

Concurrent Dilemmas:

Lateness to HIV/AIDS care as a challenge to both prevention and treatment

Third in a Series of Reports on the Status of the HIV/AIDS Epidemic in Massachusetts

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Executive summary

One of the persistent challenges in the fighting the HIV/AIDS epidemic is ensuring that persons at risk for HIV infection know their HIV status and enter medical care in a timely manner. Highly effective medical interventions enable persons with HIV infection to avoid progressing to a life-threatening AIDS diagnosis, extend years of healthy life, and reduce the likelihood of transmitting their infection to others. Due to the extended time period generally required to progress from an HIV infection to an AIDS diagnosis (often 10 years or more) individuals who are reported with HIV infection and AIDS near to the same time (concurrent diagnosis) represent a failure of efforts to help persons at risk know their HIV status and enter HIV treatment.

This report examines recent diagnoses of HIV infection (2005-2007) across the categories of age, sex, race/ethnicity, mode of exposure, and place of birth and compares these overall patterns to those of persons concurrently diagnosed with HIV and AIDS. This report also considers the proportion of persons concurrently diagnosed within each of these categories. While more sophisticated multivariate analyses are called for, these data suggest that older age, male sex, non-US place of birth, heterosexual/presumed heterosexual mode of exposure, and Asian/Pacific Islander race may be more associated with lateness to care.

This report speculates about the underlying factors that result in concurrent diagnosis, such as:

- The nature and responsiveness of the public and private HIV testing
- Lack of knowledge of personal HIV infection risk or that of partners
- Lack of awareness of the benefits of HIV testing and treatment
- Lack of knowledge of the availability of HIV care and medications independent of the ability to pay
- Lack of trust in the public health or health care systems
- Stigma/fear of being identified as being at risk for or having HIV infection
- Fear of HIV itself and associated denial of personal risk or likely HIV status
- Lack of understanding in some communities of the nature of infectious disease and its relationship to health
- Risk of HIV-related immigration action
- Competing life challenges (mental illness, substance abuse, poverty, housing issues) which compromise the ability of individuals to prioritize or seek health care services

Recommended next steps to fully understand and respond to this urgent public health issue include:

- Further research into the confluence of factors resulting in late testing and delayed entry into care
- Effective provision of information about the imminent lifting of the federal HIV visitation and immigration ban in an effort to lessen the effects of fear of immigration action
- Culturally specific public information campaigns to reduce stigma and the perception of stigma for persons with HIV infection and the behaviors associated with HIV infection
- Social and informational outreach to non-US born communities, particularly persons from Asia/Pacific Rim, Central/South America, the Caribbean Basin, and sub-Saharan Africa
- Enhanced outreach and educational efforts directed toward older individuals at risk for HIV infection
- Re-evaluate the HIV testing and screening system to remove barriers and expand routine offering without sacrificing targeted outreach
- Reinforcement of existing education and referral efforts that emphasize the availability of HIV treatment and support early entry into HIV care

Introduction

The advent of highly active antiretroviral therapy (HAART), offered people living with HIV/AIDS real hope of achieving a near-normal lifespan and a quality of life significantly improved over that of the pre-HAART era. What was commonly a terminal disease has come to resemble other chronic diseases. Though the challenges of treatment adherence and side effect management are real, persons who work consistently with their health care providers to identify and stay on an effective treatment regimen can maintain, in most cases, a low viral load and a functional immune system. Further, there is considerable published evidence that HIV+ persons who know their HIV status reduce their risk behavior. This, coupled with a lower viral load, may be contributing less transmission of HIV infection and to a declining incidence of newly reported cases of HIV infection in Massachusetts since the beginning of the decade (Figure 1).

It is crucial that people at risk of infection have opportunities to learn their HIV status and enter consistent, high quality medical care in a timely manner. Through the expansion of health insurance coverage in Massachusetts and supplementary, targeted programs for persons with HIV infection, such as the HIV Drug Assistance Program (HDAP), access to HIV medical care is virtually assured in the Commonwealth.

