

*Virtual Mentor*  
American Medical Association Journal of Ethics

December 2009, Volume 11, Number 12: 927-1019.  
HIV Care and Ethics

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# Virtual Mentor

American Medical Association Journal of Ethics  
December 2009, Volume 11, Number 12: 930-932.

## FROM THE EDITOR

### Exceptionalism and Inclusion in the Modern HIV Era

Looking through the archives of *Virtual Mentor*, one finds issues devoted to particular medical specialties, ethical principles, and particular patient populations. One doesn't find an entire issue devoted to one disease—yet this month's issue on HIV care and ethics does exactly that. So what makes HIV unique? Since it was first described in *Morbidity and Mortality Weekly Report* in 1981, HIV has been treated differently from other infectious agents. This paradigm shift, known as “HIV exceptionalism,” brought to the fore many medical ethics concerns. HIV is credited with bringing about an evolution in the patient-doctor relationship. In the face of a disease with no viable treatment options, patient autonomy became the core of the decision-making process. Informed consent took on an entirely new dimension with the introduction of a separate consent process above and beyond the consent implied by seeking medical care. In many ways patients' rights became as fundamental to the management of HIV as antiretrovirals and opportunistic infections.

But HIV also highlights the tension between preserving patient confidentiality and protecting the health of the public and raised new questions about disclosure of a devastating diagnosis. Thirty years into the epidemic, with antiretroviral therapy allowing HIV-positive patients to lead relatively normal lives, better prophylaxis rendering opportunistic infections increasingly rare, and the disease becoming a chronic condition rather than a death sentence, the question becomes, “Is exceptionalism relevant?”

Patients do not suffer from HIV in the same way that they do diabetes or heart failure. In the 1980s, a diagnosis of HIV was a significant source of stigma and discrimination. At the start of the epidemic, fear and lack of knowledge led many to shun those with a diagnosis of HIV, a divisive attitude to which the medical community was not immune. Stigma and discrimination toward those in high-risk groups hampered efforts to slow the spread of the virus, for example by limiting open discussion of the modes of HIV transmission. As Randy Shilts writes in the prologue of *And the Band Played On*, “There was no excuse, in this country and in this time for the spread of a deadly new epidemic.” A lack of action on several fronts remains an unfortunate legacy of the early days of the virus.

Even today, HIV remains primarily a disease of marginalized populations. Sex workers, men who have sex with men, intravenous drug users, and specific ethnic minorities are all considered to be high-risk groups for infection. Many of the risk factors for HIV force us to think outside our comfort zone. As a physician, I feel perfectly comfortable discussing patients' bladder and bowel habits, but pause at

asking them about their sexual habits. Similarly, patients openly discuss all sorts of aspects of their daily lives, but frequently bristle at questions about intravenous drug use. Patients with HIV traditionally come from populations that can be challenging to work with, such as those who suffer from comorbid psychiatric diagnoses or substance abuse. HIV is also prominent in communities that shun traditional venues for health care for fear of judgment or whose members cannot access affordable care until their condition is beyond salvage.

Despite growing acceptance of people living with HIV, evidence of exceptionalism can still be found in clinical practice, most notably in the separate consent process for HIV testing. Unlike the testing procedure for other infectious diseases transmitted in a similar fashion, a physician in most parts of the country must acquire signed consent to test for HIV and provide separate pretest and post-test counseling. In 2006, the CDC recommended that an opt-out policy be adopted, through which HIV testing would become part of routine care. Patients would be informed they were to be tested and could then “opt-out” if they did not want to know their HIV status. Many state laws have not caught up and still require the separate consenting process, and the question has been raised as to whether measures originally put in place to protect patients can in some instances impede their care.

On the macro scale there are discernable traces of exceptionalism as well. The U.S. HIV travel ban, a policy put in place during the early days of the epidemic, made traveling to the United States virtually impossible for people who were HIV-positive. We are seeing signs of change, however, as the Obama administration in October 2009 lifted the ban, allowing people with HIV to obtain visitor permits to the United States. While it is shocking to realize that it took 20 years for this change to come about, it does represent a step in the right direction.

Finally, it seems that, in this day and age, HIV is primarily associated with Africa. As you read through this issue, you might wonder why it addresses the HIV epidemic in America, when HIV ravages the African continent to an extent unseen in this country. The answer is that 5 percent disease prevalence—the prevalence of HIV in the District of Columbia—is unacceptable. Moreover, while the ethical issues of clinical trials and equitable distribution of resources in developing countries are of utmost concern, a separate set of dilemmas attach to the U.S. epidemic that this issue aims to explore.

The past 30 years have seen tremendous scientific strides in the face of this disease. In a remarkably short period of time researchers have been able to identify the disease’s causative agent and develop numerous effective pharmaceutical agents to combat it. The future, too, looks promising, with ongoing research into prevention and the hope of an effective vaccine. But we cannot stop there. Autonomy and confidentiality have always been pillars of HIV care, and patients’ rights should remain at the forefront of the medical decision-making process. We cannot allow fear and intolerance to guide our treatment of patients with this illness or our policies toward it. Somewhere during the course of the epidemic the line between fear of the

illness and fear of those living with the illness seems to have blurred. Thirty years into the epidemic, is it really the disease that sets people apart, or our own attitudes toward it?

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## Virtual Mentor

American Medical Association Journal of Ethics  
December 2009, Volume 11, Number 12: 933-937.

### CLINICAL CASE

#### A Surgeon with HIV

Commentary by Jay A. Jacobson, MD

Dr. Kelly paced nervously outside her colleague's door. All during surgery, her mind had been traveling back to the employee health clinic she had visited earlier in the week. Three months prior, she had suffered a needlestick injury while operating on a young boy who was receiving a liver transplant. At first she shrugged it off. She knew the boy was HIV-positive, but she didn't think seroconversion could happen to her. Occupational health gave her post-exposure prophylaxis, and she thought she would be ok. She felt as if the walls were closing in when she was informed that she had in fact become HIV-positive.

Dr. Kelly knocked on Dr. Chin's door. She and Dr. Chin had pushed each other through med school and surgery residency, and were now faculty at an academic medical center—Dr. Kelly in pediatric transplant surgery. She trusted Dr. Chin and respected her medical opinion. Dr. Kelly entered and, after exchanging the requisite pleasantries and hospital gossip, she dove straight in.

“Do you remember that needlestick injury I had a few months ago? Well I got my HIV test results back, and I'm positive.”

“What are you going to do now?” Dr. Chin asked crisply, bedside manner not her strong suit.

“Well, I have the name of one of the ID docs here who specializes in HIV. I need to set up an appointment. I guess I will start on antiretrovirals depending on my CD4 counts.”

“No I mean about your career; you won't be able to operate anymore. Have you told the chief yet? Maybe you could be switched to full-time research faculty.”

Dr. Kelly took a deep breath; this was the very issue she had been struggling with since her diagnosis. She didn't relish the thought of being the patient, having never taken as much as a single sick day throughout her residency. But, operating was her life. She wasn't married and had no kids. Being a surgeon had been her dream since she had been a little girl.

“Well, I've been reading up on transmission of HIV during surgery,” said Dr. Kelly. “The risk is negligible with proper precautions, which we routinely use.”

“But once you tell your patients’ families, they are going to demand to be treated by a different physician,” said Dr. Chin. “No parents are going to want to expose their kid to an HIV-positive doctor.”

“Well, if the risk of transmitting the virus is so low, do I really need to tell them? It’s not as if we disclose every minor risk when we consent families, so why should I bring it up? My HIV status is none of their business.”

“But aren’t you obliged to inform your patients and their families? After all it could have dire consequences for the kids if they did contract the virus from you?”

Dr. Kelly sighed and thanked Dr. Chin for her time. She retreated to her office to ponder her next course of action.

### **Commentary**

Good ethical decisions begin with good facts. Dr. Kelly just received disturbing news with serious potential implications for her and her patients. She is understandably concerned and seeks support and advice from her trusted colleague. When Dr. Kelly shares her newly discovered HIV status, Dr. Chin responds quickly, bluntly, and unequivocally that this will mean the end of surgical practice. It seems as if she made a diagnosis and recommended a treatment without verifying or gathering any information. Fortunately, Dr. Kelly does not seem to be ill or in immediate jeopardy, so this doesn’t appear to be an emergency that requires an immediate response. Perhaps it’s worth taking some time to review the presumptions that led to what may have been a premature or even incorrect conclusion.

Dr. Kelly has a positive test result for HIV infection and she has at least one risk factor we know about, a needlestick injury from an infected patient. Such exposures, however, rarely lead to infection, with the rate being in the range of 3 per 1,000 events [1]. Also, she has no reported symptoms that would suggest active infection. In light of these facts, a second test to confirm the result would be prudent. While a false positive result would be unusual, it is possible, and could arise from a mislabeled blood specimen or misreported result.

What does Dr. Kelly now need to know and why? For herself, she needs to know whether she has HIV and, if so, the age of her infection. Are there organs or systems affected? What is the status of her immune system? How can she expect this infection to affect her? What are the indications for and the benefits and risks of treatment? In this way, she is no different than others with newly diagnosed HIV infection. But she is different in a significant way. She is a physician, and her profession and role impose a set of duties and obligations. These raise additional questions and concerns. She has accepted the obligation to do no avoidable harm, be as skilled and knowledgeable as she can be, recommend and do what is best for her patients, and be honest with them. Besides these “duties of station” she also has assumed the responsibility and challenge of providing the facts that her patients need in order to give voluntary informed consent for her to perform surgery on them.



With respect to her probable and newly recognized HIV infection, this means Dr. Kelly needs to know if it will impair her ability to perform her tasks safely and competently and whether it will pose any significant risk to her patients now or in the future. If she is or becomes impaired, she should remedy or resolve the impairment. This could mean corrective lenses for decreased vision or drug treatment for infections that compromise other functions. If that's not possible, she may need to limit or change the kind of surgery she performs. Even if she is unimpaired and asymptomatic, she should be aware of the risk she may pose of transmitting HIV infection to a patient. This will depend both on the status of her infection, e.g., viral load and the likelihood that she will sustain an injury that results in a patient's exposure to her blood. For significant identified risks, she should eliminate or minimize the risk. This could involve measures like antiretroviral therapy that control infection. It could also mean taking actions to reduce the likelihood of transmission such as using gloves or avoiding high-risk procedures that increase the chance of injury.

Now let's examine Dr. Chin's reflex conclusion that Dr. Kelly will need to abandon the surgery she loves. There was an alternative presumption that, if she continued, she would have to disclose her HIV infection status. The latter came with a corollary that when patients' parents learned her status they would decline to have her operate on their children. To get beyond presumptions and pursue an evidence-based response to her situation, Dr. Kelly should consult quickly with an infectious-disease specialist with expertise in the evaluation of HIV infections. Preferably he or she should also be associated with the hospital's infection-control program.

While the authenticity and relevant details of Dr. Kelly's infection remain to be determined, some general observations can be made. Although transmission of HIV from surgeon to patient is possible, it is, in fact, extremely rare. The CDC has estimated that the average risk of sporadic HIV transmission from an HIV-infected surgeon to a patient during an invasive procedure was 2.4 to 24 episodes of transmission per 1 million procedures [2, 3]. The physician's viral load with or without treatment is a reasonable surrogate for potential infectivity, and is measured well by laboratory tests. The likelihood of actually transmitting an infection relates to the risk of an injury that causes bleeding from the surgeon's hand during an operation. This is best assessed by experienced surgeons and a review of the infection-control literature. As a rough guide, one would anticipate more such injuries in the course of orthopedic procedures with exposure to sharp bone fragments than in general surgery limited to abdominal organs or soft tissues.

Pending laboratory tests, it seems reasonable to conclude that, without treatment or after effective treatment, Dr. Kelly's viral load will be low. If colleagues and the infection-control committee believe her surgery practice does not entail high risk, then, if she is otherwise unimpaired, she should be able to resume surgery [4, 5].

Whether Dr. Kelly should disclose her HIV status to her patients is the remaining ethical question. Because of the severity, fear, and uncertainty about transmission and the social stigma associated with the debut of the AIDS/HIV epidemic, we treated this syndrome as exceptional and implemented different approaches to testing, confidentiality, counseling, and infection control. Abundant evidence has accumulated about infectivity, transmission, and the efficacy of treatment and infection-control methods on these factors. It is time to incorporate that evidence into our ethical reasoning.

