DOH). The conceptual framework of the program is the application of standard public health disease surveillance and intervention strategies to the provision of early intervention services. The intervention enhances traditional partner notification services through the col-

laboration of public health and HIV health care providers.

In order to evaluate the program, we assessed the proportion of HIV-positive youth enrolled in case management services before and after the intervention was implemented. The evaluation was designed to answer two main questions: (1) Was there significant change in the proportion of HIV seropositive adolescents enrolled in case management services after the implementation of the intervention? and (2) Did programmatic outcomes vary with participants' demographic and transmission characteristics?

## MATERIALS AND METHODS

### *Subjects*

Thirteen- to 23-year-old HIV-positive state residents who were reported to the DOH from May 1992 to November 1998 were eligible for the intervention. The comparison group was comprised of all 89 state residents who were 13 to 21 years of age when diagnosed with HIV infection from October 1985 through April 1992. Their demographic characteristics, psychosocial histories, HIV antibody counseling and testing experience, clinical course, and health care utilization patterns have been reported previously.<sup>3</sup>

Persons who were unlocatable or known to be living out-of-state were considered ineligible to participate. Youths with hemophilia also were excluded because most had been receiving health care and case management before HIV diagnosis.<sup>5</sup> With the implementation of the intervention, the upper age limit of participation was raised from 21 to 23 years in order to increase the sample size.

### *Intervention*

Prospective participants were initially identified by the DOH through the existing system of mandatory, name-linked reporting of HIV cases. Subsequently, the DOH Adolescent Early Intervention Specialists (AEIS) attempted to locate the participants, assesses their health care needs, offer information and help with partner notification, and refer them to a local

adolescent HIV/AIDS program for routine case management and other health care services as needed.

The process of locating participants, verifying their identities, obtaining informed consent, notifying partners, and referring individuals to care has been described elsewhere in detail.<sup>3</sup> Briefly summarized, the AEIS initially confirmed the participants' identifying information and then attempted to arrange an interview by telephone or field visit. With the participant's consent, the AEIS conducted a structured interview regarding health status and needs, answered questions about HIV, and provided written informational materials regarding local HIV-related resources. Persons who already were enrolled in medical and/or psychosocial services were encouraged to continue existing linkages. Those persons with outstanding needs were referred to an existing adolescent HIV/AIDS program.

If the referral to case management were accepted, written consent for release of information was requested to allow an exchange of identifying and locating information between the AEIS and a case manager. If the participant declined to release locating information, the AEIS offered to arrange an appointment with the case manager or provide a telephone number to reach the case manager directly. All HIV-positive persons were eligible to receive the following services from the adolescent HIV/AIDS program free of charge: needs assessment, education and risk-reduction counseling, case management, early intervention health care, HIV antibody counseling and testing for partners, condoms, referral services, emergency funds, and transportation. Participation in the research and intervention was voluntary and confidential. The University Institutional Review Board approved all procedures.

### *Analyses*

The AEIS used a PC to enter information from the interview into a DBase4 database. Analyses were conducted with SPSS-PC software.  $\chi^2$  Tests were used to compare the proportion of persons enrolled in case management services before and after the intervention, as well as enrollment in relation to participants'

age, gender, race, sexual orientation, mode of transmission, and year of diagnosis. In order to identify any historical factors (e.g., the advent of highly active antiretroviral treatment) that might have affected outcomes, enrollment in case management among the first half of participants was compared to the second half. The designated level of statistical significance was  $p < 0.10$ .

## RESULTS

From May 1992 through November 1998, 61 HIV-positive youths (27 males, 34 females) had been reported to the DOH. Their ages ranged from 14 to 23 years (mean 20.13 years, SD 1.78). Prior to initiating contact with these youths, the AEIS attempted to validate locating information from the original DOH HIV surveillance reports. The original HIV surveillance records ultimately provided accurate locating information in 33 cases. Other sources of correct information were key informants (16 cases), directory assistance (8 cases), the Department of Motor Vehicles (6 cases), cross directory of addresses and telephone numbers (5 cases), physicians (3 cases), and in financial worker (1 case).

Eight (13%) of the prospective participants were considered to be ineligible for the intervention because they had moved out of state ( $n = 2$ ) or because they were unlocatable by any means ( $n = 6$ ). Of the remaining 53 individuals, 24 identified themselves as African American, 20 as Caucasian, 7 as Hispanic/Latino, and 2 as Native American. The outcome of intervention with these individuals is shown in the Table 1 and summarized below.

Forty individuals completed interviews with the AEIS. They represented 66% (40/61) of the total number of prospective participants and 75% (40/53) of the actually eligible subjects.

The mean duration of time from receiving HIV-seropositive test results to the interview with the AEIS was 1.5 years. Twenty-five percent (13/53) of persons eligible for the intervention refused to meet with the AEIS.

