RISK PERCEPTION AND THE STIGMA OF HIV/AIDS:
WHY ROUTINE TESTING
WILL CHANGE HOW AMERICANS VIEW THE DISEASE

by Vanessa Lynskey

The Centers for Disease Control and Prevention (CDC) recently introduced new guidelines which will make HIV testing a routine part of a thorough medical evaluation. Given the high rates of incidence and transmission of the disease, and the startling number of people who are unknowingly infected, the number of people who seek testing on their own is unacceptably low. As this low testing rate can be attributed in many instances to an incorrect assessment of risk based on the common stigmas associated with HIV, routine testing will help to break down these barriers by normalizing the process and bringing to light the common misperceptions about risk factors. As a result, routine testing should lead to a better-informed public with lower rates of HIV transmission.¹

Since first diagnosed nearly three decades ago, HIV/AIDS has received widespread attention both in the media and the general public, with events such as the annual World AIDS Day designed to increase awareness of the disease and ways in which it may be prevented. Despite the large emphasis placed on HIV prevention, however, a recent study by the Centers for Disease Control and Prevention (CDC) reported that approximately 50 percent of individuals between the ages of 15 and 44 had never been tested for HIV,² thus explaining why such a large percentage of those infected (roughly one quarter of the estimated 1 million infections³) remain unaware of their HIV status. If HIV is such a widely prevalent disease, and knowledge about one’s infection status can prevent transmission and drastically improve the length and quality of life, why do so few people seek testing?

The answer to this question lies tangled within the social history of the disease and the way in which it was represented to the public upon first diagnosis. A highly stigmatized disease from the outset, this has created a host of misconceptions about the disease, and has consequently led people to miscalculate their own level of risk of contraction. When people feel that they do not fall into one of the groups typically affected by HIV, they fail to view themselves as vulnerable to it and hence do not get tested. For this reason, the introduction of routine testing will significantly alter the public’s perception of the disease, as well as their own susceptibility to it, by elucidating the true patterns of the disease and shifting the focus away from only those groups of people most commonly associated with HIV.

A Changing Demographic

Twenty-five years after the first diagnosis of HIV, an estimated 40,000 people become infected with the virus annually,⁴ for a combined U.S. prevalence of roughly 1 million cases.³ Of these 1 million infected individuals, approximately one quarter (164,000-264,000) are unaware of their HIV status,³ thus creating major personal and public health concerns as these individuals are responsible for nearly 65% of all new infections⁵. In order to reduce this high level of transmission by unknowingly infected individuals, it is crucial that more people undergo testing and become aware of their HIV status early.

Lack of accurate knowledge about the trends of HIV in the population and the changing face of the demographic affected by the disease strongly influence peoples’ perception of risk. When it first arose in the population, HIV immediately became associated with homosexual males, as it was first diagnosed among members of this population.⁶ As more information became available about the disease, however, scientists determined that in fact three main modes of transmission existed: “sexual contact with an infected person, exposure to infected blood or blood products (mainly through needle-sharing among IV-drug users), and perinatal transmission from an infected woman to her fetus or infant.”⁷ These three defined modes of transmission, along with summary statistics of those initially infected with the disease, quickly led to the development of risk categories referred to as the “4 H’s”: homosexuals, Haitians, hemophiliacs, and heroin addicts.⁸ These 4 H’s, though intended to define generic risk categories based on actual incidence data, actually played a major role in producing the stigma associated with HIV. Although only a minority of people from each of these groups was infected with HIV, their distinction as “risk factors” led people to falsely stereotype anyone in each of these
categories as dangerous based on their apparently inherent risk for contracting the disease. While these categories may have been a fairly accurate representation of the population of infected individuals at the time, they quickly became insufficient descriptors of risk factors as the demographic of those infected began to change.

**Historical Trends**

In the years immediately following its diagnosis in the human population, HIV remained somewhat contained among the adult male homosexual population. The first reports by the CDC that linked certain opportunistic infections to the HIV virus found in a late 1981 survey that “over 95% [of those infected] were men 25-49 years of age,” and furthermore, “ninety-four percent (95/101) of the men for whom sexual preference was known were homosexual or bisexual.” By 1988 this demographic had already begun to change as the incidence began rising in females. However, a comparison between the 1988 statistics and those from 2005 tells much more, as it reveals how drastically the affected demographic has changed over the past twenty years (Table 1). This comparison reveals that although homosexual males and males in general do still account for a significant fraction of HIV cases, the number of infected women and the number of infections attributed to heterosexual contact have increased dramatically.