The risk of HIV acquisition from an infected surgeon appears much lower than the risk of nosocomial bacterial infections, even those with lethal potential. These rates vary by surgeon and institution. It is not the practice, at least not yet, for surgeons to disclose their personal complication or postoperative infection rate to prospective patients. Similarly, most surgeons don't spontaneously disclose the number of similar cases they do annually, another factor associated with complication rates. Given this practice, it seems inappropriate to require disclosure of a lower-risk condition. That may change, of course, as risk-adjusted institutional and even surgeon-specific data become publicly available. Until then, however, disclosure of HIV status seems inappropriate. It may arouse anxiety unnecessarily and have no practical effect on risk reduction [5]. It may be that some patients would be more fearful of a low risk of perioperative HIV infection than of a serious adverse drug reaction, postoperative hemorrhage, or sepsis, but that is not a strong argument for routine disclosure. It is a reason, though, to answer a direct question truthfully. While there may be an understandable reluctance to answer a patient's pointed question about his or her surgeon's HIV status, medical ethics and respect for persons demand an honest answer, just as they would to a question about training, experience, or complication rates.

This case invites us to think, in a patient-centered and generic way, about the risks, real and potential, that surgeons pose to patients and how they should be managed. Known serious risks should absolutely be avoided. Examples include surgeons with highly communicable infectious diseases such as influenza, varicella, and hepatitis B. Abstaining from surgery during such clinical infection is appropriate. Primary prevention via immunization is an even better, more ethically appropriate, and efficient strategy. If the risk is real, but much lower and not reducible by actions available to the surgeon, disclosure may be an appropriate strategy. Examples here would be surgeon or hospital-specific infection rates.

Reasonable and truly informed consent remains a challenge, both as a process and as an outcome. If Dr. Kelly clearly explains to her patients the medical indications, expected outcomes, reasonably anticipated risks and adverse events, benefits, and alternatives, she will be doing an ethically competent job and probably a better one than most of her colleagues.

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**Related in VM**

[Hospital Reputation and Individual Patient Decisions](#), March 2007

[Managing the Care of Patients with HIV Infection](#), December 2009

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# Virtual Mentor

American Medical Association Journal of Ethics  
December 2009, Volume 11, Number 12: 938-943.

## CLINICAL CASE

### Informing Adolescents of Perinatally Contracted HIV

Commentary by Hans M.L. Spiegel, MD, and Donna Futterman, MD

Dr. Patel was a pediatrics resident on his ambulatory rotation. Picking up the chart of 15-year-old Julio, he read a lengthy discussion between the previous resident, Dr. O'Neill, and Julio's mother. Dr. O'Neill reported that as she entered the patient's room, Julio's mother had pulled him aside to inform him that Julio and she were HIV-positive. Julio had contracted HIV at birth from her but was unaware of her status or his own. His mother had gone on to tell Dr. O'Neill that Julio had never been hospitalized and had never required antiretroviral therapy. She explained that when he was younger, he was always healthy, so she thought there was no reason for him to know that he carried the virus. She then informed Dr. O'Neill that Julio's previous pediatrician had respected her wishes not to inform him of his status and she expected this behavior to continue at this new clinic.

Dr. O'Neill reported that she had urged Julio's mother to change her mind. "You need to tell him about his HIV status. He is old enough to understand now, and I would strongly encourage you to sit down with him and have a discussion about it. The longer you wait, the harder it is going to be to tell him you have been hiding something like this from him for so long."

The mother had replied that Julio was healthy and happy and had lots of friends at school. As long as he was not ill, she felt no reason for him to think he was different from other kids or to worry about getting sick.

From the documentation, Dr. O'Neill and her supervising attending physicians strongly encouraged Julio's mother to reconsider her decision. Fearing that she would avoid medical care for her son altogether, however, they decided to respect her wishes until a relationship could be built among the patient, his mother, and the clinic members.

Dr. Patel reviewed Julio's blood work. His CD4 count was suitably high, so he would not require medications. Entering the patient's room he was relieved to see that Julio's mother was not with him on this visit. Dr. Patel encountered a healthy-appearing teenage boy who seemed more concerned about whether he should be using Proactive for his facial acne than about why he was at the doctor's office again and what his blood work had demonstrated. Dr. Patel was relieved that he would not have to deal with all this HIV business on this visit. Wrapping up, he asked Julio if there was anything else he wanted to discuss.

“Um, by the way doc, I didn’t wanna bring this up last time, because the doctor was a girl and all, but uh, you see, me and my girlfriend, we have been dating for almost a year,” Julio said. “We’ve been getting really serious, and we’ve been talking about having sex. I know that we need to use condoms and I know how to use them from that class we took in school. And my girlfriend, she was gonna talk to her doctor about getting birth control pills. We are both virgins, so I’m not worried about STDs. I was wondering if there is anything else that I should know, you know, to keep us both safe?”

Dr. Patel swallowed hard, he said he needed to speak to his attending and then he would come back and address all of Julio’s questions at once. As he left the room, Dr. Patel knew there was definitely something else Julio needed to know.

### **Commentary**

The presented case study poignantly demonstrates the ethical dilemma Dr. Patel is experiencing while providing care for his new adolescent patient, Julio. Dr. Patel is convinced that Julio has a right to know his HIV status, an assessment that is supported by that of the resident and attending who saw the patient during his first visit to the clinic. Dr. Patel initially seems to also share the other resident’s concern, that posing the demand for disclosure too forcefully to Julio’s mother during this first visit could jeopardize the continuity of care for Julio, and thus avoids a discussion of the need for disclosure. At this visit, however, Julio has shared his, and his presumably HIV-negative girlfriend’s intention to become sexually active, which does not allow further delay of disclosure to wait for the “secure environment in due course.”

Many studies on the optimal timing and psychological impact of disclosure of HIV infection to children and adolescents in a wide range of cultural and socioeconomic settings have been published. Studies from the United States and abroad suggest that children and adolescents who know they are being treated for HIV have higher self-esteem and better acceptance of medical care than youth who are being treated but are unaware of their status. Nondisclosure can result in anxiety, depression, and phobias and excludes youth from peer support groups. Further, most youth in those studies had come to terms with their diagnosis by 6 months post-disclosure. Importantly, parents who disclosed the HIV status to their children experienced less depression and considered disclosure as having an overall positive effect on themselves and their families [1-3]. Reluctance to disclose the HIV status to children and youth is often based on the caregiver’s concern for possible exposure to stigma and discrimination toward the whole family once the adolescent shares the diagnosis with partners, peers, or the public [4-6].

Caregivers identify concerns about unplanned, circumstantial disclosure, HIV transmission, disease progression, interest in a closer, more trusting relationship with the youth, and the respect for the youth’s right to know as reasons for disclosing [7, 8]. With the disclosure, youth are further given the opportunity to identify role models, voice their needs more effectively, and gain experience in disease

management by interaction with other HIV-positive peers. Despite the threat of possible stigmatization, several studies have emphasized the positive correlation between HIV diagnosis disclosure and social support [9, 10].

It is on this basis that the American Academy of Pediatrics strongly recommends the disclosure of HIV status to adolescents [11]. Parents and other guardians of a child with HIV should be repeatedly counseled about disclosure, which should be individualized to the cognitive ability, developmental stage, clinical status, and social circumstances of the child. Fears and misperceptions of HIV infection should be addressed, and disclosure of HIV infection status to school-age and symptomatic children is strongly recommended. All adolescents should know their status and be fully informed about all aspects of their health, including their sexual behavior, with physicians encouraging adolescents to involve their parents in their care.

It is apparent from the vignette that a discussion of disclosure should have been a priority during Julio's second visit. Ultimately, Julio is the patient, and adolescents have the right to confidential care from physicians, especially when sensitive subjects such as sexuality, substance use, and mental health care are involved. The physician must find a way to protect the health of Julio and his potential partner—hence, an open discussion with the mother is not the only route to addressing the urgent need for disclosure to Julio, particularly in face of his mother's continued opposition. Those who care for adolescents must advocate for their patients and support timely disclosure of HIV diagnosis, since they are aware of the negative effects of non-disclosure, which include social isolation, the lack of coping skills, anxiety, loss of trust, and depression. Disclosure has also been shown to be associated with slower disease progression, probably due to the reduction of stigma and the improvement of coping skills [12].

Since Julio has clearly voiced his intention to become sexually active, confidential HIV testing for him and his partner can be offered, and all scenarios, including behavioral and perinatal and blood-product-related acquisition of HIV can be discussed. In this situation, Dr. Patel is primarily responsible for the youth in his care and all decisions made should be in Julio's best interest. Dr. Patel should consider the wishes of the parent only in this context and attempt to have the parent agree to disclosure without sharing confidential information, such as Julio's intention of initiation of sexual activity. Dr. Patel can discuss with Julio's mother his right to have all of his questions truthfully answered. It could also be helpful to explore the parent's understanding of confidentiality in the relationship between the physician and the adolescent patient. Studies have shown that parents commonly have the false expectation that physicians who learn about potential risk behavior on the part of an adolescent will tell the adolescent's parents [13].

With teens, the discussion of non-behavioral modes of HIV transmission—perinatal and transfusion-related—should emphasize that it is responsible to pursue testing for HIV. The teen has the right to initiate this testing by himself and is entitled to receive the results in a confidential manner, even without the parent, if he chooses to do so.

Regardless of whether or not Julio and his partner choose to get HIV tests, he should be provided with safer-sex information and encouraged to use a condom.

Parents often underestimate the youth's ability to handle the disclosed information and may be overly concerned about possible psychological harm to their child or their child's adversarial reaction toward them. The possible feelings of guilt in the setting of perinatal HIV infection can be addressed with the mother, possibly with support from a consumer advocate or counselor. A study reported in 2008 that women are interested in taking a leading role in the disclosure of perinatally acquired HIV infection to children and youth ages 5 to 18 years [14]. The possible parental concern that disclosure could interfere with Julio's quality of life could have been discussed with reference to results from a study among children and adolescents with perinatally acquired HIV infection, which showed no statistically significant differences between pre-disclosure and post-disclosure quality of life [15].

Some reports have suggested that diagnostic disclosure may not minimize emotional distress, indicating the need for further evaluation of the appropriate timing and type of disclosure for pediatric patients living with HIV infection [16]. The association of perceived HIV-related stigma with the decision to disclose the HIV status to children and youth 5 to 18 years had been studied by other investigators, using questionnaires and guided interviews for HIV-infected women who had been recruited from AIDS service organizations located in large Midwestern cities. In this cohort, the total score for perceived stigma among mothers who disclosed did not differ from the total score for those who did not [17].

An open discussion of the evidence stated above may be entirely sufficient to convince Julio's mother that disclosure as soon as possible is the most appropriate way to move forward. The option of disclosure with the physician or a consumer advocate taking the lead should also be offered. Since many HIV-positive youth perceive their health problem, even though it is an unspoken family secret, asking Julio about his understanding of the medical condition would be a legitimate approach under the circumstances and should be pursued with every adolescent age 16 and above, even against the parental wishes. Likewise, exploring the parental perception of the adolescent's existing understanding may keep the parent engaged and could well lead to the agreement to ask Julio directly about what he knows and thinks about his medical condition.

The overdue disclosure should be viewed as the first step in the process of diagnosis acceptance. Ideally this should have been a gradual, process-oriented introduction to living with HIV infection, based on his individual family culture, family dynamics, and established physician relationship, but not on the short timeline presented in the vignette. A validated instrument used by health care professionals to support parental HIV disclosure is the parent disclosure interview (PDI). The core components of this structured interview are questions about disclosure, reasons for non-disclosure and plans for the child's future, which can help to reveal the parents' history and attitudes toward disclosure [18]. As observations from the Swiss Mother and Child Cohort

Study among perinatally infected adolescents show, discussion of disclosing the adolescent's HIV status to sexual partners and friends can lead to ongoing conflict between the adolescent and the parent who fears that her own HIV status will become known or that the disclosure will have repercussions for the family [19]. Not disclosing one's HIV infection, however, can be viewed by the teen as burden and can lead to further stigmatization. After having learned about their HIV status, adolescents may themselves not disclose to partners and friends out of concern for rejection, but also out of a sense of loyalty to their families. Dr. Patel should be prepared to continue his dialogue with Julio and, if he wishes, his mother.

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### **Related in VM**

[Withholding Information from an Adolescent](#), August 2008

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## Virtual Mentor

American Medical Association Journal of Ethics  
December 2009, Volume 11, Number 12: 944-948.

