

FACTORS ASSOCIATED WITH DELAYED CARE SEEKING AMONG HIV-INFECTED INDIVIDUALS IN NEW YORK CITY

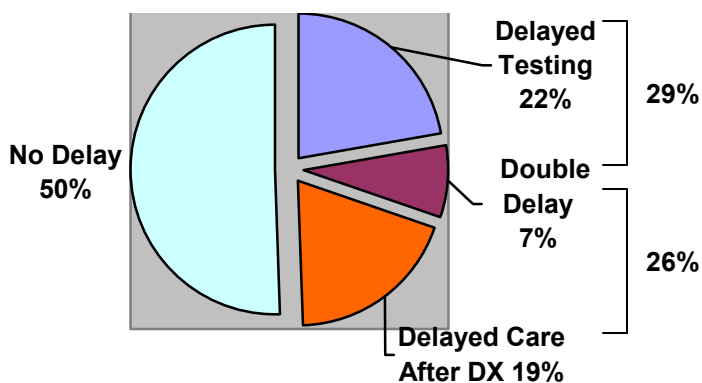
BACKGROUND

Entry into medical care as early after HIV infection as possible is associated with improved long term clinical outcomes for infected persons and with reduction in risk behaviors that could transmit infection to others. But even in the era of effective antiretroviral medications and supportive services, some people living with HIV or AIDS (PLWHAs) do not take advantage of evaluation and treatment available to them. The goal of the Delayed Entry into Care Project is to determine factors leading to delayed entry into HIV treatment among these individuals.¹

THE PROBLEM

A “delayer” is defined as someone who waits more than 3 months after the diagnostic HIV test to present for treatment evaluation *or* Is diagnosed with HIV at the time of presentation for care with an AIDS-defining illness or with fewer than 200 CD4 cells indicating an advanced state of disease.

AN ESTIMATED HALF OF ALL HIV INFECTED PERSONS IN NYC ARE DELAYERS



Source: New CHAIN Cohort, n=684

Among study participants interviewed in 2002-03, 29% reported learning about their HIV diagnosis because they were sick or in the hospital with an HIV-related disease (delayed testing). More than one-fourth (26%) did not enter medical care for 4 months or more after diagnosis (average delay =12months). Some people (7%) delayed both testing and entry into medical care.

A “DELAYER” IS DEFINED AS SOMEONE WHO:

Waits more than 3 months after the diagnostic HIV test to present for treatment evaluation

OR

Is diagnosed with HIV at the time of presentation for care with:

- Fewer than 200 CD4 cells (indicating an advanced state of disease course, even if no AIDS-defining illness has occurred)

OR

- One or more AIDS-defining illnesses (per CDC definition)

METHODOLOGY

- Personal Interview data from an ongoing study of persons living with HIV in New York City: the CHAIN Project.² A total of 968 PLWHAs were interviewed during 1994-2001, and another 684 new study participants were interviewed in 2002-2003.
- The sample was designed to be representative of the HIV-infected population receiving medical and social services in NYC.
- Study participants described how they became aware of their HIV status and when and how they first got HIV medical care.
- In addition, we conducted interviews with 32 medical and social service providers working with different risk groups and populations where problems of delayed testing or care have been significant: MSM of color, substance users, youth, homeless persons, immigrants, ex-offenders.

WHO DELAYS?

- Most of the same individual and contextual factors are associated with both delayed HIV testing and delayed entry into HIV care.
- Delayers *DO NOT* differ from nondelayers by:
 - race/ethnicity
 - birthplace
 - education level
 - insurance status at diagnosis
- Delayers *DO DIFFER* from nondelayers by:
 - not experiencing symptoms
 - history of substance use
 - mental health issues
 - housing problems
- Increasingly related to delay:
 - younger age at diagnosis (<35 yrs)
 - recent immigrant

PLWHs ANSWER: WHY DELAY?

- Concerns about stigma and rejection and fears of social and legal consequences of revealing HIV status or risk behaviors
- Distrust of the medical system based on prior experiences of inadequate care and feeling disrespected and 'unwelcome.'
- Misunderstandings about HIV disease processes, the accessibility of treatment, and the role of medications.
- "Denial" of illness and/or lack of readiness for behavior change.