However, despite this level of access, 31% of persons recently diagnosed (2005-2007) with HIV infection in Massachusetts were reported with an AIDS diagnosis within two months of being first reported with HIV infection (concurrent diagnosis). Given that

in the absence of treatment, only 2% of persons with HIV infection develop an AIDS-defining condition in the first year (and 50% within ten years), we assume that concurrently diagnosed individuals have been living with HIV infection for many years or possibly over a decade without receiving care. While the reasons for this apparent lateness to care are likely multiple, and will be explored below, the effect of these late diagnoses is avoidable illness, premature death, and possibly preventable transmission to others. Sound medical and public health practice require a close examination of the factors resulting in concurrent diagnoses and lateness to care.

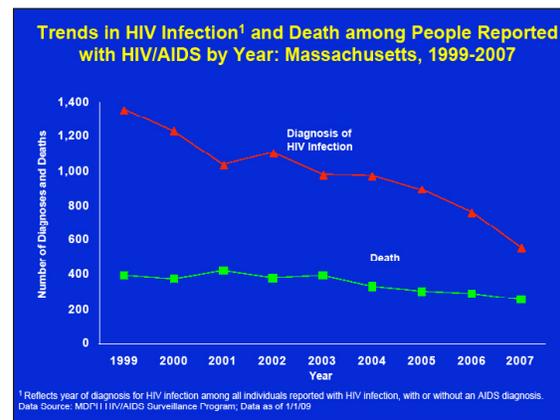


Figure 1

Epidemiology of concurrent diagnoses in Massachusetts

AIDS has been a reportable disease in Massachusetts and nationwide since 1983, while HIV infection has been reportable in Massachusetts since 1999 (states have introduced HIV reporting at various times over the past two and a half decades). Case reports of HIV infection and AIDS are generated primarily by physicians making diagnoses based on one of several HIV antibody or antigen tests plus additional laboratory and clinical evidence of immune system function and signs and symptoms of opportunistic infections and other AIDS-defining conditions. These reports, plus supplementary direct laboratory test results, are received and stored securely by the Massachusetts Department of Public Health (MDPH) HIV/AIDS Surveillance Program. A given case of HIV infection may or may not be accompanied by evidence of an AIDS diagnosis, which would be indicative of severe damage to a person's immune system. In some cases, the AIDS diagnosis is the first report of a person's HIV infection status, and in other cases, a report of an AIDS diagnosis is received following an initial report of HIV infection. When these two reports document diagnoses within two months of one another, they are termed as

concurrent by MDPH. The proportion of all diagnoses deemed concurrent varies from year to year, but the most recent three years of data (2005-2007) indicate that fully 31% of all diagnoses of HIV infection were with concurrent AIDS diagnoses.

The US Centers for Disease Control and Prevention (CDC) uses various methods for assessing concurrency, one of which examines the diagnoses of HIV infection and AIDS that were made within one year of one another. A recent summary report of the period 1996-2005 indicates that among 34 states for which the CDC had complete data, 38.3% of persons diagnosed with HIV infection during those years received an AIDS diagnosis within one year. This proportion dropped to 36.4% of those diagnosed in 2005 alone. Calculating the equivalent one-year proportion for the more recent period 2005-2007 in Massachusetts yields a slightly lower value of 34.9% of all reported HIV infection diagnoses. Despite having a lower level of concurrent diagnoses than many states, this remains an unacceptable level of late diagnosis.

How do the concurrently diagnosed compare to other persons diagnosed with HIV infection?

National and international studies have associated concurrent diagnoses and other indicators of lateness to care with male sex, older age, and a set of socioeconomic factors such as poverty, limited access to health care, low level of education, and rural residence.

While a full exploration of the factors surrounding lateness to care require data and research beyond the scope of this report, it is possible to observe differences in the distribution of persons who are concurrently diagnosed as compared to people diagnosed with HIV infection in general.