### CLINICAL CASE

#### The Challenges of Treating Patients with Multiple Diagnoses

Commentary by R. Douglas Bruce, MD, MA, MSc

Mr. Muzzio has a history of co-existing schizophrenia and heroin use. Prior to his visit at the HIV clinic, Dr. Donaldson reviewed Mr. Muzzio's discharge summary from the hospital, which described his last admission to the psychiatric inpatient ward. On admission, Mr. Muzzio had been profoundly delusional, thinking that music artists were trying to send him messages through the songs he heard on the radio. At one point during the admission, a physician suggested that Mr. Muzzio's mental status change was due to progression of HIV rather than to his underlying psychiatric diagnosis. A CD4 count and viral load were ordered, which came back low and high, respectively. Dr. Donaldson went to see his patient, and, after the usual questions about his current status and psychiatric follow-up, he inquired about Mr. Muzzio's use of antiretrovirals.

"So what medicines are you currently taking for your HIV, Mr. Muzzio?"

"I'm on Combivir and Reyataz, doc, just like you gave me last time I was here," said Mr Muzzio.

"And do you take your medicines regularly?"

"Well you see, I haven't really been taking my pills at home so much," said Mr. Muzzio. "I'm in the hospital a lot, and well, I miss a lot of my medicines when I'm sick."

"What do you mean by that Mr. Muzzio?" asked Dr. Donaldson.

"So it goes down like this, I'm doing well for a while, not using and taking my medicines, but then I screw up and I start using again, and then I hear the voices and they tell me not to take my medicines, that they're poisoned. So I stop all my pills. It's not like I don't want to take my medicines. I do. You know me, my medicine is real important to me."

"So what happened this time?" asked Dr. Donaldson. "When they checked your labs in the hospital, they were really off from where they had been."

"I know, Dr. D. That was bad. It's been a long time since I was here and I hadn't been taking my meds, I messed up. But I promise that was the last time. See this all started when my buddy got shot and I found out my girlfriend was cheating, and all

this bad stuff kept happening, and it got me down and made me start using again. They got me in rehab now, and you know when I'm clean I show up to all my appointments.”

Dr. Donaldson had been down this road before with Mr. Muzzio. His patient meant well and genuinely tried to comply when he was under psychiatric treatment. Dr. Donaldson also knew that Mr. Muzzio was a byproduct of a system that kept letting him slip through the cracks. He had tried to get Mr. Muzzio into a methadone maintenance program for years, but his patient kept being rejected due to a previous failure in a different program. He had referred him to city hospital's special program for the treatment of comorbid psychiatric illness and drug abuse, but the program had been eliminated due to hospital budget cuts. Mr. Muzzio had also required regimen changes due to resistance, probably secondary to his noncompliance. Dr. Donaldson was frustrated with the whole situation. He wanted to do what was best for his patient, but he also felt he could not keep treating him in the face of blatant noncompliance.

### **Commentary**

Dr. Donaldson is frustrated because he wants to do the best for his patient but does not know what “best” means in this situation. Is it best to give Mr. Muzzio the HIV therapy he wants? Is it ethical to provide a treatment, knowing from past experiences and the awareness of the patient's comorbidities that adherence to the treatment is difficult and that he might fail? In other medical conditions such as diabetes, there is less at stake because diabetes does not evolve with drug pressure the way that HIV can. In the former case, nonadherence means a lack of health benefit. But nonadherence to HIV treatment raises the serious possibility that the patient's HIV will develop resistance to the therapy.

Mr. Muzzio's pattern of developing resistance poses two problems. First, it limits his future treatment options and may mean that the only medications that work for him require more pills, taken more frequently, with more side effects. Any one of those outcomes would most likely result in further nonadherence. Second, if Mr. Muzzio continues to use heroin and shares his injection equipment with others, he could transmit the resistant virus to others. Dr. Donaldson is right to be frustrated, inasmuch as Mr. Muzzio's “triple diagnosis” of HIV, schizophrenia, and opioid dependence represents a complex interplay of chronic conditions that are all difficult to treat on their own and even more challenging when intermingled.

If the patient wants therapy, and therapy is medically indicated given the stage of the disease, then why is there a question of withholding therapy? After all, Dr. Donaldson has a positive duty to do good. But the action that appears, on the face of it, to do good, i.e., prescribing therapy, could—in the event of Mr. Muzzio's nonadherence and development of resistance—result in a greater harm. The most frustrating point is that the “goodness” or “correctness” of the present decision relies upon the correct prediction of the future outcome. If we knew that Mr. Muzzio would be adherent, we would be wrong to refuse therapy. If we knew that Mr.

Muzzio would be nonadherent, develop resistance, and infect someone with a resistant virus, then we would be wrong to prescribe. This utilitarian view may not be endorsed by all physicians, but it is certainly the way many physicians contemplate how to act in these situations.

Knowing that the patient needs the HIV therapy and realizing what is standing in the way of adherence to that therapy, Dr. Donaldson must resolve the problem. Mr. Muzzio is currently unable to fix his situation alone. He is a victim both of his disease and of a dysfunctional system.

Dr. Donaldson's job is tough because ethically he cannot allow Mr. Muzzio to go out into the world with HIV/AIDS without treatment. Denying HIV care is effectively "randomizing" Mr. Muzzio to the "placebo" arm of a clinical trial without Mr. Muzzio's consent and with a known outcome of increased morbidity and mortality. The patient needs treatment, and Dr. Donaldson must help him find some way to be adequately adherent to the regimen of choice. Dr. Donaldson has several treatment decisions to make related to his patient's three diagnoses, and all of them will stretch him ethically and professionally. First, let us examine the decisions related to addiction.

Mr. Muzzio has been rejected by the methadone program for a prior "failure" in another program. How can this be, given that HIV-infected heroin users should actually have a priority in admission to methadone maintenance? If a methadone program is truly refusing to admit Mr. Muzzio because of a prior failure, that program must be re-educated on the criteria for admission to methadone. Prior failures in treatment are a strong indication of needed treatment and not a justification for refusing to treat. Dr. Donaldson needs to take 10 minutes to read the federal regulations regarding methadone maintenance or obtain a free copy of TIP 43 from the Substance Abuse & Mental Health Administration that explains the rules and regulations surrounding methadone [1]. Once Dr. Donaldson is informed, he can advocate for Mr. Muzzio effectively.

Another option that Dr. Donaldson could pursue is office-based treatment for opioid dependence using buprenorphine. Dr. Donaldson would have to undergo the appropriate 8-hour training and apply for the "X waiver" to be allowed to prescribe buprenorphine [2]. The major difference between buprenorphine and methadone that can affect Mr. Muzzio's outcome is that methadone treatment has a better patient-retention record than buprenorphine. Given Mr. Muzzio's underlying psychiatric condition, he might adhere to methadone treatment better than he would buprenorphine. Opioid agonist therapy is a powerful enhancer of adherence to treatment. Mr. Muzzio's HIV and psychiatric medications, for example, could be provided with the methadone to improve adherence.

Second, Mr. Muzzio's schizophrenia is contributing to his nonadherence. A working relationship between Dr. Donaldson and Mr. Muzzio's treating psychiatrist is vital in coordinating care for this complex patient. A prior working relationship would go a

long way toward facilitating improvements in adherence to all therapies. For example, Dr. Donaldson might prescribe a once-daily HIV regimen to improve adherence. If the psychiatrist is prescribing antipsychotics twice daily, but Mr. Muzzio is only taking half his doses because adherence support is only provided in the morning, then Mr. Muzzio will fail to take his psychiatric medications, which will result in overall treatment failure. Although Dr. Donaldson is not a psychiatrist, he has an ethical and professional obligation to coordinate care with the treating psychiatrist and to advocate for the patient. Long-acting, injectable antipsychotics—depot formulations—improve adherence and patient-related outcomes. In some communities an Assertive Community Treatment (ACT) team—effectively the SWAT team of the mental health world—is available to help patients with mental illness remain in treatment and take their medications [3].

Third, the HIV therapy Dr. Donaldson selects may be a barrier to adherence for Mr. Muzzio. The more pills and the more often one has to take something, the less likely one is to take everything all the time. Although the best HIV regimen may be four pills taken twice daily, for example, it may be better to prescribe an inferior regimen with a lower pill burden than the patient actually takes. This is balancing the duty to do good with the duty to minimize harm.

The key to adherence is to mold the HIV therapy to the patient's lifestyle. Patients rarely make lifestyle changes (otherwise obesity would be eliminated from the world), so physicians must take the time to select the regimen that is best for the specific patient. This might mean compromising. If the patient refuses to take all the medications prescribed, should the physician refuse to prescribe anything? Of course not. The physician has the education to help the patient navigate all the choices. So, if the patient says, "Doc, I can't take 10 pills," the physician could respond with, "Well, you have to do it." Or he could ask, "How many do you think you can take, and I'll help you figure out the most important ones to take." This second response is going to be more helpful to the patient. The patient's answer may mean that Dr. Donaldson *should* prescribe an inferior regimen, one that the patient will take. There are HIV regimens that can withstand some nonadherence. It is evident in this case that HIV therapy is the least important medicine to any patient with Mr. Muzzio's triple diagnosis; therefore, it is key that adherence to HIV therapy not be the anchor, but rather the HIV therapy be anchored to adherence to a regimen that is more important to the patient, such as his methadone.

Mr. Muzzio represents our failure to care for those with co-occurring disorders. Health care remains fractionated so that patients are asked to go one place for mental health care, another place for methadone, and yet a third place for HIV care. Patients like Mr. Muzzio need a truly integrated health clinic that can provide excellent care for mental health, addiction, and primary medical needs. Despite this logical conclusion, few such clinics exist. The ethical and professional physician seeking to meet the health care needs of patients with triple diagnoses must be prepared to tackle an immense problem. To refuse HIV treatment to the patient with mental illness and addiction until that patient is more stable is to misunderstand the problem.

Such patients are continually struggling in one area or another, and the physician cannot be a passive observer waiting for the patient to do all the work. The active participation of the physician is necessary to improve the health outcomes of the patient. That is the ethical and professional course of action.

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### Related in VM

[Managing the Care of Patients with HIV Infection](#), December 2009

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## Virtual Mentor

American Medical Association Journal of Ethics  
December 2009, Volume 11, Number 12: 949-952.

### MEDICAL EDUCATION

#### How “Universal” Are Universal Precautions?

Shilpa B. Rao, MD

It has long been established that health care workers (HCWs) are at high risk for occupational exposure to bloodborne pathogens. Historically, the predominant concern was the hepatitis B virus. But since the emergence of HIV in the early 1980s and the first documented case of needlestick transmitted HIV infection to a HCW in 1984, the concern for risk reduction has skyrocketed as a priority [1]. In reality, the actual risk of seroconversion after a single percutaneous needlestick is relatively low—approximately 0.32 percent. The risk of infection after a mucocutaneous exposure is even lower—approximately 0.09 percent [2]. In practicality, however, the precise risk of infection per exposure depends on many factors; it is related to the overall prevalence of HIV in the patient population served and the frequency of exposure to infected blood, along with the method of exposure [2]. Regardless of the complexity involved in quantifying risk of HIV infection with each exposure, an alarming number of needlestick injuries are reported to authorities by HCWs each year, so the cumulative risk of seroconversion is clearly *not* insignificant.

Prompted by growing concern for protection of HCWs, the Centers for Disease Control and Prevention (CDC) designed guidelines, termed Universal Precautions (UP), in 1987 to decrease occupational exposure to bloodborne pathogens. These guidelines encouraged HCWs to use gloves, protective eyewear, and aprons when in contact with patients *visibly* contaminated by blood. A year later, UP became mandatory with the passage of the Occupational Safety and Health Administration (OSHA) Bloodborne Pathogens Standard. These standards required employers to establish an exposure-control plan and offer training in UP to all workers at risk [3]. In 1995, the CDC updated its UP guidelines to include standard precautions (SPs), which recommend that HCWs use barrier protection for *all* patients to reduce the risk of acquiring infection from both identified and unexpected sources [1, 4, 5].

Despite this concerted national effort to implement guidelines for risk reduction, numbers of reported occupational exposures to bloodborne pathogens remain unacceptably high. As stated by Ganguly, et al., “Guidelines...are only as effective as the number of healthcare workers who adhere to them” [6]. HCWs, specifically physicians, have been shown to practice selective rather than universal precautions, which creates unnecessary risks to themselves and patients [4]. This noncompliance is, in part, manifested by continued alarming numbers of occupational exposures each year [1]. Clearly, acceptance and implementation of UP by HCWs are not as “universal” as the CDC intended for them to be.

