HIV Testing Policy and Serious Mental Illness

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Objectives. Using opinion data from experts, we examined the context of the argument for mandatory testing of psychiatric patients.

Methods. Vignettes were distributed to experts on HIV and mental illness. Respondents were asked to provide appropriateness ratings for different hypothetical clinical decisions regarding HIV management.

Results. Respondents were reluctant to impose testing without informed consent in most circumstances. The presence of risk factors or danger to another increased appropriateness ratings modestly.

Conclusions. Despite experts' tendency to emphasize individual rights, public reluctance to mandate testing is unlikely to extend to people with serious mental illness. No argument for mandatory testing can be persuasive if improved voluntary testing can achieve adequate detection rates. Voluntary testing protocols should be studied to determine which successfully identify infected individuals. (Am J Public Health. 2002;92: 1931-1939)

Interest in the now well-documented spread of HIV among those with serious mental illness was largely confined to mental health professionals until 2 events in the late 1990s called attention to this issue in broader, policy-related discussions. The first was the 1997 passage by the New Jersey legislature of a bill that required all patients admitted to state psychiatric hospitals to be tested for HIV, even if they did not consent.1-3 Had a last-minute veto by a moderate Republican governor not forced legislators to include a requirement that patients give informed consent,4 HIV testing would have been mandatory for all new admissions throughout the state psychiatric hospital system, setting a precedent for other states. The second event was the highly publicized arrest, in the fall of 1997, of Nushawn Williams, an HIV-positive man who was believed to have infected scores of women in Chautauqua County, New York, and New York City. Shortly after Williams was arrested on a drug charge, reports indicated that he had previously been diagnosed with schizophrenia. A New York Post columnist, concerned that a claim of mental disability might be used to evade legal accountability, complained, in an inflammatory lead, that "It's crazy to put this vulture in a cuckoo's nest."5

These 2 events highlight how public attention to the spread of HIV in a population not

typically considered in this context can challenge previously established public attitudes and public policy. The working policy consensus developed in the 1980s carried an implicit image of AIDS patients, their motivations, and their likely responses to specific policies. Mandatory HIV testing was initially rejected as unworkable, politically insupportable, and ethically problematic. As changes in this implicit image begin to reflect new epidemiologic and therapeutic realities, the implications of older policies are not always clear. It remains to be seen whether HIV testing may be mandated for some people with serious mental illness. We examine the debate on this

Definitions of serious mental illness vary, 6,7 but they typically incorporate information on diagnosis, disability, and illness duration. The category usually includes many with schizophrenia and bipolar disorder, as well as other conditions, such as recurrent major depression and personality disorders, when these produce high levels of impairment.8 While many of those falling into this category have received inpatient psychiatric care at some point, all but the most severely ill spend most of their time in the community, where they rely on outpatient settings for services. Since the New Jersey legislation targeted inpatient admissions-and, as a practical matter, because blood is routinely drawn on admission, and

mandatory testing seems more likely to be adopted in inpatient rather than outpatient settings-we primarily focus on hospitalized patients, mentioning outpatient care only when it seems relevant.

Public rhetoric over mandatory testing has had an alarmist cast, but the ethical issues raised by the spread of HIV among the seriously mentally ill are by no means simple. They have been debated within the profession for over a decade. 9-19 Without an effective treatment to offer in the first years of the epidemic, some experts felt that the benefits of early detection and treatment were insufficient to justify the intrusiveness of testing and the distress it caused. 15 Counseling and confidentiality protections in the mental health system were thought to be so inadequate that knowledge of one's HIV status was arguably more burdensome than beneficial.20 Nevertheless, advocates for mandatory testing argued that knowledge of a patient's HIV status was crucial for differential diagnosis of some psychiatric complaints, 10 and that patients with severe mental illness were often unaware of their HIV risk and serostatus and thus were unlikely to seek voluntary testing.21 It was also proposed that an exception to the AIDS confidentiality rule be made for psychiatric patients deemed dangerous.11