<table>
<thead>
<tr>
<th>Demographic/Mode of Transmission</th>
<th>% of infections in 1988</th>
<th>% of infection in 2005</th>
</tr>
</thead>
<tbody>
<tr>
<td>Men who have sex with men (MSM)</td>
<td>63%</td>
<td>49%</td>
</tr>
<tr>
<td>Heterosexual contact</td>
<td>4.8%</td>
<td>32%</td>
</tr>
<tr>
<td>Males</td>
<td>91%</td>
<td>74%</td>
</tr>
</tbody>
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As a reflection of this demographic shift, new risk factors have been defined that more thoroughly address the risky behaviors which have led to an increase in incidence outside of the initially affected populations. Whereas the 4 H’s dealt only with sexual risk resulting from homosexual contact, six newly defined categories outline current risks related to sexual behavior in the past year, only two of which deal with homosexual contact:

1. Five or more opposite sex partners
2. Men having sex with other men
3. Sex with an injecting drug user (IDU)
4. Sex with an HIV-infected person
5. Exchange of sex for money or drugs
6. Having been treated for an STD
7. For females, sex with a man who has sex with a man

This comprehensive set of risks reflects the changing demographic of those infected so as to allow people to more accurately assess their own risk of contracting HIV. Unfortunately, these risk factors, used mainly as a tool for research and data purposes, are unknown to a large percentage of the general population and therefore people remain in the dark about their exposure status. Were everyone aware of these risks, however, there would still be no guarantee that they would pay attention to the warnings and seek testing on their own.

As the demographic affected by HIV/AIDS continues to evolve, ignorance of the disease trends continues to prevent individuals from accurately assessing their own risk of contraction, thus leading to lower rates of testing and higher levels of incidence. In an effort to increase testing and detection rates, the CDC has recently released a report calling for the routine testing of all individuals, regardless of their perceived risk status. Through these revised testing practices, they aim to overcome risk perception barriers and break down the social stigma associated with HIV and HIV testing.

**The Goals and Procedures of Routine Testing**

With regards to adults and adolescents, the CDC defines their objectives for routine testing as follows:

“...to increase HIV screening of patients, including pregnant women, in health-care settings; foster earlier detection of HIV infection; identify and counsel persons with unrecognized HIV infection and link them to clinical and prevention services; and further reduce perinatal transmission of HIV in the United States.”

In order to achieve these objectives, the revision of current testing recommendations was crucial. The revisions outlined in the CDC’s September 2006 report entitled “Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health-
Care Settings” differ from previously published guidelines in the following ways:

- HIV screening is recommended for patients in all health-care settings after the patient is notified that testing will be performed unless the patient declines (opt-out screening)
- Persons at high risk for HIV infection should be screened for HIV at least annually.
- Separate written consent for HIV testing should not be required; general consent for medical care should be considered sufficient to encompass consent for HIV testing.
- Prevention counseling should not be required with HIV diagnostic testing or as part of HIV screening programs in health-care settings.\(^1\)

The most notable change in these recommendations is that HIV screening would now adopt an opt-out model; rather than leaving it up to an individual to realize his or her own risk and actively seek out testing, or be referred for testing at the recommendation of a physician, the HIV test would now become standard for all individuals seen in health-care settings. This routine process eliminates the potential for bias and human error with regards to risk assessment.

**Overcoming Risk Perception and Breaking Down Stigma**

The fact that HIV testing guidelines differ from those of other medical tests provides evidence of the social stigma attached to it. Written consent and counseling are not required for blood tests that could reveal cancer or for urine tests that could reveal kidney disease; such routine tests have been accepted as necessary components of a thorough medical examination. However, when it comes to HIV, many people warn about the dangers of eliminating such practices, as they fear that patients may not be as thoroughly prepared for a positive diagnosis. This logic seems faulty as patients would likely find themselves equally unprepared for a diagnosis of cancer or kidney disease, and yet no debate exists about requiring counseling under these conditions. Especially because a diagnosis of HIV no longer implies imminent death thanks to advances in medicine over the past two decades, pre-test counseling has much less to do with preparing someone for the medical realities of a positive diagnosis than with preparing them for the social realities of such an outcome. Ironically, however, requiring counseling and written consent before testing actually helps to perpetuate the stigma associated with the disease by implying that something about HIV makes it more delicate and worthy of special attention.

What about HIV makes it different from other infectious diseases? It can be prevented easily. Because contraction of HIV usually results from involvement in so-called “risky activities”, those who contract HIV can be seen as irresponsible and even deserving of their condition as a result of their “reckless” behavior. In order to eliminate this judgmental perception and avoid placing blame on infected individuals, HIV must be treated like other communicable diseases which do not require pre-test counseling or written consent.

