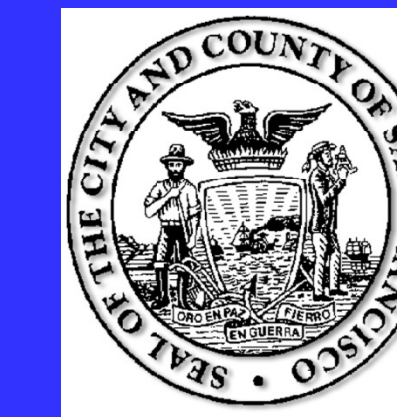




INTERVIEWING LATE TESTERS TO IDENTIFY BARRIERS TO EARLY HIV DIAGNOSIS: PRELIMINARY FINDINGS FROM A PILOT STUDY

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Objectives

- To determine the feasibility of using the San Francisco AIDS case registry to identify late-testers and their current health care providers.
- To recruit and interview 50 late-testers to identify barriers and the context of late testing.
- To develop policy recommendations to reduce late testing.

Background

- Late diagnosis of HIV infection results in increased morbidity, mortality, and health care costs.
- Persons diagnosed late in the course of HIV infection may unknowingly transmit HIV for many years.
- Most HIV-infected persons reduce risk behavior following diagnosis.
- Studies have described the socio-demographic and risk characteristics of late-testers but little is known about the contextual factors that surround late testing.
- We used the San Francisco AIDS case registry to identify persons whose HIV diagnosis occurred within 12 months of their AIDS diagnosis.
- The San Francisco AIDS case registry is $\geq 95\%$ complete and as such, provides a population-based sample of late-testers.

Methods

- Persons reported to the San Francisco Department of Public Health with AIDS undergo a medical chart abstraction at the time of diagnosis and every 18-24 months thereafter.
- Data collected for AIDS cases includes the following:
 - Patient name
 - Demographics
 - Risk behaviors (mode of transmission)
 - Health insurance at the time of diagnosis
 - Name and address of diagnosing health care provider
 - Date of AIDS diagnosis
 - Date of first positive HIV test (including self-report)
 - Date and results of CD4 and viral load testing
 - Dates of initiation and types of antiretroviral and prophylactic medications
- Eligible AIDS cases were diagnosed with AIDS anytime after January 1, 2007.
- The HIV diagnosis must have occurred within the 12 months prior to the AIDS diagnosis.
- The date of HIV diagnosis was the *earliest* of any of the following:
 - HIV-positive test result in the medical chart
 - HIV-positive test by patient-self report in the medical chart
 - CD4 or viral load test
 - Use of antiretroviral therapy (excluding pre-exposure prophylaxis)