Recent changes in the logic and prevailing discourse of prevention provide an important context for our examination of this issue. One early and influential prevention paradigm focused efforts on modifying the behavior of the entire population. Any less universal focus (on, for example, "risk groups") was viewed as undesirable because it was liable to undermine the message that each individual was responsible for his or her own protection. In the words of a popular expression of the period, "AIDS doesn't discriminate." Targeted prevention, it was held, might also foster an "usthem" attitude by the public, weakening an already fragile social solidarity.²²

The case for targeted prevention is no longer viewed with such suspicion. In 1996,

between 37% and 64% of US adults with HIV were not receiving appropriate care, either because they were unaware of infection or because they had not accessed services.²³ Yet a review of applications for Centers for Disease Control and Prevention (CDC) prevention funds found that most did not name people with HIV as a priority population for prevention.24 In this context, efforts to decrease risk behavior by people with HIV/ AIDS have acquired increased legitimacy.^{25–28} This new approach emphasizes the need to increase the number of people who know their serostatus among those already infected, who can then be brought into care and recruited as partners in prevention. This new framework has been put into action with the CDC's SAFE (Serostatus Approach to Fighting the Epidemic) initiative²⁴ and its "Know Now" media campaign to encourage testing.²⁸

Today, early detection of HIV infection is widely encouraged.29 New testing procedures may reduce the stress and inconvenience of HIV testing, since it is now possible to use urine or saliva rather than blood, and provide initial information on test results almost immediately (although it is still necessary to run a Western blot test to confirm a positive test, which takes time).30 The promise of life-extending treatments can now be weighed against the adversities of testing. Given the evidence that, among those with serious mental illness, behaviors that increase the risk of HIV transmission are comparatively common,31,32 documented rates of HIV infection are elevated, and HIV testing practices are inadequate, some action is warranted to increase rates of HIV testing. In this study, we discuss ethical and policy issues raised by the use of mandatory testing to increase testing rates, examining testing policies in the context of the historical and contemporary social context in which they have arisen.

PRINCIPLES AND POLICYMAKING

Various abstract ethical concepts have played a role in US AIDS policy, but, as Bayer describes in *Private Acts, Social Consequences*, the balancing of these principles was influenced by cultural, political, and social

forces as well.33 During the 1980s, mainstream AIDS policy coalesced around a "voluntarist consensus" forged from a combination of principled and practical considerations. As a matter of principle, the tradition of civil liberty runs deep in the United States. Numerous institutions and practices express the high regard held for values such as noninterference and autonomy, which arise from respect for individual privacy. Compulsory efforts to identify infected individuals were widely rejected.³⁴ As a practical matter, because most acts of viral transmission take place in private settings, state surveillance and control are exceedingly difficult. Rather than attempt to police private acts, require HIV testing, or quarantine the infected, the voluntarist view argued that policy should safeguard confidentiality, strengthen antidiscrimination laws, and rely on education and persuasion to promote behavior change and encourage testing.35-37 The generally moderate approach and comparatively strict confidentiality regulations in effect until recently in New York and New Jersey largely embodied voluntarist principles, but they were created with little consideration of HIV in special populations, such as those with serious mental illness.

PSYCHIATRIC ILLNESS AND HIV INFECTION

Medical care for patients with the most serious psychiatric conditions can be challenging and has historically suffered from neglect, with the result that many treatable conditions go unrecognized, leading to elevated mortality rates. ^{38,39} In the 1980s, psychiatric attention was initially focused on helping infected patients deal with the medical and psychiatric accompaniments of infection and managing the various medical and legal dilemmas raised. The risk of HIV infection among people with serious mental illness was not immediately apparent.