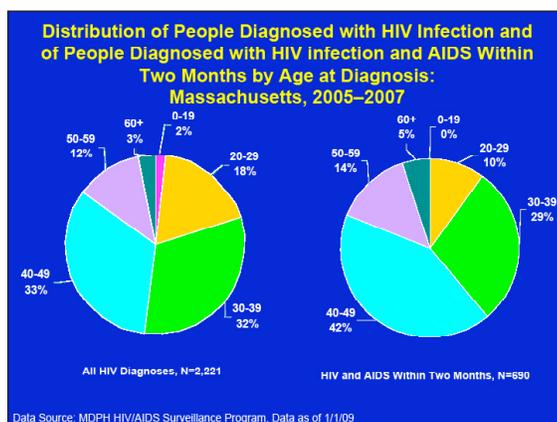


Figure 2

Figure 2 compares all HIV infection diagnoses reported in 2005 through 2007 by age at diagnosis with the age distribution of those concurrently diagnosed during that time period. Those diagnosed concurrently tend to be older. The reasons for this pattern are not immediately clear. It may be that older persons have more life years in which to have HIV infection and to progress to an AIDS diagnosis than younger persons, and this may explain a portion of the difference. But it is also possible that some persons over 40 years old may also not consider themselves as being at risk for HIV infection. Most HIV prevention messages, including those discussing sexual and injection drug use behaviors, employ language, images, and outreach strategies directed toward younger members of the community. Further, health care providers may similarly not perceive their older patients as being at risk for HIV infection and may be less likely to offer HIV screening in the context of routine medical care. Current efforts to draw attention to health care and social supports to the aging population living with HIV/AIDS may need to focus more on primary prevention and screening messages.

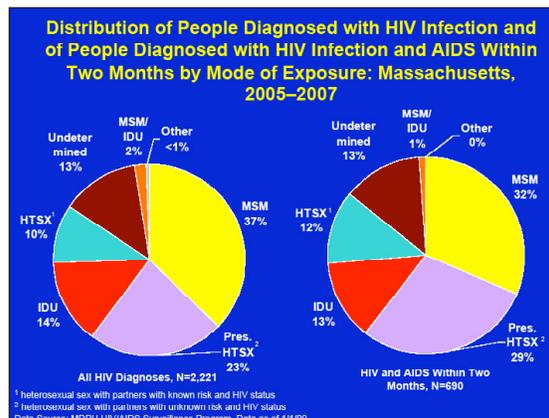


Figure 3

Figure 3 portrays the relative distribution of persons recently diagnosed with HIV infection and persons concurrently diagnosed with HIV and AIDS by their mode of exposure. The charts are similar in most respects, varying in most exposure modes by one or less than one percentage point. The exceptions are men who have sex with men (MSM) and presumed heterosexual. In other epidemiologic reports based on Massachusetts data, MSM and Presumed Heterosexual tend to grow or shrink together, so the different distribution (a smaller proportion of concurrent diagnoses are reported for the MSM with a larger proportion among presumed heterosexual modes of exposure), suggests that different forces are at work. Some possibilities include the well-documented rates of repeat testing on the part of gay and bisexual men, and the greater proportion of black and non-US born individuals assigned to the presumed heterosexual category. Black persons in general have lower rates of utilization of publicly funded HIV testing sites, and non-US born persons may introduce a confounding time factor into the analysis of concurrent diagnoses linked to possible first HIV infection diagnosis outside of the US or Massachusetts. This factor among the non-US born will be discussed further.

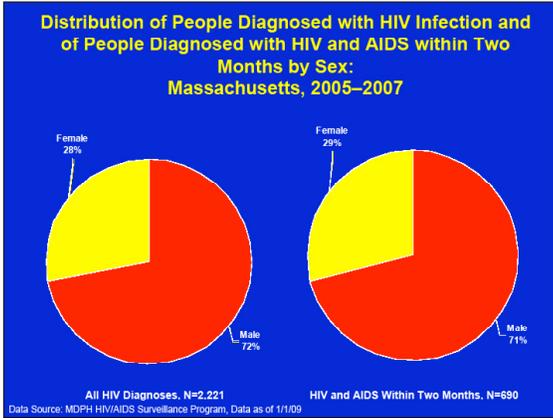


Figure 4

Multiple studies link male sex to lateness to care. Figure 4 shows the distribution of men and women in both all diagnoses and concurrent diagnoses. Among all persons who were concurrently diagnosed, the distribution by sex is similar to that of those recently diagnosed with HIV infection. Just as men make up the great majority of new HIV diagnoses, men constitute the largest share of concurrent diagnoses. Further analysis of concurrency *within* these sex categories below will show that additional sex-linked differences exist.