Physicians-in-training are at a particularly high risk for occupational exposures to bloodborne pathogens. Most published data on this subgroup of HCWs come from self-administered surveys of medical students and residents and consistently suggest that this group is indeed at high risk, possibly even at *higher* risk for needlestick injury than other HCWs. And residents have been found to be at an even higher risk than medical students [7]. Alarming, between 25 percent and 75 percent of trainees report at least one work-related blood or body fluid exposure *per year* [8, 9]. In one study, medical students surveyed before and after clinical training reported *decreasing* interest in performing recommended UP practices to protect themselves [8]. Specific activities associated with the majority of occupational exposures in this group are administering injections, drawing blood, recapping and disposing of needles, handling trash and dirty linen, and attempting to transfer blood or other body fluids from a syringe to a specimen container [10]. Lack of experience with these procedures and with direct patient care may put physicians-in-training at increased risk for injury [9]. Moreover, trainees, like other HCWs, are under considerable stress and time constraints which also tend to create a climate of poor safety behavior [1].

There are myriad reasons why medical students and residents have suboptimal adherence to UP, and it is important to investigate the formal training in occupational-exposure risk reduction offered to this group. As previously mentioned, OSHA has mandated that all HCWs at risk for exposure to blood and body fluids undergo annual instruction in UP. Medical students, however, are not officially considered employees of the hospital in which they train and thus are not covered by these regulations [8]. This suggests that the responsibility for structured education of trainees should fall on medical schools, but there is little published information on optimal training methods or the effectiveness of training in increasing students' knowledge of and adherence with UP.

High percentages (approaching 100 percent in one study) of medical students and residents report receiving prior training in UP and do not feel that lack of knowledge contributed to their suboptimal adherence [9]. One study at a Midwestern university, however, found that less than one-third of residents who responded knew the risk of contracting hepatitis B after percutaneous exposure, even though 40 percent of those same residents reported having had a needlestick injury during that clinical year [8]. In another study, only about one-half of students correctly identified the proper protective equipment needed for specific clinical procedures. These and other data suggest that the current formal training in UP may not correlate with better use of UP or reduced risk of occupational exposure [10].

An additionally unsettling finding is that many, if not most, needlestick injuries to medical students and residents go unreported. Surveillance studies show that only about 15 percent to 40 percent of incidents in this group are officially documented [7, 10]. Effective prophylaxis after exposure for both hepatitis B and HIV does exist, but, appropriate medical treatment cannot be offered if injuries go unreported. The practice of underreporting also undermines the validity of surveillance data,



including incidence of exposure, the circumstances surrounding their occurrence, the HIV and hepatitis status of source patients, and, thus, the actual risk of seroconversion posed to residents and medical students [7]. The scope of the problem may be far greater than we are currently able to appreciate.

While exposure to serious and potentially fatal bloodborne infections is an inherent occupational risk in the medical profession, that risk *can* be reduced. With a striking three-quarters of medical students and residents reporting work-related exposure each year, additional efforts are essential [8]. The optimal algorithm for risk reduction, however, has not been outlined and is likely multifaceted, including education, workload modification, adequate role models, and periodic feedback. First, it is essential for medical school administrators to implement structured educational and clinical programs for risk reduction. Details of personal risk and specifics regarding UP procedures must be introduced during the preclinical years and constantly reinforced by peers and superiors during each clinical rotation. Second, efforts should be undertaken to design a strategy that incorporates both education and systems changes to ensure a sustained appreciation of and adherence to UP [4]. Lastly, students and residents should be informed of the hospital's policies for reporting incidents and encouraged to report promptly all occupational exposures and receive proper follow-up care [10]. With early and continually reinforced training in risk reduction strategies, medical students and residents can develop behaviors that they will carry with them safely through their careers [9].

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**Related in VM**

[Universal Precautions](#), October 2005

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# Virtual Mentor

American Medical Association Journal of Ethics  
December 2009, Volume 11, Number 12: 953-957.

## MEDICAL EDUCATION

### HIV/AIDS Ethics Education

Divya Ahuja, MD, Sabra Smith, MS, RN, and Charles S. Bryan, MD

The University of South Carolina School of Medicine (USCSOM) opened in 1977 and graduated its charter class in May 1981, just weeks before what we now call HIV/AIDS came to public attention [1]. Issues related to the ethics of HIV/AIDS—for example, physicians' obligations to assume risk of exposure to the virus and patients' rights to know whether their providers were seropositive—engendered heated controversy at the USCSOM as they did elsewhere.

An article in 1989 documented the paucity of courses focusing on HIV/AIDS in medical schools at that time [2]. While other universities were trying to figure out the role of HIV/AIDS in their curricula, the University of California-San Francisco (UCSF), this article reported, offered an informal lecture on safe sex to first-year medical students on their first day of orientation, and subsequently discussed various aspects of AIDS in several courses over the next 2 years [2]. Even at the UCSF, however, it was believed that a separate course on the ethics of HIV was unnecessary due to the omnipresent nature of ethics throughout medical education. Our formal medical ethics curriculum at the USCSOM has integrated HIV/AIDS into other topics (for example, professionalism, confidentiality, truth telling, and informed consent) as opposed to treating the viral disease as a unique entity.

### The Early Years (1981 to 1995) and a Profile in Courage

A series of editorials by Charles S. Bryan in the *Journal of the South Carolina Medical Association* chronicles many of the topics that came to the forefront and were widely discussed at the USCSOM and elsewhere during years before the introduction of highly active antiretroviral therapy (HAART) [3-9]. USCSOM students were sensitized to the ethical issues in a positive way by the heroic example of one of their own: Sue Piggott Kuhlen (1956 to 1993) [10].

In the spring of 1988, Kuhlen, a registered nurse, was working in the emergency room of one of the major teaching hospitals affiliated with USCSOM. She had been accepted into the school of medicine and was the recipient of a scholarship from the county medical society. While drawing blood from a patient with HIV, she suffered an accidental needlestick injury. Despite postexposure prophylaxis with zidovudine (ZVD; known then as AZT) she quickly seroconverted to HIV status. She started therapeutic doses of zidovudine and, upon beginning medical school that fall, informed the chair of the Department of Anatomy of her HIV status. Several faculty members called for her withdrawal from medical school. The entire student body was highly supportive of Kuhlen, as were other faculty members. A meeting was

called with university President James B. Holderman during which it was determined that Kahlenbecker be allowed to continue medical school. She completed medical school and 6 months of residency training, becoming a model of the caring physician despite the relentless progression of her disease. Planning her own funeral, she told the minister: “Don’t make it sad.” Today, the medical student lounge in the hospital where she acquired HIV disease is named for her.

### **The Middle Years (1996 to 2003): Reflection and Analysis**

The introduction of HAART to treat HIV in 1996 was a watershed occasion at many levels of HIV care. Even though the causative agent and transmission avenues had been identified, the lack of successful treatment contributed to fear and stigmatization of the disease through the 1980s to the mid-1990s [11]. At a keynote address at a symposium on HIV/AIDS and bioethics, Bryan made the following observations [12, 13]:

- HIV/AIDS struck society during the coming-of-age of molecular biology and bioethics, and the epidemic stimulated the growth of both disciplines.
- The number of articles published about AIDS and ethics (as identified by a MEDLINE search) peaked in 1990, just before the incidence of HIV/AIDS peaked in the United States. Thereafter, the number of articles rapidly declined, so that, beginning in 1995, fewer than 10 articles were published each year on ethics and AIDS.
- Articles written about HIV/AIDS and ethics prior to the early 1990s focused on familiar moral quandaries such as civil liberty (including individual privacy and autonomy) versus public welfare. Those published after 1995 focused on a different set of issues, such as the ethics of vaccine trials and public policy toward the developing world.
- The introduction of HAART made the care of patients with HIV/AIDS a highly technical process in which the disease could be diagnosed, staged, and treated using the latest tools of molecular biology. Patients needed technical expertise more than they needed caring and compassion. Put differently, no amount of caring could compensate for want of technical competence when adequate technology became available.
- Reflecting on the impact of HAART on medical practice, Bryan proposed that “medical professionalism” should not be construed as a monolithic entity but rather as a tiered construct. A distinction was made, and subsequently amplified, between basic professionalism and higher professionalism [14-17]. Basic professionalism can be defined as “doing the right thing well” using discipline-specific competence. When the patient’s medical condition is well-defined and when there is available technology to deal with it, basic professionalism suffices. Higher professionalism can be defined as a service that clearly transcends self-interest. It involves compassion in the strict sense of suffering with—compromising one’s own social, emotional, financial, or even physical well-being to care for the less fortunate. Higher professionalism is called for when the patient’s medical condition is poorly defined or when treatment is unavailable.

When a formal curriculum in clinical ethics was introduced at the USCSOM, HIV/AIDS was integrated into other topics such as truth-telling, confidentiality, end-of-life issues, and informed consent, as had been done in the preclinical curriculum.

### **Recent Years (2003 to 2009): A Vertical Curriculum**

Disclosure of a patient's HIV status is a familiar ethical dilemma. It can arise when a physician is aware that a patient with HIV is knowingly exposing others or when discussing critically ill HIV-positive patients with family members who are unaware of the patient's HIV status. One study compared medical residents' views on disclosing the status of a newly diagnosed HIV-positive patient to the patient's partner without the patient's consent with their views on disclosing a cancer diagnosis under the same circumstances [18]. Medical residents were found to place significantly higher importance on the rights of the partner in the case of an HIV diagnosis than on those of the partner in the case of a cancer diagnosis. Commonly stated reasons for supporting disclosure without patient's consent included the infectious nature and "public health threat" of HIV [18].

In 2001, instruction in ethics and professionalism at the USCSOM was made a vertical curriculum, meaning that the two areas of study were integrated into the subject material in all years of medical school. Existing instruction during the preclinical years was determined to be adequate, based on prevailing standards. The challenge was to integrate material pertaining to ethics and professionalism into the clinical years, during which the class is exposed to a process of enculturation known as "the hidden curriculum" in diverse clinical settings under different mentors. After much discussion and deliberation, the committee decided that each third-year student would be required to write a one-page essay pertaining to some aspect of ethics and professionalism, chosen from topics covered in a synoptic manual of clinical ethics given to the students during the second year. Students were instructed to base these essays on experiences (either specific or general) encountered in the wards and clinics during the third year. These essays were then brought to small-group discussions attended by no more than five students and one or two faculty members. Ground rules for these discussions included: (1) anonymity of specific persons and places involved, and (2) confidentiality. Summary data were presented to fourth-year students just prior to graduation. These data and also a tabulation of the scenarios were also presented to clinical department chairs. The overall purpose of the exercise was to encourage ethical reflection as a lifelong habit [19].

During the years 2003 to 2007, 350 third-year students wrote essays [20]. Strikingly, only 22 of those pertained specifically to patients with HIV/AIDS. None of the 77 essays on physician behavior and professionalism—the most common topics chosen—involved HIV/AIDS. The most common HIV/AIDS-related topics had as their focus: confidentiality and privacy exclusive of minors (8 students); patient-physician relationships, including difficult patients (4 students); confidentiality and surrogate decision making involving minors (4 students); and end-of-life issues, advance directives, and surrogate decision making (3 students). None of the 350

essays commented on unethical or unprofessional behavior of physicians toward HIV-positive patients.

One student, who reported that a patient notified his or her partner after confrontation by the ward team, wrote: “I found the hardest part of ethical behavior is not determining the correct course of action but following through with it in a professional manner that does not hinder patient care.” Inexorably, HIV/AIDS has entered the mainstream of clinical ethics. The burning ethical issues of the late 1980s—the subjects of so many task forces, conferences, and papers—have been, by and large, figured out, as evinced by the paucity of recent literature pertaining to these issues. HIV/AIDS has, at least in developed countries, become “medicalized.” Its ethical dimensions, like its clinical dimensions, are now part and parcel of the daily practice of medicine. Still, the issues presented by HIV/AIDS exemplify the truism that character-building should be regarded as a lifelong process, built upon the habit of ethical reflection on daily events [17]. Although the frameworks for addressing issues related to ethics and professionalism in the care of patients with HIV/AIDS are now well-delineated, specific issues and cases will continue to challenge medical students and physicians for the foreseeable future.

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20. For the purpose of this tabulation, essays that touched on more than one topic were assigned to the predominant topic.

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# Virtual Mentor

American Medical Association Journal of Ethics  
December 2009, Volume 11, Number 12: 958.

## THE CODE SAYS

### *AMA Code of Medical Ethics Opinions on Physicians with Infectious Diseases*

#### **Opinion 9.13—Physicians and Infectious Diseases**

A physician who knows that he or she has an infectious disease, which if contracted by the patient would pose a significant risk to the patient, should not engage in any activity that creates a significant risk of transmission of that disease to the patient. The precautions taken to prevent the transmission of a contagious disease to a patient should be appropriate to the seriousness of the disease and must be particularly stringent in the case of a disease that is potentially fatal.

