Delayers and Dropouts: Dropping Off the Care Continuum

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Background
Timely linkage to HIV care and regular medical visits are necessary to monitor clinical status of HIV disease, to derive maximal benefits from antiretroviral therapy and other treatments, and to control the epidemic. However, surveillance data indicate that almost half of people with HIV (PWH) in New York City delay either HIV testing, delay entry into medical care, or both. An estimated one in four who are linked with care are not continuously engaged in care over time.

This study examines delayed entry to care (Delayers) and dropping out of care (Dropouts) among people diagnosed with HIV. The purpose of the Delayers study is to examine: 1) HIV testing and entry into care experiences among people with HIV in New York City and in the suburban Tri-County Region; 2) patterns of delayed vs. timely entry into HIV care after a focus on individual characteristics and situational factors associated with delayed entry into care; 3) the reasons that delayers give for not entering HIV care in a timely manner; and 4) a multivariate analysis of risk factors for delayed entry into care. The Delayers study examines retention in care over time, asking similar questions: 1) Who drops out? 2) What predicts dropping out compared to sustained engagement, and 3) what are the reasons people with HIV give for dropping out of the care continuum.

Data are provided by in-person interviews with 1603 PWH recruited in 2001–2002 or 2008–2010 with follow up interviews conducted approximately yearly.

Delayers Key Findings
* One-third (34%) of NYC and one-quarter (27%) of TC participants delayed testing after infection, delayed entry into HIV medical care after diagnosis, or both.
* Health problems/experiencing symptoms was the reason most often given for testing for HIV. Personal motivation based on awareness of risky behavior or simply to know one’s status was mention much less often.
* The most common self-reported reasons for delayed entry into care include denial about infection, feeling fine (no symptoms), drug use, and not wanting to take HIV medications.
* In NYC, persons diagnosed with HIV who delay entry into care are more likely to be younger at diagnosis (<35 years), male, and not experiencing symptoms at time of diagnosis. They are more likely to report homelessness, actively using drugs, having no regular source of income, and not having a regular source of medical care or medical insurance at the time of diagnosis.
* Among TC study participants, neither age at diagnosis nor sex were associated in delayed entry into care. MSM were less likely than PWH from other risk exposure groups to delay. Homeless experience, lack of income and active drug use during the year prior to diagnosis are associated with delayed entry into care, consistent with patterns seen in among NYC study participants.
* Test site activity, especially active referral and linkage to care, has the strongest association with timely entry into care in the year prior to diagnosis are associated with delayed entry into care, consistent with patterns seen in among NYC study participants.

Delayers Methods
Data for Delayers analysis were obtained from in-person baseline interviews conducted between 2001 and 2020 for study of 863 PWH who were diagnosed between 1996 and 2010 residing in New York City or in the Tri-County region north of the city. The sample was designed to be representative of the HIV-infected population receiving medical and/or social services in the study area. The sample is 45% female and predominantly Black and Latino. The poverty rate is high (71% in NYC and 50% in TC). Sixty percent of the sample is 45% female and predominantly Black and Latino. The poverty rate is high (71% in NYC and 50% in TC).

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