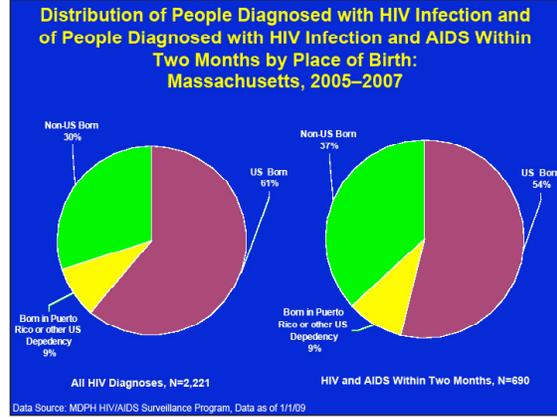


Figure 6

Massachusetts makes extraordinary efforts to analyze place of birth as a factor in HIV/AIDS risk, incidence, and prevalence. As explored in previous reports, being born in Puerto Rico or in a non-US country is associated with higher risk for HIV infection and AIDS as compared to being born in a US state. Among those concurrently diagnosed, the greater disparity between those with a non-US place of birth and US-born individuals is striking (no difference is seen among those born in Puerto Rico and other US dependencies). The difference in larger proportion of non-US born individuals among those concurrently diagnosed as compared to overall incidence is second only to those over the age of 40 years.

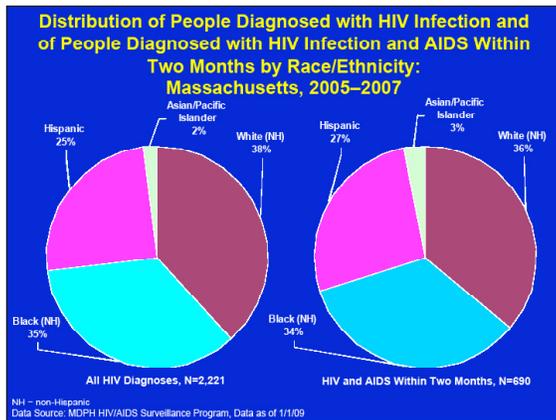


Figure 5

Given the extent of racial/ethnic disparities in the HIV/AIDS epidemic in Massachusetts, it would be reasonable to assume these emerge in the distribution of concurrent cases. As explored in previous reports, the proportion of new HIV diagnoses among black (non-Hispanic) and Hispanic individuals greatly exceeds the relative representation of these communities in the Massachusetts population. This is no less true among those who are concurrently diagnosed (Figure 5). The relatively larger proportion of Asian/Pacific Islander residents who are concurrently diagnosed bears further investigation.

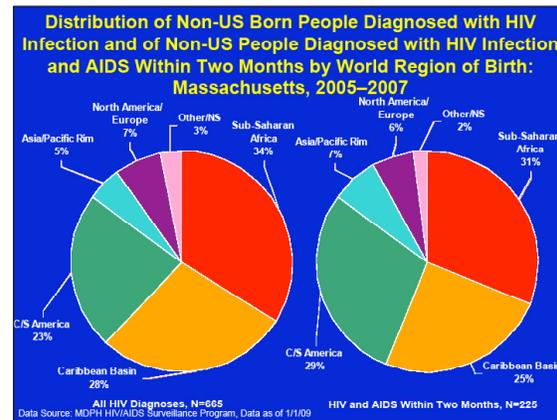


Figure 7

Figure 7 illustrates the distribution of all non-US born persons and of persons concurrently diagnosed by world region of birth. While generally comparable, larger proportions among the concurrently diagnosed are seen among Central/South American born individuals and those born in Asian/Pacific Rim.

Who is most at risk for being concurrently diagnosed?