More than 40 cases of HIV disease had been identified in New York's state psychiatric hospital system by 1987, 40 but sustained interest in infection rates among those with serious mental illness arose comparatively recently. Published estimates based on studies in psychiatric settings suggest that, at least in

high-prevalence areas like New York City where most data have been collected, the rate of HIV infection among people with severe mental illness ranges from 4.0% to 22.9%. ⁴¹ One New York City unit for patients with combined substance abuse and psychiatric illness reported an infection rate of 23%. ⁴² Using figures from published studies, city officials in New York City estimated in 1996 that between 1130 and 1189 known HIV-positive individuals with serious mental illness were being served in the mental health system. ⁴³

Studies conducted in psychiatric settings in other areas reported lower, but still troubling, rates. 41 A recent study that included outpatients and inpatients from a mixture of high-prevalence urban areas, smaller metropolitan areas, and rural settings found a lower infection rate (3.1%) but noted that this rate was still 8 times that of the general population. 44

Few seroprevalence data exist on large populations. Among HIV-positive Medicaid recipients in New Jersey, 5.7% are diagnosed with schizophrenia and 6.8% with major affective disorder. 45 Blank and colleagues compared Medicaid and welfare recipients with and without serious mental illness and found that, after they controlled for age, sex, race, and time on welfare, schizophrenia and affective disorder significantly increased the odds of an individual being HIV positive. 46 On the basis of data from emergency room visits and hospital discharges in South Carolina, patients diagnosed with a mental illness are 1.44 times more likely to have HIV/AIDS than those not so diagnosed. 47 Inasmuch as Medicaid claims and hospital discharges capture only cases in the treatment system, these figures do not count patients who may have a major psychiatric illness but do not receive treatments that produce claims or discharge

Ironically, despite the high prevalence of HIV in New York State, the evidence leaves little doubt that statewide efforts to promote testing for psychiatric patients have been grossly inadequate. Using data collected from visits to half the general hospital psychiatric units in the state, Walkup and colleagues found that 70% of the units urged

testing for only "a few" or "almost none" of their patients. 48 A 1995 statewide survey of licensed outpatient mental health facilities in New York State found that fewer than half the sites responding had staff trained to provide HIV counseling and testing. 49 A similar survey in 1997 found that fewer than one third of sites reported that HIV risk assessment was routine.50 Two decades into the epidemic, data collected from mental health agencies between March 2000 and January 2001 indicate that, despite gains made from focused efforts to increase HIV/AIDS preparedness, significant gaps in service remain.51

RISK ASSESSMENT AND HIV TESTING

Awareness of infection is a practical precondition to treatment in almost all circumstances. Grassi has warned that many HIVpositive psychiatric patients are unaware of their status.⁵² The limited data available confirm this fear.⁵³ Even in New York State, where risk screening interviews are mandated, staff fail to identify as many as two thirds to three quarters of HIV-infected patients in some settings. 42,54-56 Some blame can be assigned to a "passive" approach to HIV testing derived from a diagnostic test paradigm, in which "ordering the test is appropriate only if test results are positive at some regular frequency."57(p1995) In many psychiatric settings, HIV testing is provided only when it is considered appropriate for an individual patient, either when it has been requested by the patient or urged by staff on the basis of information about risk behavior.

Routine clinical judgments about when to order testing are highly fallible. As in other medical settings,58 information on high-risk behavior is frequently missed by psychiatric staff 39,59 and commonly goes unrecorded in the charts of HIV-positive inpatients. 60 Routine intake questions may not provide enough information to alert clinicians to suggest testing. Only about 1% of psychiatric patients in a New York City study reported intravenous drug use in the past 6 months, yet detailed questioning found that 1 in 5 had used intravenous drugs since the start of

the US HIV epidemic in 1978.61 A study of inpatients with schizophrenia in 4 New York City hospitals found that fewer than 1 in 5 had recently been tested for HIV; even the majority of injection drug users had not recently been tested.62

Inaccurate stereotypes about the mentally ill may cause staff to underestimate risk. Even experienced clinicians may sometimes mistakenly view people with serious mental illness as asexual. While it is true that many seriously mentally ill people report having sex infrequently, studies indicate that the sexual intercourse that does occur is often unprotected, involves multiple partners, or both. 63,64 Marriage and long-term relationships are comparatively rare.65 Many of those who are sexually active meet partners in public places, such as bars or on the street,66 trade sex for material gain, or report a history of sexual contact with an injection drug-using partner.31,67 High rates of sexual victimization are reported as well.68,69