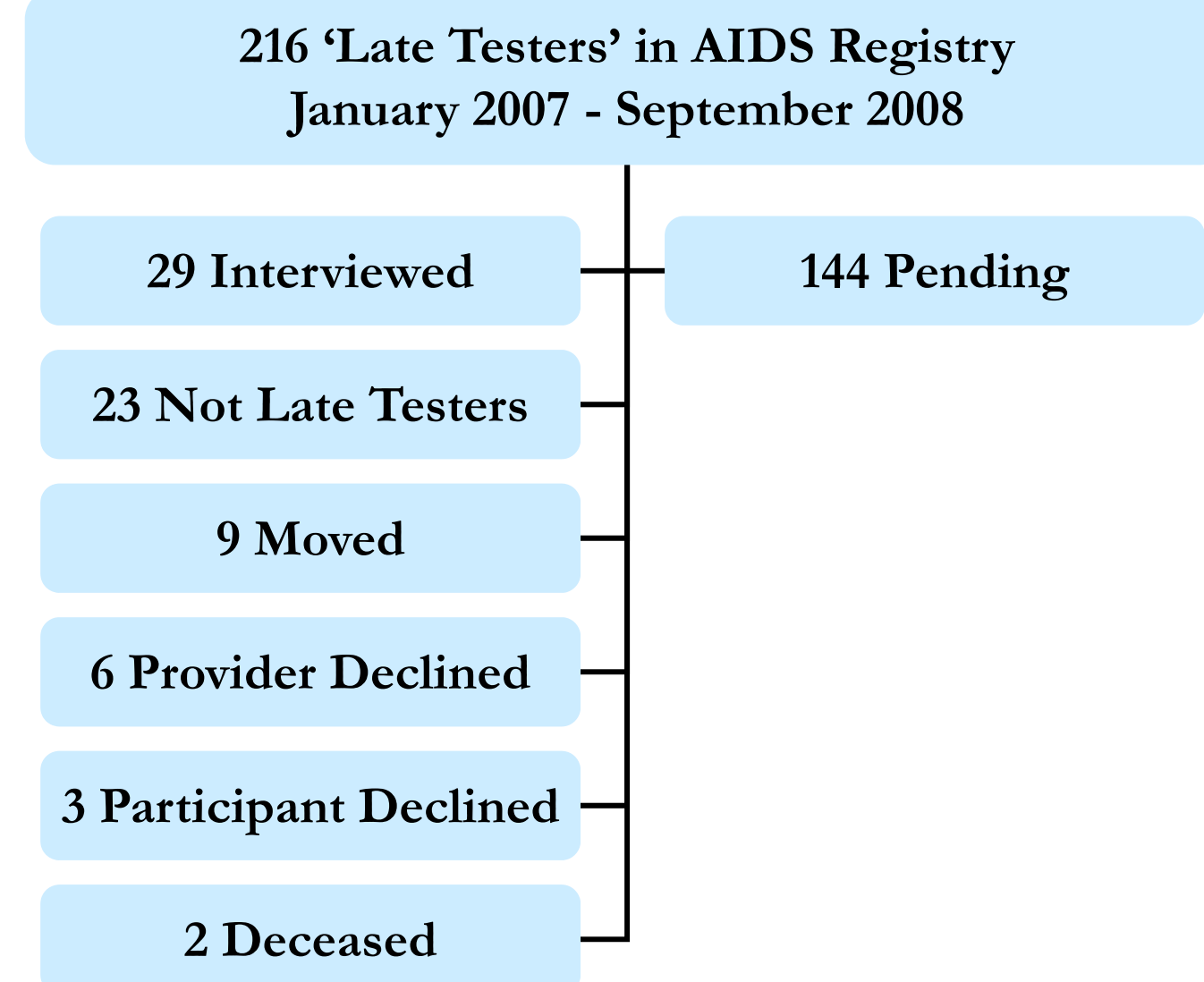
Recruitment

- The diagnosing or current health care provider was contacted and asked to recruit the identified patients.
- Recruitment was done:
 - On-site at selected public health clinics by study staff following introduction of the study by the provider
 - Via telephone or letter by the health care provider who asked interested patients to contact the study investigators
- Participants were interviewed using a qualitative interview guide followed by a structured questionnaire.
- Interviews were conducted in English or Spanish and audio-recorded for transcription.

Preliminary Results

- Between January 1, 2007 and September 15, 2008, 216 persons reported with AIDS met our eligibility criteria.
- 100% of health care providers contacted agreed to assist with recruiting their patients.
- Recruitment began June 2008 and is on-going.
- A total of 50 interviews is expected.

Recruitment Outcomes



Characteristics of Participants

Total (N=29)	N	%
Gender		
Male	24	83%
Female	3	10%
Male to Female transgender	2	7%
Race/Ethnicity		
Asian	1	3%
Black/African American	4	14%
American Indian/ Alaskan Native	2	7%
Native Hawaiian/ Pacific Islander	0	0%
Latin American/ Hispanic	8	28%
White	11	38%
Multi-Race	3	10%
Age (years)		
18-29	5	17%
30-39	9	31%
40-49	10	35%
50 years or older	5	17%
Sexual Orientation		
Heterosexual/Straight	10	35%
Homosexual/Gay/Lesbian	14	48%
Bisexual	4	14%
Other	1	3%
Maximum educational achievement		
8 th grade or less	3	10%
Some high school	6	21%
High school graduate or GED	5	17%
Some college, Associate's degree, Technical school	11	38%
College graduate or post graduate	4	14%