#### **Opinion 9.131—HIV-Infected Patients and Physicians**

A physician may not ethically refuse to treat a patient whose condition is within the physician's current realm of competence solely because the patient is seropositive for HIV. Persons who are seropositive should not be subjected to discrimination based on fear or prejudice.

When physicians are unable to provide the services required by an HIV-infected patient, they should make appropriate referrals to those physicians or facilities equipped to provide such services.

A physician who knows that he or she is seropositive should not engage in any activity that creates a significant risk of transmission of the disease to others. A physician who has HIV disease or who is seropositive should consult colleagues as to which activities the physician can pursue without creating a risk to patients.

Based on the report, [Ethical Issues in the Growing AIDS Crisis](#).

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## Virtual Mentor

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

### JOURNAL DISCUSSION

#### Ethics in Consent for HIV Testing

Natalie Stein, MD

**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.

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### Related in VM

[HIV Screening in Health Care Settings in the United States](#), December 2009

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# Virtual Mentor

American Medical Association Journal of Ethics  
December 2009, Volume 11, Number 12: 962-968.

## CLINICAL PEARL

### Managing the Care of Patients with HIV Infection

William R. Short, MD, MPH

HIV/AIDS refers to all cases of HIV infection, whether or not the infection has progressed to AIDS. The diagnosis of AIDS is based on surveillance case definitions established by the Centers for Disease Control and Prevention (CDC), which are the same for adults, adolescents, and children.

#### Definitive AIDS Diagnosis

*(With or without laboratory evidence of HIV infection.)*

- Candidiasis of esophagus, trachea, bronchi, or lungs.
- Cryptococcosis, extrapulmonary.
- Cryptosporidiosis with diarrhea persisting for more than 1 month.
- Cytomegalovirus infection of an organ other than the liver, spleen, or lymph nodes.
- Herpes simplex virus infection causing a mucocutaneous ulcer that persists more than 1 month, or bronchitis, pneumonia, or esophagitis of any duration.
- Kaposi sarcoma in a patient less than 60 years of age.
- Lymphoma of the brain (primary) in a patient less than 60 years of age.
- *Mycobacterium avium* complex or *Mycobacterium kansasii* infection, disseminated (at a site other than or in addition to the lungs, skin, or cervical or hilar lymph nodes).
- *Pneumocystis jiroveci* pneumonia.
- Progressive multifocal leukoencephalopathy.
- Toxoplasmosis of the brain.

#### Definitive AIDS Diagnosis

*(With laboratory evidence of HIV infection.)*

- Coccidioidomycosis, disseminated (at a site other than or in addition to the lungs or cervical or hilar lymph nodes).
- HIV encephalopathy.
- Histoplasmosis, disseminated (at a site other than or in addition to the lungs or cervical or hilar lymph nodes).
- Isosporiasis with diarrhea persisting more than 1 month.
- Kaposi sarcoma at any age.
- Lymphoma of the brain (primary) at any age.
- Other non-Hodgkin lymphoma of B cell or unknown immunologic phenotype.

- Any mycobacterial disease caused by mycobacteria other than *Mycobacterium tuberculosis*, disseminated (at a site other than or in addition to the lungs, skin, or cervical or hilar lymph nodes).
- Disease caused by extrapulmonary *M. tuberculosis*.
- Salmonella (nontyphoid) septicemia, recurrent.
- HIV wasting syndrome.
- CD4 cell count less than 200/uL or a CD4 lymphocyte percentage below 14 percent.
- Pulmonary tuberculosis.
- Recurrent pneumonia.
- Invasive cervical cancer.

### **Presumptive AIDS Diagnosis**

*(With laboratory evidence of HIV infection.)*

- Candidiasis of esophagus: (a) recent onset of retrosternal pain on swallowing, and (b) oral candidiasis.
- Cytomegalovirus retinitis: characteristic appearance on serial ophthalmoscopic examinations.
- Mycobacteriosis: specimen from stool or normally sterile body fluids or tissue from a site other than the lungs, skin, or cervical or hilar lymph nodes showing acid-fast bacilli of a species not identified by culture.
- Kaposi sarcoma: erythematous or violaceous plaque-like lesion on skin or mucous membrane.
- *Pneumocystis jiroveci* pneumonia: (a) a history of dyspnea on exertion or nonproductive cough of recent onset (within the past 3 months); and (b) chest radiograph evidence of diffuse bilateral interstitial infiltrates or gallium scan evidence of diffuse bilateral pulmonary disease; and (c) arterial blood gas analysis showing an arterial blood PO<sub>2</sub> of less than 70 mm Hg or a low respiratory diffusing capacity (DLCO) of less than 80 percent of predicted value or an increase in the alveolar-arterial oxygen tension gradient; and (d) no evidence of bacterial pneumonia.
- Toxoplasmosis of the brain: (a) recent onset of a focal neurologic abnormality consistent with intracranial disease or a reduced level of consciousness; and (b) brain imaging evidence of a lesion having a mass effect or the radiographic appearance of which is enhanced by injection of contrast medium; and (c) serum antibody to toxoplasmosis or successful response to therapy for toxoplasmosis.
- Recurrent pneumonia: (a) more than one episode in a 1-year period; and (b) acute pneumonia (new symptoms, signs, or radiographic evidence not presented earlier) diagnosed on clinical or radiographic grounds by the patient's physician.
- Pulmonary tuberculosis: (a) apical or miliary infiltrates and (b) radiographic and clinical response to antituberculosis therapy.

### **Initiation of Care**

Ideally, the initial encounter occurs in the outpatient setting with an asymptomatic person who has been electively tested and found to be positive for HIV. In actual fact, however, the first encounter often occurs in the office or hospital following the development of signs and symptoms of immune compromise or opportunistic infection. In this setting, some patients may not be aware of their HIV status.

After HIV-positive status is confirmed, the initial evaluation includes a complete history and physical examination. The patient's social support system should be evaluated, and his or her reaction to learning about HIV infection should be explored because anxiety, depression, and adjustment disorders commonly occur early in the course of infection. If the patient has a previously established diagnosis of HIV/AIDS, a complete antiretroviral treatment history should be obtained. The patient should be educated about precautions needed to avoid virus transmission as well as the indications and goals of antiretroviral therapy and the need for preventive care. Patients should have some knowledge of resistance mechanisms and understand the importance of adhering to the treatment regimen. Providing appropriate counseling and education generally requires several visits.

### **Laboratory Testing**

Laboratory testing is performed to assess immune status and rule out concomitant diseases or exposure to previous infections possibly requiring treatment, prophylaxis, or immunization. Assessment of liver, bone marrow, and kidney function is important. Serum lipid levels should be measured before beginning antiretroviral therapy because hyperlipidemia can be a complication of HIV infection or antiretroviral therapy. Testing also includes a CD4 count, which should be monitored every 3 to 4 months and guides prophylaxis therapy as well as initiation of treatment.

Viral load testing, which measures the amount of HIV-1 RNA present in the plasma, is also undertaken at baseline and every 3 to 4 months. The plasma HIV RNA viral load is the best predictor of prognosis and the rate of decline of CD4 lymphocytes and is used to assess and monitor the efficacy of antiretroviral medications and to guide ongoing treatment decisions. It should be checked 4 weeks after antiretroviral therapy is initiated or changed. An "undetectable" viral load refers to a result that is below the lower threshold of the test, generally less than 50 copies/mL. An undetectable viral load does not mean that virus is no longer present in the body or that cure has been achieved. Individuals with undetectable viral loads are still considered infectious.

### **Preventive Care**

A number of preventive measures contribute to disease avoidance for patients with HIV infection. These include routine immunizations, cervical cancer screening, and medications for primary and secondary prophylaxis of opportunistic diseases. Routine immunizations include pneumococcal vaccine every 5 years and influenza vaccine annually. Hepatitis A and B vaccines should be administered unless the presence of protective antibodies is documented.

A tuberculin skin test using purified protein derivative should be performed annually. In patients with HIV infection, a skin test resulting in 5 or more mm of induration is considered positive. At baseline a patient should also be screened for hepatitis B and hepatitis C, *Toxoplasma* IgG antibody, cytomegalovirus IgG antibody and syphilis using the RPR test. Women with HIV infection have a higher incidence of cervical dysplasia and invasive cervical carcinoma, and many experts therefore suggest more frequent Pap smear screenings in these patients.

Several drugs have been shown to provide effective prophylaxis against opportunistic infections in patients with HIV infection and to prolong life in some patients. The CD4 cell count is an indicator of immune competence. Recommendations regarding when to initiate prophylaxis are based on CD4 cell count levels below which these infections are likely to occur.

### **Opportunistic Infections**

Opportunistic infections remain a significant cause of morbidity and mortality in patients with HIV/AIDS. These infections result from an imbalance in cell-mediated immunity. The immune system is no longer able to maintain control in patients with HIV infection, allowing fungi, bacteria, and viruses to invade impaired hosts and cause disease. Healthy persons infected with these pathogens may experience mild illness followed by recovery; those infected with HIV can become severely ill. The major AIDS-defining opportunistic infections are cryptococcal infection, cytomegalovirus infection, *Pneumocystis jiroveci* pneumonia, *Mycobacterium avium* complex infection, and toxoplasmosis.

*Cryptococcal Infections.* Cryptococcal meningitis is the most common form of meningitis in patients with AIDS, typically causing symptoms that mimic other disorders such as headache, irritability, and nausea. Most patients have a CD4 cell count of less than 100/uL. The diagnosis is based on detection of cryptococcal antigen or culture of *Cryptococcus neoformans* in the cerebrospinal fluid (CSF). Treatment is divided into three phases (induction, consolidation, and maintenance). The usual induction therapy is amphotericin B, with or without flucytosine, for 14 days followed by fluconazole for 8 weeks during the consolidation phase. Therapy during the maintenance phase is continuous fluconazole until the patient has successfully completed a course of initial therapy, has no signs and symptoms of cryptococcosis, and has a documented sustained increase in the CD4 count (more than 200 cells/uL for more than 6 months).

*Cytomegalovirus Infection.* Cytomegalovirus is a common pathogen that occurs in late stages of HIV infection, usually in patients with a CD4 cell count of less than 50/uL. It can be associated with either disseminated or localized end-organ disease. Many organs may be involved, including the retina, gastrointestinal tract, and nervous system. Cytomegalovirus only rarely invades the lungs in patients with HIV infection. Treatment involves the use of ganciclovir induction followed by maintenance therapy. In patients who are intolerant to ganciclovir or have dose-

limiting toxicity, foscarnet and cidofovir have been used. The length and type of treatment depends on the specific organ system involved.

*Mycobacterium avium Complex Infection.* Disseminated *Mycobacterium avium* (MAI) complex infection is common in patients with advanced-stage HIV infection and a CD4 cell count of less than 50/uL. Weekly azithromycin is the standard regimen for MAI prophylaxis. Symptoms are fever, weight loss, hepatosplenomegaly, malaise, and abdominal pain. The diagnosis is generally confirmed by recovering the pathogen from a sterile tissue (usually blood). Treatment consists of a combination of a macrolide and ethambutol with or without rifampin.

*Pneumocystis jiroveci Pneumonia.* *Pneumocystis jiroveci* pneumonia (PCP) remains the most common AIDS-defining illness and cause of death in patients with AIDS. The diagnosis should be considered in any patient with a CD4 cell count of less than 200/uL who has fever, dry cough, and dyspnea developing over several days or weeks. The chest radiograph typically shows bilateral interstitial infiltrates, but findings can vary from a normal film to consolidation or a pneumothorax. The diagnosis is established by silver stain examination of induced sputum or a bronchoscopic sample showing characteristic cysts. A 3-week course of trimethoprim-sulfamethoxazole (TMP-SMX) is the standard treatment. Corticosteroids are required for patients with evidence of hypoxia (arterial blood PO<sub>2</sub> of less than 70 mm Hg or an alveolar-arterial gradient greater than 35 mm Hg) and should be continued for the entire course of treatment. Daily TMP-SMX is the medication of choice for prophylaxis against PCP when a patient has a CD4 count less than 200/uL.

*Toxoplasmosis.* Toxoplasmosis almost always presents as reactivation disease in patients with HIV infection and typically occurs when the CD4 cell count is less than 100/uL. Additional findings are fever, neurologic deficits, and an MRI showing ring-enhancing lesions. Sulfadiazine plus pyrimethamine and folinic acid are given initially. Daily TMP-SMX is the standard prophylaxis for toxoplasmosis.

### **Treatment of HIV Infection**

The U.S. Department of Health and Human Services (DHHS) and the International AIDS Society–USA (IAS-USA) frequently update guidelines for use of antiretroviral therapy in patients with HIV infection [1, 2].