Screening for risk factors may also suffer because professionals are reluctant to bring up HIV with psychiatric patients, often out of well-meaning concern for the patient's welfare. They may overestimate the anxiety caused by taking a sexual history⁷⁰ or fear that discussing emotionally charged issues, such as sexual behavior and HIV, may worsen psychiatric symptoms. They may assume that patients' sexual histories are unreliable and see little point in obtaining them. Yet there is evidence that patients give reliable information and that many welcome the opportunity to discuss sexual issues.⁷¹

Newly admitted inpatients are often considered too disturbed for testing. However, workers also fear that, as discharge approaches, a positive HIV test may increase a patient's length of stay or create logistical problems with posttest notification and counseling if the test result arrives after discharge. In a time when most inpatient stays are short, the period during which testing is considered acceptable becomes short indeed. Commentators have noted that the current failure to detect HIV relieves overburdened care systems of a difficult, potentially costly, responsibility.⁷² Even when everyone involved is highly motivated to improve screening, changes that

are likely to increase costs are typically difficult to implement.

METHODS

In designing a survey to aid in developing treatment guidelines for patients with comorbid HIV and schizophrenia, we included some questions on the topic of mandatory HIV testing. We report responses to selected items in order to shed light on expert opinion regarding this controversial issue.

Participants

Our approach was to solicit opinions from nationally known experts. We developed our list in several ways. We recruited most of our experts from the list of participants who had attended a 1996 consensus conference on HIV and serious mental illness sponsored by the National Institute of Mental Health. Subjects were initially called by telephone. When someone could not participate, we asked him or her to nominate a replacement. In a few cases, we also sought out experts known to us through their publications. Of the 28 subjects who agreed to participate, 22 completed and returned a survey. Over three quarters (77%) were physicians (mainly psychiatrists). Most had direct clinical experience with HIV/AIDS (63%) or with serious mental illness (68%). The average length of time spent working with patients with HIV/AIDS was 7.5 years. The nonclinicians in the group either conducted research or worked on policy issues in the area.

Instrument

We developed our instrument in several phases. Interviews were conducted with clinicians and administrators whose jobs required them to confront clinical and ethical dilemmas associated with the spread of HIV among people with serious mental illness. On the basis of the interview data and our experience, we chose a series of clinical dilemmas that a clinician working with clients with serious mental illness might face. The questions concerned a hypothetical young man with schizophrenia (Mr A). Respondents were told he lives in a community residence, is generally stable when he takes his medication regularly, but has an occasional acute exacerbation of his psychiatric condition. Questions

Sample Scenarios From Questionnaire Asking Experts on HIV and Mental Illness to Rate Appropriateness of Different Hypothetical Clinical Decisions

Mr A is a young man with schizophrenia. Between periods of acute exacerbation, he is generally stable and has been maintained with a low dose of a high-potency antipsychotic (e.g., haloperiodol, 5 mg PO, QD). He lives in a community residence and is seen monthly for medication checks and case management.

Would you urge Mr A to undergo voluntary HIV testing with informed consent if he denied HIV risk factors and he has been psychiatrically stable for a long period and—

- · resides in a community with a high rate of infection?
- · resides in a community with a low rate of infection?

Would you be prepared to test Mr A for HIV without his consent if he became grossly psychotic, was hospitalized, lacked the competence to judge health care needs and—

- · had no known history of high-risk behavior?
- and had no medical condition noted on physical examination?
- and had a positive VDRL test?

(If Mr A is HIV positive) Now suppose that Mr A has not revealed his diagnosis to other patients, but during the hospital stay, he reports he had unprotected sex with another patient, Ms B, who confirms his account. Suppose, too, that Mr A is sexually preoccupied and will not give assurance that he will avoid sex while on the unit. Would you—

- isolate Mr A?
- put Mr A on one-to-one observation?
- counsel Ms B that she has been exposed to HIV?
- advise the patient community of rule violation without identifying Mr A and Ms B?
- · reinforce rules against sex on the unit?

Note. VDRL=Venereal Disease Research Laboratory; PO=orally; QD=daily.

were reviewed for realism and appropriateness by other clinicians and were modified on the basis of their comments. Sample scenarios are included in the box on this page.