Reflecting the changing demographic characteristics of adolescents with HIV/AIDS, persons who were interviewed by the AEIS were more likely than the preintervention comparison group to be women (58% [23/40] *vs.* 27% [16/60],  $\chi^2$  value 9.6,  $df = 1$ ,  $p = 0.002$ ) and people of color (58% [23/40] *vs.* 35% [21/60],  $\chi^2$  value 4.9,  $df = 1$ ,  $p = 0.026$ ). However, people of color were less likely than Caucasians to be successfully located and interviewed during the intervention (59% [23/39] *vs.* 85% [17/20],  $\chi^2$  value 4.1,  $df = 1$ ,  $p = 0.043$ ).

At the time of the intervention, none of the 40 interviewees reported having a case manager. Twenty-seven eventually enrolled in case management services, all but 1 in the adolescent HIV/AIDS program. Six (15%) refused any kind of referral, and seven (18%) did not complete the referral to case management. Overall enrollment in case management services increased from 33% (30/60) to 51% (27/53) after implementation of the intervention ( $\chi^2$  value 3.6,  $df = 1$ ,  $p = 0.058$ ). There were no statistically significant differences in this outcome related to participants' age, race, gender, sexual orientation, mode of transmission, or the year of case report.

## DISCUSSION

The purpose of this study was to evaluate the use of a statewide HIV surveillance system to link infected adolescents with care. Case management, rather than medical care, was chosen as the main outcome measure. In research that led to the development of the intervention, most of the HIV-positive youths in the state

TABLE 1. DISPOSITION OF ELIGIBLE PARTICIPANTS (31 FEMALE AND 22 MALE) BY ETHNICITY

<i>Disposition</i> <i>[No. and (%F) of cases]</i>	<i>Caucasian (n = 20)</i>	<i>People of Color (n = 33)</i>	<i>Total (n = 53)</i>
Accepted interview	17 (85)	23 (70)	40 (75)
Received case management	11 (55)	16 (48)	27 (51)

(87%) had received HIV-related medical care in the previous year, whereas only one-third reported having an HIV case manager. Case managers play a vital role assessing the needs of vulnerable youths, identifying resources, and coordinating care.<sup>3</sup>

Although the participants in the intervention were more likely than the comparison group to belong to traditionally under-served populations,<sup>6</sup> the system of name linked reporting of HIV/AIDS cases was successfully used to increase case management by 55% above baseline levels, from 33% to 51%. Ultimate programmatic performance was neither related to participant characteristics nor historical factors. However, people of color were more difficult to locate and more likely to refuse to meet with the AEIS than were Caucasians.

*A priori* refusal to meet with the AEIS may have reflected fear and/or distrust of public agencies and officials. Also, the fact that two Caucasian women were employed as the AEIS may have deterred some youths from participating. Other investigators have found that young people of color perceived racism to be a serious barrier to health care services in the same locality as this study.<sup>6</sup>

Persons of color who did agree to speak with AEIS were as likely as Caucasians to accept case management. By way of explanation, persons who accepted interviews might have been more amenable to intervention than those who did not. Alternatively, the interview process itself might have helped to establish rapport and reduce barriers to care.

The use of a control community (i.e., without intervention) and a larger sample could have strengthened the design and power of the evaluation. Yet, this report does provide unique data from the collective experience of 150 HIV-positive youths studied over a 13-year period of time (i.e., from 1985 to 1998). It is reasonable to credit the AEIS with increasing enrollment in case management because they directly facilitated the referrals. Prior research has found that name-linked reporting alone is not associated with early health care for HIV-positive persons.<sup>7</sup> Also, had other historical factors (e.g., the availability of new treatments or resources) been responsible, differences in case management rates in the first and second

half of the intervention period might have been observed.

Despite the benefits of the intervention, it is sobering that only about half of the HIV-positive youths ultimately enrolled in case management with intensive outreach and support. Relatively soon after diagnosis, a sizeable percentage of prospective participants were unlocatable or refused professional help. These observations help explain why the number of HIV-positive adolescents receiving health care nationwide is fewer than expected,<sup>7</sup> and morbidity and mortality greater.<sup>1,3</sup>

### *Implications*

The intervention capitalized on a preestablished system of name-linked reporting of HIV/AIDS cases to link infected youths with care. The approach could be adapted to other localities with similar disease surveillance mechanisms. However, this strategy cannot help individuals who are unlocatable or whose cases have not been reported because of the use of pseudonyms during testing, testing out of state, or clinicians' oversight.

Although all states mandate that persons with AIDS be reported by name to public health departments, 31 states require the reporting of non-AIDS HIV cases.<sup>7</sup> Linking infected persons with care is a convenient and compassionate extension of the work of disease intervention specialists, who already contact individuals to offer voluntary partner notification services.<sup>4</sup> Beyond the usual costs of disease surveillance and partner notification, this initiative requires added time and effort of disease intervention specialists. Other requisites are a collegial relationship between local public health and health care systems and the ability of health care systems to accommodate the influx of needy individuals. Although designed for adolescents, this type of intervention may benefit other populations who face barriers to health care.

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