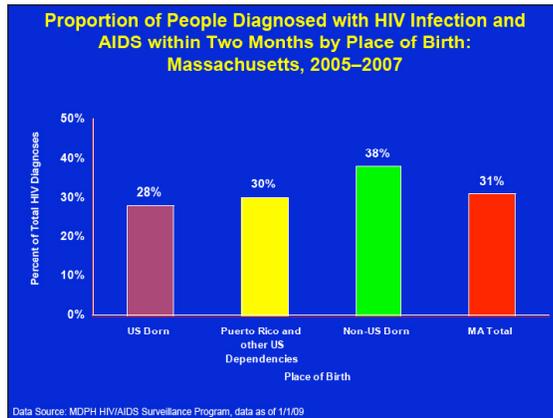


Figure 8

Figure 8 presents the proportion of persons concurrently diagnosed by place of birth. Here the influence of non-US place of birth is most evident. While the overall Massachusetts concurrent diagnosed is 31% of all recent HIV diagnoses, among those non-US born the proportion is 38%. Both US born and Puerto Rico born individuals actually have rates of concurrent diagnosis lower than the statewide average, suggesting an influence of citizenship (and implied eligibility for various government health programs such as Medicaid and Medicare) on this outcome. This finding also raises questions about the effect of immigrant/refugee status on the likelihood to be tested for HIV and enter medical care. Numerous challenges exist for non-US born individuals of various immigration status that may compromise access to screening services and general medical care. These include difficulty obtaining employment and education due to documentation status, language differences, fear of deportation on the basis of HIV status (as of this writing, the federal ban on visitation and immigration for HIV+ persons was still in effect, though President Obama has announced its imminent lifting), and social isolation. Public health programs and messaging urging frequent testing for persons at risk and early entry into medical care for HIV+ persons directed to immigrant and refugee populations remain limited, and may not address the full range of languages and cultures represented in Massachusetts.

These data, however, should be interpreted with caution. One limitation of utilizing surveillance data is that they only describe reports of diagnoses made in Massachusetts. This fact introduces the confounding time factor referenced above. A person may have learned of their HIV status in another country, but this may not be known by their reporting clinician and therefore not available to state epidemiologists. Further, a person with HIV infection may have entered care and received treatment for their HIV infection in another country, but to state authorities would

appear to have entered care *de novo* in Massachusetts once the case was reported by the person's physician. The effect of this is that an apparent concurrent diagnosis may be in fact be a previously identified HIV infection that has progressed to AIDS over time. Additional research into non-US born individuals presenting with seemingly concurrent diagnoses may tease out these factors to help identify the true proportion of late diagnoses in this population. Nonetheless, concurrent diagnosis in Massachusetts raises the same issues of lateness to care.

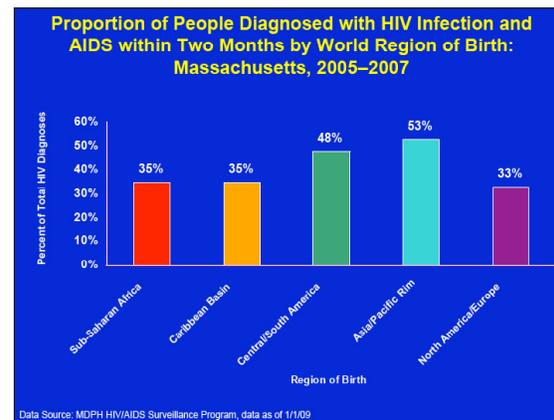


Figure 9

Figure 9 breaks out non-US born individuals who were concurrently diagnosed by the world region of birth. Remembering that some of these regions represent a relatively small numbers of persons, this figure nonetheless reveals some surprising levels of risk for late diagnosis among persons born in Asia/Pacific Rim and Central/South America (53% and 48% of all recent diagnoses, respectively). In fact, persons born in sub-Saharan Africa, the Caribbean Basin and (non-US) North America/Europe, though they represent larger absolute numbers of people than those from these other regions, have rates of concurrent infection only 2-4% above the statewide average. The reasons for the higher rates among individuals born in Asia/Pacific Rim and Central/South America are not immediately clear, but legal concerns and health care access issues linked to linguistic and cultural differences may be operative.

Among non-US born black (non-Hispanic) individuals, persons from the countries of Haiti and Uganda have the highest proportion of individuals concurrently diagnosed. Among non-US born Hispanic individuals, persons born in Brazil (who were reported with Hispanic ethnicity) and the Dominican Republic have the highest proportions of concurrency. Among Asians/Pacific Islanders born outside the US and concurrently diagnosed, persons born in Cambodia and Vietnam predominate.