The goals of antiretroviral therapy are to prolong life, avoid destruction or allow reconstitution of the immune system, prevent opportunistic infections, and provide improved quality of life by reducing HIV-related symptoms. Effective therapy aims to lower the HIV RNA viral load to less than 50 copies/mL. Such dramatic reductions in viral load improve prognosis, minimize the development of resistance, and prolong the duration of the antiretroviral response.



The most appropriate time to begin treating patients with HIV infection is an issue of great debate. Current guidelines recommend initiating antiretroviral therapy in patients with a history of an AIDS-defining illness or a CD4 cell count of less than 350/uL. Strong evidence from clinical trials suggests that treating patients with an AIDS-defining illness and a CD4 cell count of less than 200/uL improves survival and reduces disease progression. The guidelines have recently been changed to include the recommendation to treat all patients with HIV infection, regardless of their CD4 cell count, who have evidence of HIV nephropathy or hepatitis B co-infection that requires treatment or are pregnant.

*Antiretroviral Agents.* Twenty-five antiretroviral agents are currently approved for treating HIV infection. Six different antiretroviral drug classes are licensed. These are nucleoside/nucleotide reverse transcriptase inhibitors (NRTIs), non-nucleoside reverse transcriptase inhibitors (NNRTIs), protease inhibitors, fusion inhibitors, integrase inhibitors, and co-receptor antagonists. The NRTIs are nucleoside/nucleotide analogues and act as chain terminators that impair the transcription of viral RNA into DNA. The NNRTIs inhibit reverse transcriptase by binding to the enzyme. Protease inhibitors impair the packaging of viral particles into a mature virus capable of budding from the cell and productively infecting additional lymphocytes. The fusion inhibitors impair membrane fusion of HIV to T cells, thus preventing one of the key steps in entry. Coreceptor antagonists block a second major step in entry by binding to the chemokine receptors (CCR5 or CXCR4), and integrase inhibitors prevent incorporation of viral DNA into the host cell genome. Recommended first-line regimens include two NRTIs plus either a NNRTI or a protease inhibitor.

*Resistance Testing.* Two types of resistance tests, genotype and phenotype, are used in clinical practice. Genotype testing identifies mutations in reverse transcriptase and protease genes. Phenotype testing measures the ability of HIV to grow in the presence of varying concentrations of antiretroviral drugs. This procedure involves recombining the patient's gene sequences with a laboratory HIV clone and measuring the replication of the virus in different drug concentrations. Resistance testing is recommended for patients who develop acute HIV infection (within 6 to 12 months of virus transmission), compliant patients who fail to benefit from adequate therapy, and treatment-naïve patients with chronic HIV infection.

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### **Further Reading**

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# Virtual Mentor

American Medical Association Journal of Ethics  
December 2009, Volume 11, Number 12: 969-973.

## HEALTH LAW

### Testing Newborns for HIV

Kristin E. Schleiter, JD, LLM

Perinatal HIV refers to infection with the virus that is transmitted from an HIV-positive mother to her child during gestation, labor and delivery, or after delivery as a result of breast feeding [1-4]. It would seem that a child born to an HIV-positive mother is doomed to contract the virus, but an HIV-positive mother does not automatically transfer the virus to her child [1]. Although perinatal transmission is not perfectly understood, newborns have only about a 25 percent chance of contracting HIV during gestation [1]. Most babies who contract the virus perinatally do so during labor and delivery (70 to 75 percent) [1, 4].

The low transmission rates from mother to child are the result of the nature of HIV infection and transmission. When HIV enters a person's bloodstream, his or her immune system reacts by producing antibodies to fight the virus [5]. Since newborns keep their mother's antibodies until they produce their own antibodies at around 18 months of age, a positive neonatal HIV test result reveals the presence of maternal antibodies that indicate exposure to the virus, not necessarily infection by the virus. A baby born to an HIV-positive mother will thus always test positive for HIV, whether that newborn is truly seropositive or not. If the virus did not infect the baby, the baby will eventually lose its mother's antibodies and test negative for HIV. Diagnosis of HIV infection in newborns can be made during the first weeks of life using virologic assays, specifically HIV-1 DNA or RNA assays [6].

It is possible to prevent transmission of the virus to HIV-exposed infants, but early recognition of the maternal antibodies is essential to ensuring these benefits. When treatment of newborns whose exposure to HIV was first detected after birth was begun within the first 48 hours of life, the transmission rate was approximately 9 percent; when begun on day 3 of life or later, the transmission rate rises to approximately 18 percent [7, 8]. The survival rate for HIV-infected infants is extremely low. These infants suffer from a variety of preventable or manageable infections, including meningitis, *Pneumocystis carinii pneumonia* (PCP), and tuberculosis. Though there is no cure for HIV, the duration and quality of life of an infected child can be enhanced by antiretroviral drugs and other drug therapy, nutritional monitoring, and a proper immunization schedule.

To promote early diagnosis of newborns who have been exposed to or infected perinatally with the HIV virus, some states have enacted laws that call for routine or mandatory screening of newborns for HIV. Newborn screening programs are not new and can be mandatory, voluntary, or routine with an opt-out provision [4]. Five

criteria generally must be satisfied before a disease is considered appropriate for newborn screening [9]:

1. The disease is well-defined and serious enough to justify mass screening.
2. An accurate testing method is available.
3. The cost of the test is reasonable.
4. There is available treatment for the disorder.
5. There are adequate medical management facilities to refer infants for confirmatory diagnosis and treatment.

All states have statutes, regulations, or policies requiring newborn screening for specified health risks. Most states routinely test newborns anonymously for the presence of HIV antibodies (blind testing), and nine states have enacted legislation pertaining to unblind newborn HIV testing [5]. The most restrictive statute is New York's, which requires unblind testing of all newborns born to mothers whose HIV status is unknown or undocumented. New York chose unblind newborn HIV testing after deciding that the public health benefits of testing warranted infringement of individual liberty.

#### **New York Public Health Law 2500-F**

New York accounts for roughly one-fourth of the country's pediatric HIV infections, with more than 87 percent of those infections in New York City [2]. In the 1980s, New York was among a group of states that enacted blind newborn testing under the CDC's guidance. While names and test results were not connected, other demographic data from the mother were recorded and tracked. Blind newborn testing caused controversy because the practice released HIV-positive newborns to their mothers, who may or may not have known of their infants' status, so there was not an opportunity to allow the newborns to receive treatment that may have prolonged their lives. This concern led New York to pass the AIDS Baby Bill [2].

Under the New York public health statute that resulted from the AIDS Baby Bill, all newborns must be tested for HIV, whether or not the mother consents [10]. Before a newborn is tested, the mother or parent must be informed about the purpose and need for the test [11]. New York's Department of Health also requires all prenatal caregivers to: (1) counsel and encourage pregnant women to be tested as early as possible during the pregnancy, and (2) inform pregnant women about the mandatory newborn testing requirements [1, 3, 12]. Further, hospitals must conduct expedited HIV testing of any newborn whose mother is not on record as having been tested for HIV during pregnancy and who declined a rapid HIV test during labor and delivery [3, 12]. If a newborn tests positive for HIV antibodies, the regulations state that the "responsible physician" shall take further steps, such as arranging for post-test counseling, health care, case management, and other health and social services for the newborn and mother [11].

As the commissioner of the New York State Health Department has explained, this essentially means that women in labor who were not tested during prenatal care will learn their HIV status during or immediately after delivery [3]. The stated purposes

of the regulations are to “achieve the goal of universal prenatal counseling and testing,” and to “ensure that newborns who are born exposed to HIV receive prompt and immediate care and treatment that can enhance, prolong, and possibly save their lives” [1, 3].

A primary criticism of New York’s law on newborn testing for HIV is that it fails to provide for needed counseling and long-term care for those mothers whose infants test positive for HIV. Critics of the law say that the mandatory testing thus does not effectuate the goal of preventing the spread of HIV/AIDS [9]. Concerns have also been raised over the law’s constitutionality.

### **Questions of Constitutionality**

New York’s newborn testing policy does not provide for the right to refuse the test, with the practical result that the test can indirectly reveal the serostatus of the mother. This forced disclosure compromises the mother’s constitutional rights, particularly her right to privacy (confidentiality and autonomy) and procreative rights.

New York’s newborn testing policy also compromises the right of parental autonomy under principles of informed consent. Parents have an independent interest in parenting that shields family privacy from coercive state intervention [4]. That is, parents have a constitutionally protected liberty interest in establishing a home and rearing children and are presumed under the law to be acting in the best interest of their child when they make decisions on the children’s behalf [4]. The state, however, maintains a *parens patriae* interest in child’s well being, which the courts have used to allow the state to compel medical treatment for a child over a parent’s objection [4]. Newborn testing programs invoke the state’s *parens patriae* interest. Therefore, while mandatory newborn testing programs may violate the right of parental autonomy, the state’s interest in protecting the health of its newest citizens may lead a court to conclude that such a mandatory program is justified.

Because mandatory newborn screening for HIV potentially infringes on a woman’s constitutionally protected rights and does not, in the view of its detractors, represent the most effective or least restrictive alternative to accomplish the state’s purpose of bringing HIV-positive children into treatment, it is not the best solution to the problem of neonatal HIV transmission [5, 9]. Research has shown that efforts to reduce HIV transmission should be taken during pregnancy and in conjunction with counseling and education programs [9]. Further, the state cannot fulfill its stated purposes—preventing the spread of HIV/AIDS—without ensuring access to care or treatment for HIV-infected women and their children [4, 5]. As Linda Farber Post points out,

only by enlisting the cooperation of those at risk through counseling, education, support, and access to needed medical and social services will the behavior modification necessary to prevent AIDS transmission be accomplished, and there is no evidence that disclosure to parents of their

newborns' HIV status results in either the mothers' modification of high-risk behavior, or their obtaining medical treatment for their children [5].

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# Virtual Mentor

American Medical Association Journal of Ethics  
December 2009, Volume 11, Number 12: 974-979.

## POLICY FORUM

### HIV Screening in Health Care Settings in the United States

Bernard M. Branson, MD, and Salaam Semaan, MPH, DrPH

In 2006 the Centers for Disease Control and Prevention (CDC) recommended routine HIV screening in health care settings of all patients aged 13 to 64 years, irrespective of lifestyle or perceived risk behaviors [1]. As part of those recommendations, the CDC stated that separate signed informed consent and prevention counseling should not be required for HIV-screening programs in health care settings. Depending on the policy of the individual setting, patients would be provided with verbal or written information about HIV testing, told that testing was recommended as part of routine care, and afforded the opportunity to decline—"opt-out." Those recommendations represented a shift from previous policies that had encouraged testing only for persons at high risk for HIV infection or in health care settings with high prevalence of HIV. Previous testing policies usually required separate written consent and pre- and post-test prevention counseling [2].

Aspects of the CDC's 2006 recommendations have engendered considerable controversy, especially as they relate to the ethical principle of respect for autonomy. Several authors have discussed the ethics of universal HIV screening based on different paradigms, highlighting and weighing different benefits and risks [3-8]. In this article, we present the clinical and public health rationale for the 2006 recommendations and discuss several ethical considerations as they relate to the principles of beneficence, respect for autonomy, and justice, focusing especially on physicians' dual responsibility to patients and the public.

#### **Beneficence**

From both clinical and public health perspectives, the primary justification for HIV universal screening stems from the large number of infections that go unrecognized until late in the course of the disease. An estimated 1.1 million persons in the United States were living with HIV or AIDS in 2006, of whom 238,000 (21 percent) had not been diagnosed. In that same year, an estimated 56,300 were newly infected [9, 10]. Without treatment, the interval between infection with HIV and onset of AIDS averages 10 years. In one CDC study, 38 percent of newly diagnosed patients developed AIDS within 1 year of their first positive HIV test, indicating that the tests came long after their initial infection with the virus [11]. Many HIV-infected patients are not tested despite multiple encounters with the health care system [12].

Thus, the purpose of screening is to identify patients with undiagnosed HIV infection earlier to offer timely treatment and reduce transmission to partners. HIV screening is especially important now that significant advances in antiretroviral therapy (ART)



have made the infection a manageable chronic disease. Timely diagnosis and effective ART can yield a near-normal life expectancy. ART provides an average per-person survival benefit of 160 months, much greater than that realized by medical interventions for other serious medical conditions such as comprehensive care following myocardial infarction (50 months) [13].

