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American Medical Association Journal of Ethics
December 2009, Volume 11, Number 12: 959-961.

JOURNAL DISCUSSION

Ethics in Consent for HIV Testing

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Landor M. Clinical problem-solving. A hidden agenda. *N Engl J Med.* 1998;338(1):46-50.

In January 1998, a case published in the *New England Journal of Medicine* discussed the hospital course of a patient admitted with a fever of unknown origin [1]. During this patient's workup, his doctors became increasingly concerned that the cause of his fever was related to HIV infection, but the patient refused to be tested. After more and more uncommon causes of fever had been ruled out, the patient's T-lymphocyte subgroups were analyzed, revealing a CD4 to CD8 ratio of 0.7, which was very suspicious for HIV infection, whereupon the patient was again urged to consent to testing. Once again he refused. Eventually, after a long hospital stay and numerous tests, the patient admitted to having tested positive for HIV 8 years prior to admission. By this time a non-Hodgkin's lymphoma was diagnosed by whole-body nuclear scan. The patient's fever abated after treatment for the lymphoma was begun.

HIV is a disease for which we required specific consent for testing for many years. This is a direct result of the history of HIV infection and treatment. The first HIV antibody test was developed in 1985, at a time when there was no effective treatment for the disease. Infected patients could only be offered counseling, and, because the infection was lethal at the time, diagnosis was associated with great psychosocial suffering. Because the general population considered HIV a "homosexual disease," testing positive led to stigmatization. As a result, testing was treated differently than testing for other diseases with emphasis on counseling, confidentiality, and consent. Hence, the process for HIV testing became known as "HIV exceptionalism" [2].

When the first antiretroviral therapies were developed in the mid 1990s, HIV became less a death sentence and more like other treatable chronic diseases. But stigma still attached to the infection; it remained life-altering and incurable and, therefore, psychologically distressful. Now that effective treatment exists, it is important to determine how a patient is best served—by early diagnosis and access to therapy (which have been proven more effective), or by respecting an individual's right to refuse testing to avoid the discrimination that often accompanies HIV infection, even though this means a delay in possibly life-prolonging treatment.

In the case recounted in the *New England Journal* article, the patient declined testing despite multiple requests. As a result, his workup took longer, but had he consented to testing earlier, his fever might have been blamed on the HIV infection, and the lymphoma might not have been detected as early as it was. Although the knowledge

that the patient was HIV-positive helped to explain the lymphoma, the former diagnosis was not necessary for the latter. One could argue, on the other hand, that his doctors might have been more likely to investigate the possibility of lymphoma earlier if they had been aware of his HIV status. So this case raises the question of whether the physician was justified in testing T-lymphocytes without the patient's consent when knowledge of his HIV status was not truly necessary for diagnosing the cause of his fevers. The nuclear scan that led to the diagnosis of lymphoma was done before the patient admitted to being HIV-positive, therefore his diagnosis could have been made without knowledge of his HIV status. It could be argued that the idea of beneficence would support testing this patient's lymphocytes if there were no other way to make a diagnosis, but it was unnecessary in this case.

Faced with the patient's refusal to be tested for HIV directly, his doctor ordered a test that is an indirect indicator of HIV infection, in effect sending the message that he knew better than the patient and could get around the requirement for consent if he desired. By doing so, the patient's autonomy (which is meant to be protected by the HIV consenting process) was purposefully undermined. This is just the kind of situation that was anticipated when the original HIV testing policies were developed. If a patient has been fully counseled regarding HIV testing and infection and still declines to be tested, no matter what the situation may be, it does not seem right to undermine his or her autonomy.

It has been argued that more widespread HIV testing would be beneficial to both individuals and society. Individuals would be able to seek care earlier, which would allow them to live healthily for longer periods of time. Society would gain because individuals who are aware of their disease status earlier are less likely to spread the infection unknowingly. So why do patients continue to avoid HIV testing? Several reasons can be inferred from the case described in the journal article. Many of those who are at high risk for infection belong to marginalized populations, and the questions posed during screening for the presence of HIV risk factors ask about intimate and unlawful behaviors. As a result, patients pay careful attention to how they reply, fearing that their responses may alter how they are perceived by physicians and other health care workers. The patient in the reported case was careful to deny any homosexual activity, despite having several homosexual friends who were themselves infected with HIV. He also denied drug use and extramarital affairs. By denying these activities he distanced himself from marginalized populations like drug users and homosexuals and activities that are frowned upon like adultery.

Fear of discrimination and stigmatization continues to be a barrier to HIV testing in the United States. Some argue that until HIV testing is treated in the same manner as testing for other diseases, it will be impossible to remove the stigma of HIV infection [3]. I do not believe that changing the requirements for testing—from explicit consent to implied consent—will reduce the stigma of being seropositive. And, in fact, patients might avoid health care settings altogether in an effort to avoid universal HIV testing.

But routine testing might at least assure patients that they are not being perceived as members of the marginalized populations. From that vantage point, we must encourage patients' questions, offer support, and educate them in how to manage what is now a serious, chronic—but not fatal—disease.

References

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