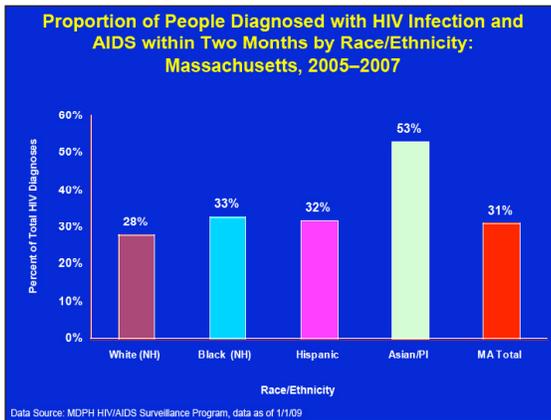


Figure 10

Returning to an analysis of both US born and non-US born individuals, Figure 10 demonstrates the difference in concurrent diagnosis by race/ethnicity. Recalling again relatively small absolute numbers of persons, the data continue to point to a higher rate of concurrent diagnoses among Asians/Pacific Islanders. This figure also documents concurrency rates greater than the statewide average among black (non-Hispanic) and Hispanic individuals.

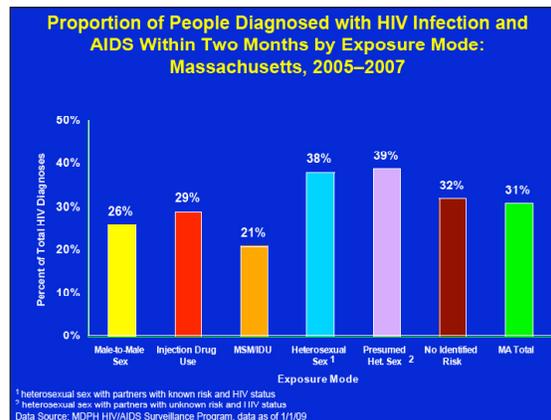


Figure 12

Figure 12 builds on the data presented in Figure 3 by examining the proportion of concurrent diagnoses within each exposure mode category. Concurrent diagnoses in several categories, which represent the bulk of new HIV infections in Massachusetts, MSM, Injection Drug Users (IDU), and MSM/IDU are proportionally lower than the statewide average. This may reflect persons with clear-cut risk histories who are offered or seek HIV testing on a more frequent basis than those whose risk is less evident. Individuals whose sexual risk is apparently limited to opposite-sex partners (heterosexual sex and presumed heterosexual sex) may not consider themselves at risk or be seen by their health care providers as being at risk for HIV infection, and therefore may not access HIV testing and screening services as frequently. Also, a larger number of black and non-US born individuals are reported with the presumed heterosexual sex mode of exposure and, as noted above, more commonly report concurrent diagnoses.

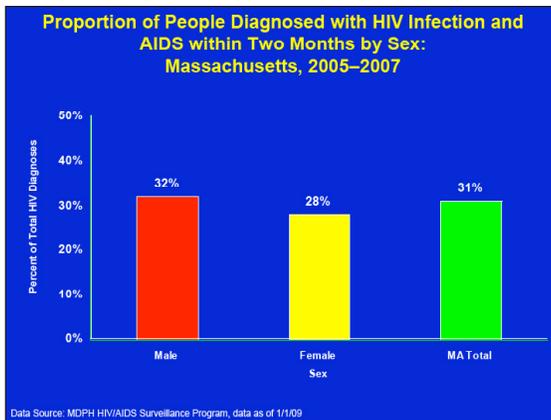


Figure 11

In this report above, the distribution of concurrent diagnoses by sex appeared roughly equivalent to the distribution of all recent diagnoses, but examining the proportion of concurrent within each sex category confirms what other studies have indicated: that men in general have a higher rate of being concurrently diagnosed than do women, slightly exceeding the statewide average (Figure 11).