Peoples’ levels of risk are directly correlated to the evolving demographics of those affected, leaving many susceptible to contraction that would not normally recognize this vulnerability. Just as individuals may miscalculate their own risk, so too can physicians miscalculate the risk of their patients. Physicians are not always above the influence of society’s biases, and they therefore may fail to recognize a patient’s risk if he or she does not fit into the supposed “typical demographic” of an HIV patient. Although exposure to HIV may have been associated with social factors such as race, class, and sexual orientation in the past, those ties do not hold as strong now and therefore these social markers should no longer be given such heavy weight when assessing a patient’s risk.

In addition to those who remain unaware of their risks, many people who do recognize their vulnerability are unwilling to disclose this important information to their physicians,\(^1\) reflecting again the power of social stigma. The fact that individuals would go untested and therefore potentially untreated rather than disclose to their physicians their risk for HIV indicates that there still exists great fear of discrimination based on risky behaviors. While routine testing cannot address outside discrimination resulting from a positive test, it will allow these individuals to receive the medical care they need without having to “incriminate” themselves to their physician by requesting the test.

For each of the aforementioned reasons and certainly many more, routine testing will help to break down the social stigma associated with HIV and HIV testing.

**Skepticism and Opposition**

Despite the numerous personal and public health
advantages afforded by routine testing, many people remain skeptical of the revised testing practices. Sources of concern include the elimination of pre-test counseling and the lack of sufficient resources to ensure that treatment is available to all who test positive, as well as patient privacy rights and informed consent.5,11-15

Because the new recommendations eliminate the currently mandated pre-test counseling, a fear exists that people would be unprepared for a positive test result and that they would not receive accurate knowledge about HIV, HIV risk reduction, and HIV testing; however, in their article “HIV Counseling and Testing: Less Targeting, More Testing”, Koo et al. report that “there are no studies establishing the additive value of pretest counseling in counseling and testing services.”16 On the contrary, making testing routine and involving every patient in the screening process will open the door to more honest communication between physicians and patients. Such dialogue will allow doctors to discuss HIV and HIV prevention with patients early, hopefully leading to more widespread adoption of prevention strategies.

Lack of access to treatment is also a major concern when it comes to HIV. According to Thomas Coates, director of the Program in Global Health at the University of California, Los Angeles, “The people most likely to get HIV are the least likely to have access to healthcare.”17 Citing this claim as an argument against routine testing does not provide constructive solutions to overcome the various barriers to health care access. If people who lack sufficient resources test positive for HIV, it is possible that they will be unable to obtain treatment; however, if they are never given the test it is certain that they will not receive treatment. A rise in the number of identified infections as a result of routine testing could even put pressure on the government and other private sources to allocate more funds for treatment of individuals who cannot afford it. Additionally, an increase in the number of early detections should decrease the transmission rate as people will become aware of their need to take extra precautions. This would in effect reduce the amount of people needing treatment and therefore in the long run reduce the amount of money being spent on HIV treatment. For this reason, all parties with a financial stake in the care of HIV-infected individuals should support routine testing.

Issues of privacy, while a valid concern when dealing with HIV, do not differ when discussing opt-out or opt-in testing. Whether a person requests a test or simply does not opt-out of the test, there exists an inherent risk of his or her medical status and sexual history becoming public, and therefore this argument should not be taken into account in discussions of routine testing. People also worry that eliminating the need for written consent could lead to some patients being tested without their consent or knowledge, “whether due to vulnerability, lack of initiative, lax hospital procedures, or cultural differences.”13 This concern is a valid one, and therefore it will be crucial for physicians to thoroughly explain to their patients these new procedures, especially during the first few years of their use. Media campaigns and the availability of more literature regarding the topic could also help to inform the public so that people are aware of the new practices and their rights with regards to refusing a test.

While these concerns do raise some interesting scenarios that deserve careful consideration, the benefits of routine testing are great enough that any potential sources of conflict can be dealt with and adjusted so as to ensure that every patient receives optimal care.

Conclusions

While certain individuals and activists remain skeptical of routine testing, this new process offers enormous benefits not only with regards to individual and public health but also in dealing with the social stigma of HIV and individuals’ perception of risk. Routine testing conquers stigma in a simple way: there can be no stigma associated with testing if everyone is being tested. When only certain individuals or groups regularly seek out testing, it becomes easy for society to associate these groups with the disease and discriminate against them as a result. However, when there ceases to be a division among “those who get tested and those who don’t” or “those who are at risk and those aren’t,” there ceases to be a basis for exclusion or discrimination. This latter distinction is especially irrelevant in light of recent trends, which indicate that while some individuals are decidedly more at risk than others, everyone sexually active or injection-drug-using individual faces a risk for contracting HIV, regardless of sexual orientation. Therefore, routine testing represents a crucial step in the process of breaking down the social stigma of HIV and HIV testing, and in effectively detecting and preventing the transmission of HIV in the population.
References