HIV Testing History and Access to Health Care

Total (N=29)	N	%
Number of times tested for HIV		
Once	9	31%
2 to 5 times	11	38%
6 to 10 times	5	17%
More than 10 times	4	14%
Health insurance in the 12 months prior to HIV diagnosis		
Public	4	14%
Private	3	10%
None	22	76%
Seen by a medical professional in the 12 months prior to HIV diagnosis		
Among those seen by a medical professional (N=17), an HIV test was suggested	7	41%

Importance of Each Reason for Delayed Testing

Reasons	Somewhat important	Important	Very important
Afraid to find out	21	10	38
Denial about risk for HIV	24	21	17
Did not want friends or family to know	28	17	17
Did not know what to do if HIV-positive	31	10	21
Did not recognize physical signs or symptoms of HIV	31	24	4
Did not recognize personal risk	21	3	7
Did not know where to get a HIV test	7	0	3

Identified Barriers to Testing from Qualitative Interviews

- Afraid to Find Out**
One participant tested at the suggestion of his partner who had just learned he was infected. This was the participant's first test despite his known risk from sex with men. Although he had received routine care for a chronic disease his health care provider had never suggested testing for HIV. When asked if he had considered testing before he tested positive he responded:
"No, I was afraid to, you know?"
- Denial of Personal Risk**
Prompted by learning that his boyfriend was HIV-infected and developing HIV-related illnesses, the participant sought testing. He was hoping to prevent experiencing the progression of disease that he observed in his partner. This was the participant's first HIV test. His explanation for not testing before was:
"I didn't consider myself to be at risk. I was having sex but it wasn't anything that I would consider risky."
- Unaware of Benefits of HIV Treatment**
This participant had tested previously but time elapsed since last test. He was aware that his sex with other men and use of drugs put him at risk for HIV. He had lost more than 30 friends to HIV. He had presented for care of multiple skin infections but had not been offered HIV testing. He was diagnosed some time after symptoms developed. He responded well to treatment and was stabilized when interviewed. He indicated that his clinical course was not what he had anticipated.
"...chances are the quality of my life will be exactly what it is since I started doing that (i.e. medical care). You know, I think if maybe people saw that more they would have a clearer picture as to what living with HIV really is as opposed to dying with HIV."
- Did Not Know Free Care was Available**
Several participants did not have health insurance prior to developing AIDS. Although aware of their risk for HIV and that HIV was treatable, they did not test because they did not know that free or low cost care was available.
- Unaware of Symptoms of HIV**
One participant was diagnosed with HIV when he learned he had syphilis from the city STD clinic. He had oral thrush for several months prior to his diagnosis but was not aware that he might have HIV disease. Another man was at high risk for HIV disease because of sex with other men, was diagnosed with shingles in an emergency room. He was not offered HIV testing, he did not know that shingles might occur with HIV disease.

Limitations

- This is a small pilot study from one urban area and the final sample may not be representative of all late-testers in other parts of the country.
- Social desirability responses may be present and participants may be under-representing their attitudes about testing or their behaviors.

Conclusions

- The AIDS case registry, although not completely accurate, can provide a method of identifying late-testers and their health care providers.
- Recruitment and interviewing of late-testers using this methodology is feasible.
- Interviews with late-testers is effective at identifying the circumstances and factors surrounding late testing.
- Themes identified in the qualitative interview are supported by responses collected from the structured questionnaire, providing support for the validity of these contributory factors.
- Interventions to facilitate early testing should focus on public awareness campaigns regarding the effectiveness of HIV treatment and its availability at low/no cost.
- Additional efforts to reduce denial of risk and fear of learning of one's infection should be pursued.
- The lack of access to regular primary care services points to the need to increase availability of such services.
- Expanding routine opt-out testing in health care settings, especially STD clinics, is likely to identify some HIV-infected persons prior to their development of HIV symptoms.
- Health care providers should be taught to think of HIV infection as a possible cause of associated symptoms/signs (eg, shingles, etc.).