Individual questions proposed dilemmas regarding HIV testing and confidentiality. 1) Questions asked respondents to rate a clinical decision on a scale from 1 ("extremely appropriate") to 9 ("extremely inappropriate") or to mark an "X" if they were unable to answer because, for example, they lacked the necessary technical knowledge. Following a format widely used in previous studies of consensus judgments on clinical issues, choices rated 2 or 3 were labeled "usually inappropriate," those rated 7 or 8 "usually appropriate," and those rated 4, 5, or 6 "equivocal." 73,74 2) Unreadable and skipped responses were not counted; the average number of usable responses was 20.6. Experts not included in the original sample were asked to comment on the clinical and policy significance of the findings.

RESULTS

Experts approached testing with caution but varied their views on the basis of the presence of various indicators. Even when they were told to imagine that Mr A lived in a community with a high rate of infection, the mean appropriateness rating for recommending voluntary testing fell short of the "usually appropriate" standard (mean=5.67, SD=2.35). To investigate circumstances under which it might be thought appropriate to test a patient without informed consent, respondents were asked if they would be prepared to test Mr A without his consent if he became grossly psychotic and incompetent to judge his health care needs. When Mr A had no known history of high-risk behavior and no medical problems, the mean rating indicated that forced testing was usually inappropriate (mean=2.5, SD=1.73). Ratings rose into the "equivocal" range when we added either a history of high-risk behavior (mean=

5.1, SD=2.6) or the presence of a non-HIV sexually transmitted disease (mean=5.35, SD=3.08). When both factors were added to the vignette, mean ratings reached the high end of the "equivocal" range (mean=6.19, SD=3.04).

Respondents were given a space to describe any other circumstances in which they might support mandatory testing. One wrote, "Perhaps if the person had a high probability of having HIV disease clinically, lacked capacity to understand actions that could lead to HIV transmission, [and] regularly has these behaviors. But this is a complex civil rights vs public health issue." A second wrote, "[When] violent acts on the unit [cause] harm [and] blood injury results to other patients." A third wrote that mandatory testing would be appropriate if Mr A sexually assaulted another patient, in which case prompt combination therapy could be given to the exposed rape victim, but raised concerns about treating Mr A himself since he might not comply with a complicated oral medication regimen, thus increasing the risk of developing a resistant viral strain.

In the event that Mr A was tested and received a positive result, a series of questions inquired about the circumstances under which it would be appropriate to disclose that Mr A was HIV positive without his consent. Disclosure to emergency medical services personnel treating Mr A received a mean rating of 4.62 (SD=3.25), and disclosure to a nonphysician primary therapist or case manager received a mean rating of 4.52 (SD=3.2). Disclosure to staff at a residence considering Mr A for admission was rated as less appropriate (mean=3.33, SD=2.69) than disclosure to a primary therapist.

Respondents gave disclosure to a known sex partner a somewhat higher appropriateness rating of 5.95 (SD=2.58). Disclosure to family members without consent was considered inappropriate, with the degree of inappropriateness depending on whether Mr A lived with his family. The mean score was 2.33 (SD=1.74) if he resided with his family and 1.71 (SD=1.01) if no mention was made of living with his family.

Some of the main challenges to the voluntarist approach to testing among individuals with serious mental illness concern the risk

that they might infect others-a topic given special urgency in clinical settings where physicians have responsibility for the welfare of other patients. The questionnaire presented a scenario in which Mr A is hospitalized and has not revealed his HIV status to other patients. He reports to a counselor that he has already had unprotected sex with a another patient, Ms B, and refuses to give assurances that he will not have sex with other patients while on the unit. Several possible responses to this situation are presented. The possibility of isolating Mr A from other patients received a mean rating of 4.21 (SD=2.68), while the mean rating for one-to-one observation was 7.32 (SD=1.53). Notifying Ms B that Mr A is HIV positive fell into the usually appropriate category (mean=7.53, SD=1.93). The breach of confidentiality was apparently justified by the individual risk to Ms B. In contrast, notifying the entire patient community of Mr A's HIV status was rated as usually inappropriate (mean=3.11, SD=2.45). An approach deemed more appropriate, with a mean rating of 7.84 (SD=2.22), was to advise the patient community of high-risk behavior on the unit and to reinforce rules against sex between patients.