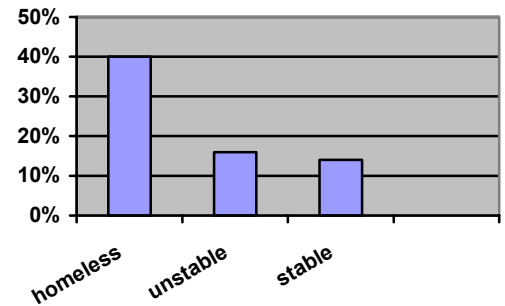
CONTEXTUAL FACTORS

- Contextual factors at the time of diagnosis constrain timely entry into HIV treatment:
 - actively using drugs
 - little or no social support
 - no regular source of medical care prior to diagnosis
 - homeless
 - tested in correctional settings

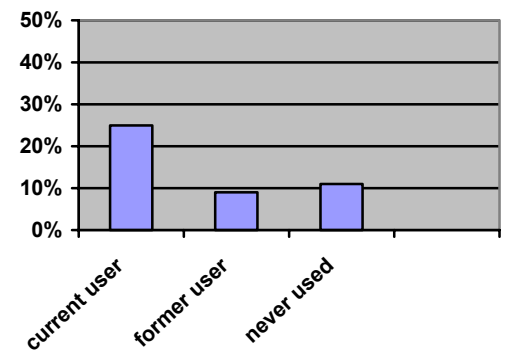
THE POST-TEST EXPERIENCE

- What happens at the testing site is strongly associated with risk for delay. If the testing site actively facilitates entry into medical care, delay is much less likely than if no information provided about treatment options, or only general referral given. The 'testing site effect' remains when controlling for client demographics, substance use history, or contextual factors at time of diagnosis.

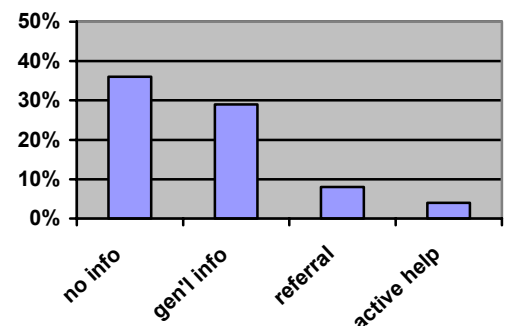
% Delay Medical Care by Housing During Year of Diagnosis



% Delay Medical Care by Drug Use During Year of Diagnosis



% Delay Medical Care by Testing Site Help with Care



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RECOMMENDATIONS

- **Distribute realistic information** about HIV treatment -- its potential effects and benefits as well as liabilities -- in advance of testing or the need for treatment.
- **Improve the ease, speed, and convenience of HIV testing** by expanding testing sites and encouraging wider use of the newer HIV rapid testing technologies.
- **Pre and post-test counseling must adequately prepare the client** for a preliminary positive result when using rapid HIV testing technologies.
- **HIV testing sites must actively facilitate entry** of HIV positive persons into appropriate medical care. Strategies may include provision of patient escorts or direct telephone contact between the test site and medical treatment facility.
- **Bring HIV testing and health care to stigmatized** populations in settings where they are already comfortable. Adolescents are particularly vulnerable to avoiding testing and care when treatment settings fail to create a youth-friendly and non-judgmental atmosphere.
- **Incorporate testing and medical referral into housing programs** that can address housing and other concrete service needs of their clients who are at high risk for delay.
- **Make it easier for cultural sub-populations**, and/or highly stigmatized groups to use existing mainstream services by providing "advocates" or "patient navigators" who can help clients navigate treatment systems.
- **Maintain and expand outreach efforts** that target marginalized populations such as substance users and the homeless, for whom there is a continued need to actively engage persons infected with HIV into HIV testing and systems of care.
- **Expand 'on the street' outreach** initiatives that can locate areas of after-hours high-risk activity that require flexible approaches and sensitivity to local community cultures and conditions.

Additional resources:

New York City DOHMH HIV Epidemiology Program
http://www.nyc.gov/html/doh/html/dires/epi_reports.html

HIV Health and Human Services Council of New York, "Needs Assessment"
http://www.nyhiv.org/pdfs/FINAL - Update to the 2002 Needs Assessment_1.pdf

Footnotes

1. The Delayers Project is funded as a contract to the Center for Applied Public Health, Mailman School of Public Health, Columbia University (#PE06Y11). It is closely coordinated with the ongoing CHAIN (Community Health Advisory & Information Network) study, which is also carried out by the Center.
2. The CHAIN study provides longitudinal information on study participants' needs for health and human services, their use of services, their satisfaction with services, and the impact of these services on their physical, mental and social well being. This information is specifically prepared for the NYC HIV Health and Human Services Planning Council to assess the full spectrum of services for HIV infected persons in NYC. CHAIN participants comprise a representative sample drawn from organizations providing medical or social services for persons living with HIV in New York City .