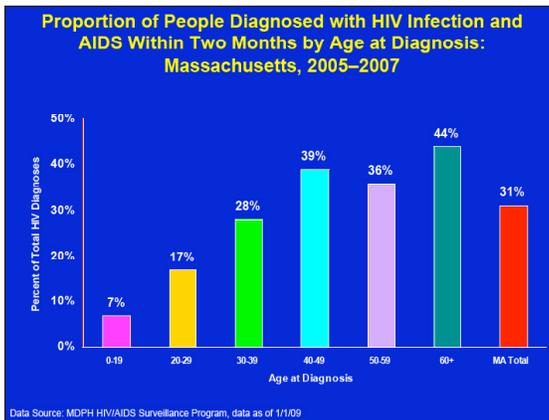


Figure 13

Figure 13 returns to an analysis of age as a factor in lateness to care. Calculating concurrent diagnoses by age category reinforces the observation that older age is strongly associated with concurrent diagnosis. Again, this is consistent with published reports of lateness to care from US and international studies. As noted above, older individuals have more life years to live with an undiagnosed HIV infection, but it is unlikely that this fact alone explains the dramatically higher rates of concurrency in those over the age of 40. Similar in scale to Asian/Pacific Islander race, being over the age of 60 carries a strong association with lateness to care (recognizing low absolute numbers of individuals in both categories). As seen in other categories, such as exposure mode, presumptions about lower levels of HIV risk behavior among older individuals may lead to lower rates of routine HIV screening or voluntary testing. These findings reinforce calls for expanded prevention and care outreach to older individuals at risk for HIV infection.

What do concurrent diagnoses tell us?

A concurrent diagnosis represents a missed opportunity to intervene in the progression of HIV infection to the life-threatening AIDS. With the widespread availability of quality HIV specialty care and medication in Massachusetts, no individual needs to miss the benefits of early treatment for HIV infection that can extend life and maintain health. A true concurrent diagnosis also means that a person did not have critical information to guide their behavior choices, potentially resulting in avoidable transmission of HIV infection.

We must assume that multiple factors influence the likelihood that a person learns their HIV status and enters HIV medical care and related support services.

These factors may include the following:

- The nature and responsiveness of the public and private HIV testing system (e.g. Are testing resources sufficient? Is the Massachusetts testing system properly offering the right mix of targeted vs. routine testing? Does it offer adequate cultural specificity? Does it situate itself properly in communities at risk?)
- Lack of knowledge of personal HIV infection risk or that of partners
- Lack of awareness of the benefits of HIV testing and treatment
- Lack of knowledge of the availability of HIV care and medications independent of the ability to pay
- Lack of trust in the public health or health care systems
- Stigma/fear of being identified as being at risk for or having HIV infection
- Fear of HIV itself and associated denial of personal risk or likely HIV status
- Lack of understanding in some communities of the nature of infectious disease and its relationship to health
- Risk of HIV-related immigration consequences
- Competing life challenges (mental illness, substance abuse, poverty, housing issues) which compromise the ability of individuals to prioritize or seek health care services

More research is needed to understand the intersection of race/ethnicity, immigration status, age, risk, and other factors as they influence the likelihood to receive timely HIV care. The analyses above present a simple approach to these demographic factors (univariate analysis). Further, more detailed quantitative and qualitative information and more sophisticated analytical methods are needed.

We do not understand the relative effect of being untested for HIV versus knowing one's HIV status and not entering care. National estimates of the untested HIV+ population suggest that 21% do not know their status. This figure may be higher or lower in Massachusetts, and MDPH is seeking assistance from the CDC to develop a methodology for estimating this figure at the state level. We also have inadequate data to estimate accurately the degree of late entry to care among persons who know their HIV+ status. One unpublished local study, based on a convenience sample of HIV+ persons in medical care, indicated that over 85% entered care within three months of testing HIV+. However this may not capture the experience of individuals not in care. Additional data about persons concurrently diagnosed is needed to more fully understand this outcome.

What needs to be done to address lateness to care?



- Further research into the confluence of factors resulting in late testing and delayed entry into care
- Effective provision of information about the imminent lifting of the federal HIV visitation and immigration ban in an effort to lessen the effects of fear of immigration action
- Culturally specific public information campaigns to reduce stigma and the perception of stigma for persons with HIV infection and the behaviors associated with HIV infection
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