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OP-ED

HIV Stigma and Discrimination Persist, Even in Health Care

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HIV *is* different from many other diseases. Finding out that one has HIV presents complex physical, emotional, social, and legal concerns that do not arise when one is tested for other conditions, including other communicable diseases. Advances in treatment have dramatically transformed the lives of many people living with HIV, but understanding and acceptance within U.S. society have not improved as dramatically. Almost 30 years after the onset of the epidemic, HIV stigma and discrimination—fed largely by ignorance and animus—persist and continue to have a forceful impact on people living with HIV.

Despite legal protections and some reduction in the ignorance and fear about HIV, people in the United States are still denied and fired from jobs, kicked out of residences, ordered to limit contact with family, and discriminated against in many other ways because they have HIV. Perhaps most shockingly, health care personnel have been known to stigmatize patients with HIV, in some cases refusing to treat them or providing substandard care. Frequently, individuals find that even family and friends behave differently around and toward them after learning they have the virus. As health care workers consider ways to expand HIV testing and link those who test positive to care, they must consider the persistence of stigma and discrimination, both within the health care system and in the larger society.

The risks associated with testing positive for HIV are not at all routine or comparable to those incurred by routine medical tests. As the American Bar Association's AIDS Coordinating Committee recently stated,

whether a patient can be deemed legally to have consented to a procedure depends on the extent to which the patient was informed of the nature and foreseeable results and consequences of the procedure, which, as with HIV testing, can encompass both physical and societal dimensions [1].

Among the most significant societal dimensions is the risk of stigma and discrimination, which is fueled by ignorance about the basic modes of HIV transmission and unfounded fears of contagion, as well as moral judgment and personal prejudice against the groups most affected by the epidemic.

Far too many people in the United States still lack basic knowledge about how HIV is and is not transmitted. According to a 2009 national survey conducted by the Kaiser Family Foundation, one-third of Americans believed that HIV could be transmitted by sharing a drinking glass, touching a toilet seat, or swimming in a pool

with someone who has the virus—all persistent misconceptions. The same survey found that half of adults said they would be uncomfortable having their food prepared by someone with HIV, 42 percent would be uncomfortable with a roommate who had HIV, 23 percent would be uncomfortable with a co-worker with HIV, and 35 percent would be uncomfortable if their child had a teacher with HIV [2].

The link between ignorance about HIV and stigma toward those with it is clear: 71 percent of the survey respondents who gave incorrect answers about HIV transmission said they would be uncomfortable having their food prepared by someone who had HIV, while only 40 percent of those who gave correct answers said they would be. Forty-three percent of those who gave incorrect answers said they would be uncomfortable working with someone with HIV, while only 13 percent of those who gave correct answers said they would be [3].

But it is also clear that more than ignorance is behind stigma: of those who gave *correct* answers about HIV transmission, only 58 percent said they would be comfortable with having their food prepared by someone with HIV, and only 85 percent said they would be comfortable working with someone with HIV [4]. Every week, Lambda Legal's help desk receives calls and e-mails from individuals living with HIV throughout the country who are seeking advice or assistance. These callers and correspondents report changes in behavior by others who learn—or even suspect—that the caller/e-mailer has HIV, such as taking food-preparation duties away in a cafe, seeking to limit the caller's/e-mailer's access to children in a custody dispute, and laying off the caller/e-mailer shortly after learning that he or she has HIV.

It should be reasonable to assume that one group of Americans—those who provide health care—do not share such misconceptions and do not discriminate against or stigmatize people living with HIV. Regrettably, that assumption is incorrect. Discrimination based on HIV status persists even within the health care system. Surveys of health care workers themselves document this reality. For example, a 2006 study of specific-service health care professionals in Los Angeles County found HIV discrimination to be prevalent. The researchers surveyed 131 skilled nursing facilities, 102 obstetricians, and 98 plastic and cosmetic surgeons to determine how many of these institutions practice a policy of blanket discrimination against people living with HIV. Of the institutions surveyed, 56 percent of the skilled nursing facilities, 47 percent of the obstetricians, and 26 percent of the plastic and cosmetic surgeons refused to treat people living with HIV and had no lawful explanation for their discriminatory policy [5].

A recent survey of individuals living in transitional housing in New York City found that almost one-quarter reported experiencing discrimination—ranging from hostility, lack of respect, and less attention paid, to outright refusals of service—in the health care system because they had HIV [6]. Reactions of health care personnel to patients with HIV documented in another study included ignoring the patient,

spending inadequate time on the patient's needs, providing inadequate or substandard care to a patient in pain, trying to steer the patient to other clinics rather than provide services, refusing to draw blood, refusing to pull a tooth, defaming the patient to other health care personnel, and physically mistreating the patient [7].

In addition to raising serious ethical concerns, discrimination by health care personnel is illegal. Lambda Legal is currently representing a woman, Melody Rose, in federal court in Wisconsin, claiming violation of federal and state antidiscrimination laws. When Ms. Rose met with a surgeon to obtain needed gallbladder surgery, the physician told her that he did not want to perform surgery on her because of the risk he thought her HIV posed to his surgical team. Later, a surgeon at another medical facility removed Ms. Rose's gallbladder in what is considered a routine surgical procedure, which includes universal precautions taken to prevent the transmission of bloodborne pathogens such as HIV. Other Lambda Legal cases have challenged the refusal of nursing homes in Louisiana to admit a man with HIV and another surgeon's refusal to perform needed back surgery, as well as discrimination in nonhealth care contexts, including refusals to hire and firings of workers because they had HIV.

Because the stigma and discrimination prevalent in today's society have a profound psychological impact from the moment of diagnosis, receiving an HIV diagnosis is not comparable to learning that one has high cholesterol, hypertension, tuberculosis, or syphilis. Accordingly, those in health care should not treat HIV testing the same as testing or diagnosing other medical conditions. Efforts to test more people for HIV must not lose sight of the real purpose of such efforts, which is not to simply increase the number of people tested, but rather to identify people who have HIV so that they can get care and avoid infecting others. Providing individuals with information about the meaning and consequences of an HIV test, modes of HIV transmission, and the availability of treatment and legal protections will ensure that the decision to accept or refuse testing is adequately informed. Counseling and obtaining specific consent for an HIV test protects patients from non-consensual testing. Moreover, supplying pretest information and allowing the patient to ask questions will further the goal of getting people with HIV into care. Studies show that patients' adherence to prescribed treatment correlates with increased physician disclosure [8, 9]. By contrast, if patients are tested without their knowledge or informed consent, they may be alienated from the health care system. Ensuring that HIV testing is truly voluntary, informed, and consensual will benefit individuals and the public.

The health care profession has an ethical duty to avoid engaging in stigmatizing behaviors and a legal duty not to discriminate. To provide maximally effective and ethical HIV testing and care, health care personnel also need to recognize and take into account the realities faced by people living with HIV.

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