DISCUSSION

Overall, our expert respondents showed little enthusiasm for testing psychiatric patients without their consent. Instead, they seem to approach testing primarily as a clinical-not a policy-issue, varying their ratings of appropriateness in response to changes in clinical circumstances described in the vignettes. Further research might identify the sources of the attitudes found here. Do they derive primarily from values associated with professional identity, or do they draw on personal, political, and social values? Future work might identify and analyze differences between values expressed by these elite professional opinion makers and administrators or direct care workers. Also valuable would be evidence that could clarify how stable these opinions are and what sorts of events or considerations might prompt changes.

It is far from clear, however, what role the opinions of mental health professionals will play in future policy discussion. Policy

changes can be initiated in various quarters, some of which assign little weight to professional opinion. We believe there are several reasons to anticipate that the tenets of the voluntarist consensus will be put under strain by the spread of HIV among the seriously mentally ill.

First, the very tradition of civil liberty that provided a foundation for the voluntarist consensus includes a long tradition of allowing indeed, sometimes requiring-exceptional treatment of mentally disabled persons. Civil procedures allow for involuntary commitment. When someone is judged incompetent to make a treatment decision, treatment can be provided over that person's objection, using the doctrines of substituted judgment or best interests. In criminal law, defenses of insanity or diminished capacity are allowed. These judicial exceptions have generally been framed as humanitarian, not discriminatory.

While not linked directly to the context of HIV, several aspects of the current atmosphere may indirectly increase the perception that creating exceptions for people with mental illness is often necessary and reasonable. Data from the 1996 General Social Survey indicate that a very high proportion of the public supports use of legal means to coerce people with schizophrenia into treatment.⁷⁵ Recent acts of violence by persons with serious mental illness have prompted some to conclude that protection of public safety requires increased authority to restrict the behavior of psychotic persons.76-78

Second, as a practical matter, certain types of surveillance and control are significantly easier to administer with psychiatric patients than with the general population. Most major psychiatric illnesses require medication, and many people with serious mental illness have trouble maintaining employment and finding safe, affordable housing. 79,80 For these reasons, many people with serious mental illness have regular contact with public mental health and social service workers, who are socially authorized to inquire about private matters (e.g., sexual activity, drug use) and seek to influence behavior. These mental health and social welfare contacts provide a ready infrastructure for testing, particularly since new HIV testing procedures can be easily implemented by individuals without

specific medical training.30 While it is unlikely anyone would publicly say that the practical ease of implementation counts in favor of mandatory HIV testing, the inability of opponents to cite practical difficulty as a reason to oppose mandatory testing would likely influence the outcome of any policy discussion.

The circumstances of people with serious mental illness can be compared with those of another group considered in the debate over mandatory testing, pregnant women. With very few exceptions, these women come into contact with the medical care system for a delivery. New York State now requires that newborn infants be tested for HIV. Had most pregnant women avoided contact with medical care for delivery, implementation of the program would probably have been impossible.

Before implementation, opponents voiced the fear that the prospect of newborn HIV testing might make some women reluctant to seek prenatal or obstetric care-since, in effect, the test establishes the mother's serostatus-thus producing an unintended outcome that undermined public health. Interestingly, the limited evidence available indicates that mandatory testing of newborns did not have the feared effect on health care.81 If access to psychiatric care is made conditional on HIV testing, opponents will certainly object that it may lead to avoidance of care. Given that the newborn testing program does not seem to have led to high levels of avoidance of care, and that there have so far been no highly visible negative outcomes associated with the program, less weight may be given to concern about avoidance of care by psychiatric patients.

Third, comparatively limited political opposition is likely to result from adoption of an exception-making strategy for psychiatric patients. Despite changes in attitudes, serious psychiatric disability remains highly stigmatized.82 People with serious mental illness rarely have effective informal or institutional ties to the legal and political resources needed to influence testing policy. Since psychiatric advocacy groups have so far paid comparatively little attention to HIV, and since AIDS advocacy groups have paid comparatively little attention to people with psychiatric disabilities, there are fewer opportunities to lobby

legislators, influence provider organizations, or take part in class action suits.