In addition to the health care and quality-of-life benefits associated with treatment, clinicians have a public health responsibility to prevent the transmission of infectious diseases. The prevention benefits from HIV testing are considerable. Persons aware of their HIV infection are 2.5 times less likely to engage in behaviors that transmit HIV than are HIV-infected persons who have not been tested [14]. Those unaware that they are infected account for 50 percent to 70 percent of new sexually transmitted HIV infections [15]. Thus, increasing knowledge of HIV status could substantially curb the epidemic, because infected persons take steps to protect their partners. Clinicians need to discuss with patients the importance of partner notification and the measures patients can take to minimize potential harm that might be associated with disclosing their HIV serostatus.

In short, universal HIV screening and early HIV diagnosis have a favorable benefit-risk ratio both to patients and public health. These benefits make universal HIV screening consistent with the ethical principle of beneficence.

### **Respect for Autonomy**

Respect for autonomy is given preeminent ethical status, and informed consent is the practical application of this principle. To exercise respect for autonomy, clinicians must be able to communicate well with their patients, giving them adequate, comprehensible information that allows them to make decisions about testing or treatment options that shows respect for their right to privacy [16]. Clinicians must also ascertain whether patients assume that HIV screening has already occurred. Anecdotes suggest that patients may think that they have been tested for HIV when in fact they have not. Debate continues about the considerations for and against the need to have separate written consent for HIV testing and counseling [17]. Obtaining consent and providing counseling for an HIV test are influenced by concern for privacy, confidentiality, comprehension, and stigma. Because HIV testing has traditionally been encouraged based on risk factors that are stigmatized (e.g., same-sex behavior, multiple sex partners, injection drug use), opt-in HIV screening—asking for specific consent from asymptomatic persons—may be declined by persons who are concerned about disclosure of risk behaviors. In a New York survey, 39 percent of men who reported recent sexual contact with other men did not disclose this information to their health care professional [18]. Some patients worry that agreeing to an HIV test might be perceived erroneously as an admission of their engagement in high-risk behaviors. Opt-out screening (informing patients that they will be screened for HIV unless they decline) can minimize perceived prejudice or rejection, and thereby offer a more acceptable procedure for testing those who do not consider themselves at risk or who do not wish to discuss their sexual or drug-use behaviors.

It is possible that some patients might be tested for HIV unknowingly, due to lax procedures or lack of initiative. Health care settings should adopt appropriate safeguards and protocols to ensure that patients are not tested without their knowledge [8]. Published studies are limited, but it appears that many patients and clinicians agree that HIV should be equated with other chronic diseases—such as diabetes and elevated cholesterol—for which testing is routine, and for which written informed consent and pretest counseling constitute time and cost barriers in the clinical encounter [19]. Many patients indicate that they would be more likely to accept a test if testing were recommended as a general policy, rather than based on suspected risk behaviors. Patients prefer that HIV testing not be conducted without notification or discussion [19]. They also want to talk in depth with a clinician about HIV when the test result is positive [19].

The CDC's recommendation for opt-out screening in health care settings (where the doctrine of informed consent is well established) is intended to preserve the essence of informed consent and show respect for the right of patients to choose not only the testing and care that they would like to receive but also the information they wish to receive and disclose. Numerous studies have found that patients are most likely to accept testing when it is recommended by a clinician. Whether patients opt in or opt out, the end result should be the same: a voluntary and informed decision by the patient to accept or decline the health care professional's recommendation of an HIV test [17].

Evidence provides the impetus for national public health recommendations, but each state is responsible to interpret and implement recommendations based on its circumstances. When the CDC recommendations were issued in 2006, statutes or regulations in 20 states required separate written consent for HIV testing. Since 2006, 13 of those states removed the requirement (Arizona, California, Connecticut, Hawaii, Illinois, Indiana, Iowa, Louisiana, Maine, Maryland, New Hampshire, New Mexico, and North Carolina) [7]. Proposed similar legislation continues to provoke heated debate in the remaining 7 states (Massachusetts, Michigan, Nebraska, New York, Pennsylvania, Rhode Island, and Wisconsin) [7].

It is relevant to note that other HIV-related policies have evoked similar controversy and required time for adoption. For example, it was not until April 2008 that name-based reporting of HIV-positive status was adopted by all 50 states. State and federal health laws require providers to report cases of many communicable diseases to public health authorities. AIDS cases have been reportable by name in all states since 1986. The CDC recommended the use of name-based reporting of positive HIV status in 1999, when it was required in only 34 states. Although both state and federal public health laws protect privacy of patients, and staff members receive training in protecting safety and confidentiality of surveillance data, concerns about confidentiality fueled debate in many states until 2008 [20].

## Justice

Universal screening is intended to reduce the stigma associated with targeted testing, which carries negative social and public health ramifications. Social stigma can result when certain subgroups of the population are assumed to be the ones who are infected with HIV, and opportunities for treatment and public health interventions can be missed entirely if we believe that only certain groups are likely to be infected. Universal screening can help eliminate the stigma associated with taking an HIV test, but stigma related to HIV infection persists and must be addressed. The goal of screening is to help identify patients with unrecognized HIV infection and allow them to avail themselves of relevant treatment and prevention services. To accomplish this overall goal, it is essential to ensure availability of and access to appropriate services for prevention and care. Access to prevention and care can pose a particular challenge to persons who may not perceive the value of early treatment, have difficulty adhering to a lifelong regimen of monitoring and treatment, or have limited resources.

In conclusion, clinical and public health benefits justify recommending and implementing universal HIV screening in health care settings in the United States. Ethical considerations for the principles of beneficence, respect for autonomy, and justice indicate that universal HIV screening in health care settings is warranted, provided that follow-up is assured and adequate prevention and care are accessible.

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**Acknowledgment**

The findings and conclusions in this article are those of the authors and do not necessarily represent the views of the Centers for Disease Control and Prevention.

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# Virtual Mentor

American Medical Association Journal of Ethics  
December 2009, Volume 11, Number 12: 980-987.

## MEDICINE AND SOCIETY

### HIV/AIDS Prevention Messages

Seth M. Noar, PhD, and May G. Kennedy, PhD, MPH

As the HIV/AIDS epidemic swept across the United States and the world over the past 25-plus years, those engaged in prevention activities recognized that effective health communication was vital to stemming its progress [1-3]. Given that no cure or vaccine is on the horizon, prevention information—from knowledge of HIV transmission routes to behavior-change messages that encourage individuals and communities to reduce sexual and drug-risk behaviors—remains a key intervention strategy.

The mass media have traditionally played an important role in this effort, serving as the conduit for scores of public-service campaigns [4, 5]. In addition to such traditional campaigns, the development, launch, and evaluation of entertainment-education (EE) initiatives have increased in the United States and worldwide [6, 7]. More recently, Internet-based media are playing a role in HIV/AIDS prevention efforts [8].

This article provides an overview of these three (distinct but overlapping) areas of health communication and HIV/AIDS prevention: (1) traditional health communication campaigns, (2) entertainment education, and (3) Internet- and computer-based media technologies.

### Traditional Campaigns

Health-communication campaigns are typically defined as efforts “to generate specific outcomes or effects in a relatively large number of individuals, usually within a specified period of time, and through an organized set of communication activities” [9]. Campaigns employ single or multiple media at the national, regional, and local levels, either as stand-alone efforts or as part of multicomponent programs involving such strategies as community coalitions, peer education, counseling, group discussions/support groups, hotlines, and provision of campaign-related materials (e.g., brochures, condoms, etc.). While media spots such as televised public service announcements (PSAs) are often an essential element of campaign efforts, in practice they are typically only a single part of a larger campaign [5]. In fact, only about one-quarter of published campaigns use a single media channel; the remainder use multiple media channels, and most involve multiple campaign strategies to get the message out.

The earliest major HIV/AIDS PSA campaign initiative in the United States was America Responds to AIDS, launched in 1987 to raise the public’s awareness of the

disease. The campaign continued to be designed generally for the public at large, although some messages were aimed at higher-risk audiences [10, 11].

More recent campaigns have been designed specifically for at-risk audiences—sex workers and injection drug users—with the goal of changing high-risk behaviors rather than simply raising awareness about AIDS [5, 12-15]. The Kaiser Family Foundation has partnered with several media organizations in recent years to prevent HIV/AIDS among youth. The campaigns and partners include Rap it Up (with Black Entertainment Television), Staying Alive (with MTV), Fight for Your Rights: Protect Yourself (with MTV), and KNOW HIV/AIDS (with Viacom) [16]. In addition to using PSAs, these youth-centered initiatives integrate HIV/AIDS storylines into popular television programs, a concept known as entertainment education. Finally, the CDC is preparing to introduce Act Against AIDS in the United States, a multiyear, multifaceted prevention campaign that will use mass media and direct-to-consumer channels with the hope of reducing new HIV infections among the highest-risk populations, notably African Americans. The theme for the kick-off phase is “9 1/2 minutes,” emphasizing the fact that someone becomes infected with HIV in the United States every 9-1/2 minutes [17].

Can we measure the impact of the campaign efforts described above? Given that health-communication campaigns are conducted in the field and therefore cannot typically be evaluated using randomized controlled trials, many campaigns have suffered from poor evaluation design [5, 11]. Despite this, there is evidence from several studies with quasi-experimental designs that media campaigns can reduce rates of unprotected sex and increase HIV testing behaviors, although effects are typically short term [5, 14, 18, 19]. Future evaluation studies will apply more rigorous designs tailored to assessing health-communication campaigns [20].

### **Entertainment Education**

The EE approach integrates health information into offerings that are primarily entertaining, especially those with narrative structures [21]. Prevention messages that use mass media EE reach large audiences and engage them through memorable plots and appealing characters. EE weaves health information into a short-term storyline within an ongoing commercial television series [22]. Most HIV storylines are in afternoon soap operas or evening dramas, but some situation comedies (e.g., “Girlfriends”) have included HIV storylines. The narrative format makes it possible to demonstrate strategies for overcoming barriers to a recommended behavior and the consequences of either adopting the behavior or failing to do so. Hollywood writers and producers retain creative control over content, and their primary concern is increasing viewership, not promoting public health, but they often collaborate with HIV experts to ensure that the health information in their shows is accurate and that prevention messages are compelling.

One evaluated example was a storyline in “The Bold and the Beautiful,” an afternoon soap opera. After an episode in which a character disclosed his positive serostatus to his fiancée, viewers were urged to call the National AIDS Hotline if

they wanted more information about the disease. Calls to the hotline spiked dramatically during those time slots, and the spikes were significantly higher than others that year that coincided either with PSA campaigns representing much more air time (e.g., the week-long Rap it Up campaign) or AIDS information spots on shows (e.g., “60 Minutes”) with substantially larger audiences [23].

Other TV shows have addressed risk factors for HIV infection. One storyline in the primetime drama “ER” concerned syphilis, a disease that increases the risk of HIV infection among urban gay men [24]. In a post-episode online survey of men visiting chat rooms, viewers were significantly more likely than nonviewers to say they intended to be screened for syphilis and tell others to be screened [25]. Another disease risk factor—the perception among 12-to-17 year olds that condom use is sufficient protection—was affected by a mixed-message episode of the situation comedy “Friends” [26]. The episode dramatized a pregnancy that resulted from one night of sexual activity during which there was condom use. Meanwhile, “Condoms are only 97% effective,” flashed across the screen. More than half of the viewers remembered the message to be: “...lots of times, condoms don’t prevent pregnancy.” Forty percent of teen viewers, however, watched the show with an adult, and these teens were more likely than either nonviewers or solo viewers to say that condoms are highly effective.

We need a better understanding of how EE works, so that positive effects can be strengthened. It is also important to learn how transmitting EE offerings through new, social, and interactive media affects outcomes.

### **New Media Technologies**

The Internet, a communication channel with the ability to deliver multimedia and interactive content to specific audiences, has become a portal for HIV/AIDS prevention messages [27]. While mass media are often concerned with reaching general audiences, the Internet offers the possibility of narrowcasting to more carefully defined groups and even tailoring HIV-prevention messages to individuals [28, 29].

The Internet also presents an opportunity to reach high-risk individuals who may not be accessible through traditional community-based settings [30]. Indeed, studies show that many use the Internet to seek sex partners online, and, moreover, that those who use the Internet for this purpose tend to engage in higher-risk sexual behaviors than those who do not [31, 32]. For these reasons, many cities have undertaken major Internet-based outreach and intervention initiatives to find and engage members of these high-risk populations. The Internet has been used for banner ads, chat-room outreach, and online-partner notification [33].