Fourth, efforts to retain pure voluntarism have often relied on versions of the camel'snose-in-the-tent argument. They warned that a limit on the rights of pregnant women, for example, would eventually open the door to limitations on the rights of other groups.83 But these arguments may be difficult to apply to HIV testing for people with serious mental illness, since the arguments probably overstate the objective risk entailed by making an exception for psychiatric patients. They almost certainly presume a higher level of social solidarity concerning this issue than now exists. Testing has been required for many groups, such as newborns, prisoners, and those in the armed services, without widespread protest. It is difficult to imagine the public fearing that mandatory testing of psychiatric patients would be a harbinger of more widespread mandatory testing.

The current perception of psychiatry can be contrasted with its position in the 1980s, when there were several concrete events that could reasonably have been interpreted as efforts to use psychiatric authority to create a back door to quarantine.84 For example, an Orange County, California, task force was set up to respond to risky behavior by persons with HIV infection and required hospitalization for several patients whose behavior seemed to have been associated with severe psychiatric illness.85 Other actions represented a more unambiguous effort to stretch traditional psychiatric authority to cover situations in which behavioral control was desired but recognizable psychiatric disorder played little role. Psychiatrist Paul Applebaum agreed with the then-current American Psychiatric Association guidelines in questioning whether psychiatric facilities ought to be used for the detention of HIV-infected patients, but he argued that an HIV-infected person's unwillingness to desist from risky behavior could constitute legitimate grounds for involuntary confinement to a psychiatric facility. In a case cited by Bayer,84 a probate judge in Alabama relied on the authority of the state's mental health law to commit a male patient to a state psychiatric hospital to control HIV transmission-related behavior. In another instance, a Florida judge, responding to a petition by the

state's Department of Health and Rehabilitative Services, ordered an adolescent confined to a psychiatric ward as a threat to public health. Bayer notes the unusually explicit link between social control and a psychiatric conceptualization of recalcitrant risky behavior found in a similar approach taken by Indiana, which public health officials characterized as "non-punitive." 84(p1474)

These efforts to extend the purview of psychiatry arose not primarily from mainstream psychiatry but from public officials who wanted to find alternatives to criminal prosecution or explicit quarantine. Indeed, the epidemic spread during a period when most psychiatric leaders thought psychiatry needed to narrow its mission, focusing on the diagnosis and treatment of mental disorders and rejecting as "nonmedical" broader social roles proposed for the profession.86 In the years since AIDS was identified, openly gay psychiatrists have occupied leadership positions in defining appropriate roles for psychiatry, lobbied for increased support for service provision, and worked to forge alliances between psychiatry and community-based agencies. More recently, concern over psychiatric coercion has abated, and there is little reason to believe that opposition to this social control function of psychiatry could now be mobilized.

Finally, an argument can be made that a pure voluntarist position undervalues the current benefits to individuals and to public health. Early detection of HIV can sometimes function as a substantial prevention intervention, according to a meta-analysis of the effects of HIV testing on risk behavior. Tombination antiretroviral treatments can now reduce viral load and effectively extend periods of healthy living for many patients.

An important ethical issue is the probable scope of treatment-related benefits that may come from testing. If only a few patients with serious mental illness ultimately benefit from the new highly active antiretroviral treatments (HAART), then the loss of autonomy by a larger group is more difficult to justify. There are indeed grounds for concern that many patients with serious mental illness may not be in a position to benefit. In an August 1998 survey of infectious disease physicians who treat patients with HIV/AIDS, most said a patient's prior psychiatric hospitalization

counts against initiation of HAART.⁸⁸ This self-reported reluctance is echoed in a recent finding that protease inhibitor therapy is initiated later for patients with depression.⁸⁹

Caution in the use of HAART is reasonable, since suboptimal adherence increases the probability of producing resistant viral strains, harming the patient's prospects of successful treatment and increasing the danger that these strains can be spread into the uninfected population by patients who continue risky behavior. Patients who lead socially disorganized lives may not be equal to the demands of a complex medication regimen.⁹⁰ Yet recent data challenge stereotypes regarding the adherence problems of people with mental illness. One study found that, in a population of Medicaid beneficiaries with HIV, patients with schizophrenia had higher levels of antiviral adherence than other patients with HIV-perhaps because they had previously been integrated into the care system as a result of their psychiatric illness. 91 While this example of superior adherence by people with schizophrenia dates from the pre-HAART era, recent data suggest that adherence to combination therapies by patients with schizophrenia is not significantly below that of other patients. 92 (The same study, however, indicates that patients with recurrent major depression or bipolar disorder do have adherence problems.) A San Francisco program has recently reported good adherence to protease inhibitor therapy in a substantial proportion of homeless and marginally housed patients.93

The strongest argument against mandatory testing proposals for psychiatric patients is the clear evidence that efforts to promote voluntary testing in mental health settings have thus far been half-hearted and insufficient. Unless and until more aggressive, systematic, and well-funded efforts to promote voluntary testing are made, we cannot know if acceptable levels of HIV detection can be achieved while the patient's freedom to choose is upheld.

Specifically, 2 overlapping problems must be addressed. First, the decision to test for HIV in this population needs to follow a different logic. The diagnostic approach characteristic of clinical medicine needs to be replaced by the logic of screening tests associated with public health. Rather than

aiming to determine whether a suspected illness is present or not, testing should be motivated to identify as many cases as possible, even when fewer positive results are expected.⁵⁷ Second, clinicians tend to overvalue their own judgment of who is and is not at risk. Asch and colleagues found that clinicians treating tuberculosis patients tended to perform HIV testing only for patients they perceived to be at risk.94 We believe that, as among tuberculosis patients, HIV is too prevalent among those with serious mental illness for testing to be instigated by a process as fallible as clinicians' opinions on a case-by-case basis. Moreover, when testing proceeds in this way, infection rates cannot be properly interpreted, since they are confounded by unknown selection factors.

We therefore propose that more strenuous promotion of voluntary HIV testing programs such as those proposed by the American Psychiatric Association⁹⁵ should be pursued by state mental health authorities and hospital associations for all psychiatric admissions and seriously mentally ill individuals seeking or currently receiving outpatient services. We know that many people with serious mental illness currently accept voluntary testing when it is offered to them. 96,97 Various protocols should be specified that rely on existing behavioral methods such as motivational interviewing, 98 which can reasonably be expected to yield higher levels of voluntary testing. Researchers can examine the effectiveness by comparing cases identified by these protocols with anonymous studies of discarded blood samples at the same site. Results could help determine which procedures produce the fewest missed cases over time.

Advocates and civil libertarians may question whether consent can be altogether voluntary in psychiatric settings. Inpatients in particular are subjected to a level of surveillance and enforced dependency that usually makes it hard to resist pressure from caregivers, however delicately applied. Nevertheless, we believe that, so long as risks and benefits are understood by patients, confidentiality is protected, counseling is provided, and infected patients are guaranteed high-quality HIV treatment, aggressive promotion of voluntary testing is not only ethically acceptable, it is ethically imperative. Certainly, a failure to detect one half to two thirds of cases among inpatients is unacceptable and justifies concern for the health of the public. Moreover, on its face, inadequate detection is inconsistent with the ethical obligation of health care professionals to promote the physical well-being of their patients.

Discussions of mandatory testing are prone to polarization and the adoption of fixed positions. Nevertheless, we believe that people who want to stress one or another of the various values at stake can agree that accurate information on the effectiveness of voluntary protocols is necessary for any discussion of policy. The absence of such data leaves citizens with mental illness largely unprotected from policy initiatives driven by tomorrow's tabloid headlines, and leaves the public all too ready to curtail patients' rights with little concern that the sacrifices of these vulnerable citizens yield proportional benefit.

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J. Walkup, J. Satriano, P. Sadler, and F. Cournos contributed to instrument design and data interpretation. J. Walkup, J. Satriano, D. Barry, and F. Cournos contributed to the writing and editing of the manuscript.

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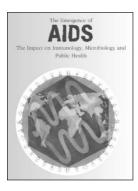
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