Studies have shown that safer-sex and HIV/AIDS-prevention resources on the Internet vary widely. While many web sites consist merely of safer-sex information, others feature animation, video clips, video games, quizzes, and polls [34-36]. More sophisticated web sites offer communication opportunities, such as message boards



and chat rooms, with some providing peers or experts who are available to talk, e-mail, or reply on message boards [36]. Many web sites are stand-alone ventures, while others are associated with campaigns like those described above, although it is not yet clear how they can best contribute to campaign effectiveness.

Most online safer-sex resources have not been evaluated for efficacy, but there is a growing literature on computer-based interventions in general, and these studies include rigorous evaluations. By way of definition, computer-based interventions are those that use computers as the primary or sole medium from which to deliver a message [37]. Some of these applications are Internet-based; others are stand-alone computer programs or CD-ROMs that run on local computers in community or clinical settings. These programs vary widely in their make-up; some tailor responses to individual characteristics, others address particular at-risk groups, while interactive-video applications seek to simulate the decision-making experiences that one encounters in a sexual situation [38-40].

A recent meta-analytic study synthesized the literature on the first 12 randomized controlled trials on the effect of computer-based interventions on safer-sexual behaviors [37]. Results indicated that the interventions were effective in improving condom use and that the effects were similar to those produced by previously tested human-delivered messages. While only a small number of studies measured other outcomes, such as number of sexual partners and incidence of sexually transmitted diseases, results in those studies indicate a positive impact on these outcomes [37]. These results are promising for the future application of programs and other computer-based technologies to communicate HIV-prevention messages.

The area of new media technologies and HIV prevention is ripe for research and innovation. Studies are needed to help us understand how to best harness the potential of the Internet as a prevention tool. Given the broad use, and increasing sophistication of cell phones (and various mobile devices), studies are beginning to examine HIV prevention via mobile devices, including text messaging [41, 42]. Finally, studies of HIV-prevention messages using social networking web sites such as Facebook and MySpace are warranted [43].

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#### **Acknowledgement**

We would like to thank Rick Zimmerman for helpful comments provided on an earlier draft of this article.

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# Virtual Mentor

American Medical Association Journal of Ethics  
December 2009, Volume 11, Number 12: 988-992.

## HISTORY OF MEDICINE

### The Rise and Fall of AIDS Exceptionalism

Gerald M. Oppenheimer, PhD, MPH, and Ronald Bayer, PhD

In the late 1980s, a group of social scientists convened in France to examine the question of how democratic societies in North America and Europe had confronted the challenges posed by AIDS [1]. As each collaborator recounted the history of the political, social, and public health responses evoked by HIV in his or her country, three questions remained constant, even though the precise language reflected unique cultural differences. Did the history of responses to lethal infectious diseases provide lessons about how best to contain the spread of HIV infection? Should the policies developed to control sexually transmitted diseases or other communicable conditions be applied to AIDS? If AIDS were not to be treated like other communicable diseases, what would justify using different policies?

In some instances, these questions were explicitly addressed; on other occasions, they were simply implied in the critical policy discussions [2]. In summarizing the 2 days of discussion that ensued, one of us [RB] present at the meeting was struck by the “exceptional” nature of what had been decided in virtually every one of the cases considered. The term “HIV exceptionalism” thus emerged. It first appeared in print in an article in the *New England Journal of Medicine* in 1991 [2]. Since then, the term has been used in numerous policy settings, domestic and global, as well as at many AIDS conferences. A MEDLINE search identifies more than 50 citations in the literature.

Public health approaches to communicable disease are rooted in the late 19th century, when the threat of infectious disease provided a warrant for such forceful interventions by health authorities as compulsory examination and screening, named reporting of those infected, and the confinement of individuals through isolation and quarantine [3, 4]. Over the arc of the 20th century, the more coercive aspects of conventional public health became increasingly rare, following the introduction of effective vaccines and therapies and the subsequent waning of infectious disease-related morbidity and mortality. But the shock and alarm generated by the AIDS epidemic left proponents of civil liberties and advocates of gay rights fearful that traditional public health responses might be imposed on newly susceptible or infected populations [5]. What developed instead was a policy in which public health authorities further reduced coercive interventions, at least in their response to AIDS.

Reacting to the prevailing climate of anxiety and fear, intensified by a sense of clinical powerlessness, AIDS activists and their allies in public health fought for policies that would protect the autonomy and privacy rights of those with, or at

greatest risk of contracting HIV infection and forestall discrimination. Their actions were critical to populations—gay men, IV drug users, their partners—who were already socially stigmatized and vulnerable. Coercive measures, many feared, would only serve to thwart efforts to reach those groups within which the epidemic was spreading.

In the United States, the argument for HIV exceptionalism, although used to limit public health surveillance and partner notification, was particularly important in defining antibody testing policy. Following the licensure of the HIV antibody test in 1985, AIDS activists warned of potential dangers, including the probability of stigmatization and discrimination and the psychological burden of knowing of one's infection in the absence of effective therapies. But public health authorities viewed the test as central to their preventive strategies. From the ensuing tension emerged new standards requiring pretest counseling and written informed consent [5]. These requirements distinguished the HIV test from other blood tests routinely ordered by clinicians, often without explanation to the patient.

As physicians' confidence in their competence to manage AIDS grew, they began to criticize the exacting restrictions tied to the antibody test. This was particularly true of pediatricians, who argued that babies, deserving close care if infected, had a right to be tested that superseded their mothers' right to privacy. In the late 1990s, New York and Connecticut mandated HIV testing in newborns.

By then, the AIDS exceptionalism perspective was already under fire, especially as it affected infants. In 1994, a clinical trial reported that treating mothers during pregnancy and newborns directly after birth with zidovudine could reduce the vertical transmission rate of HIV by two-thirds. Two years later, the House of Delegates of the American Medical Association resolved in favor of mandatory testing of all pregnant women. The Institute of Medicine recommended routine testing of all expectant mothers in 1998 but allowed them an informed right of refusal [6]. In 1999, the same year as the New York and Connecticut statutes, the American Academy of Pediatrics and the American College of Obstetricians and Gynecologists together supported universal routine testing with an opt-out provision. In 2001, the Centers for Disease Control and Prevention (CDC) also supported universal screening, but without recommending an opt-out provision [7]. By 2004, 13 states required clinicians to offer testing to pregnant women, and four required routine testing.

If the argument for treating HIV tests like other diagnostic tools was first given voice in the face of the need to manage opportunistic infections in infants, it became an insistent demand when therapeutic prospects radically changed in the mid-1990s with the advent of effective treatment with antiretroviral drugs. Sometimes the call for change was framed in terms of "mainstreaming" HIV, but frequently critics explicitly decried HIV exceptionalism.

A striking feature of the debates that ensued was that, although the term “exceptionalism” was first employed descriptively as a way of characterizing broadly consonant policy decisions, the term itself was transformed into the subject of controversy. Those distressed by HIV testing decisions and those who believed that, from a clinical and public health point of view, change was necessary, saw exceptionalism as the problem. Those who sought to defend the new rights-protective regime were loath to use the term and, in fact, repeatedly asserted that what had emerged in the first years of the AIDS epidemic was simply good public health practice. Therefore, any effort to force HIV into a preconceived or traditional mold of public health would be counterproductive.

Because of the role he would play as a critic, both within the CDC in the United States and at the World Health Organization (WHO) as director of its AIDS program in 2006, Kevin De Cock is pivotal to understanding the continued critique of the exceptionalism perspective. Shocked by a patient whose positive serostatus had gone unrecognized despite multiple visits to his clinic in the United Kingdom, De Cock began in 1996 to demand a reevaluation of the norms governing HIV testing. Specifically, what had once been justified as protecting the rights of individuals could now be viewed as clinical negligence and an impediment to HIV prevention. To remedy this, he began to support routine testing [8, 9].

While working for the CDC in Kenya in 2002, De Cock attempted to challenge the international parameters for HIV testing, expressed in terms of the human rights of those who might be infected by the virus. In a hard-charging critique, “Shadow on the Continent,” De Cock asserted that those who defended such rights had spurned strategies that might better meet the public health crisis posed by AIDS in developing countries [10]. Rather, by treating AIDS like other communicable diseases and increasing HIV testing, public health and medicine would be protecting the rights of the uninfected, enhancing access of those already infected to therapies and clinical advice, and providing nations with tools to reduce the depredations of HIV/AIDS.

In September 2006, the CDC issued long-awaited recommendations for routine HIV testing in clinical settings [11]. Examined from the perspective of the standards established 2 decades earlier, the new approach was indeed a radical departure, an end to the exceptionalism that the CDC had at first embraced without ever using the word. Analyzed in the light of the CDC’s own emerging disenchantment with the strictures surrounding exceptionalism, the 2006 decision represented a culmination rather than an abrupt departure. Its new recommendations (states would still have to act through their laws and regulations) stipulated that patients be told that HIV testing was a routine part of care and be given the opportunity to opt out. Specific written consent would no longer be required because “general consent for medical care is sufficient to encompass consent for HIV testing.” What the CDC had proposed mirrored suggestions made by Dr. Thomas Frieden, now director of the CDC, then commissioner of the New York City Department of Health and Mental Hygiene [12]. The resistance that greeted Frieden’s proposals was emblematic of the



opposition that would surface across the country as efforts were made to pass beyond exceptionalism. But despite such resistance, it was clear that the social, clinical, and political foundations of exceptionalism no longer held sway.

Also in 2006, the WHO, which De Cock had just joined, issued a draft document that stressed a clinician's obligation to initiate HIV testing, with pretest information rather than counseling, and the patient's right to opt out [9]. The result was a year-long debate. The struggle within the WHO to fashion global recommendations for HIV testing reflected the fissures that existed between human rights advocates and public health officials who fought the exceptionalism that had informed the WHO's earlier recommendations. The former feared that proposals to weaken standards of explicit informed consent would render vulnerable populations even more vulnerable without, in fact, extending to them the benefits of antiretroviral therapy. While the outcome of this controversy was by no means as clear cut as that which had occurred in the United States, a close reading of the debate underscores how the exceptionalist paradigm retained its capacity to engender conflict, even when it was no longer hegemonic.

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## Virtual Mentor

American Medical Association Journal of Ethics  
December 2009, Volume 11, Number 12: 993-997.

### MEDICAL NARRATIVE

#### Public Response to Risk: HIV and H1N1

Monica S. Ruiz, PhD, MPH

*"90 people get Swine Flu and everybody wants to wear a mask. A million people have AIDS and no one wants to wear a condom!"—Unknown*

As a public health professional, I have been astounded at the degree of attention that has followed the discovery and spread of the H1N1 virus in the United States. While it is, of course, reasonable that we—as professionals and members of the general public—are aware of emerging infectious diseases and ways to prevent transmission, the level of media coverage and awareness of this disease since the first American case was reported in April 2009 seems to have gone from cautious observation to occasional hysteria. Hand sanitizer dispensers are now ubiquitous in restrooms and at the entryways of buildings. The public is being urged to adopt preventive behavior changes, such as frequent hand washing and sneezing into one's sleeve or elbow if tissues are not available [1]. While the use of facemasks has diminished since the early days of the outbreak, one can only wonder whether or not this behavior will resurface as the 2009 to 2010 flu season gets underway [1, 2].

Perhaps one of the reasons for the vigilance being exercised to prevent H1N1 transmission is that it is indeed a contagious disease that can be spread from person to person. The Centers for Disease Control and Prevention (CDC) has estimated that, during the 1990s, approximately 36,000 people in the United States died each year of seasonal flu-related causes [3]. Anyone—young or old, black or white, rich or poor, can be infected. While some individuals are at greater risk of H1N1 infection, we're all vulnerable to the disease.

But can't the same be said about HIV?

Like H1N1, HIV is a contagious disease that can be spread through interpersonal contact. Mortality data from the CDC shows that, in 1990, there were approximately 26,000 deaths in the United States attributable due to HIV/AIDS; that number rose to a high of approximately 45,000 deaths in 1995 [4]. While the advent of highly active antiretroviral therapies has contributed to a much lower mortality rate, there are still 15,000 deaths each year from HIV/AIDS-related causes [5]. And anyone can be infected. While some individuals are at greater risk for HIV infection, we're all vulnerable to the disease.

Unlike H1N1, though, the media coverage of and public vigilance about HIV has, at best, been sporadic throughout the 25-plus years that this virus has been active in

humans. While public attention to HIV/AIDS does occasionally spike, these spikes are usually connected to the occurrences of large international conferences and periodic scientific advances. A total of 1.1 million Americans are currently living with HIV/AIDS. Revised estimates showed that more new infections (56,000) occur each year than we had previously thought (40,000).

At this point, a word must be said about the obvious difference between H1N1 and HIV: mode of transmission. For any epidemic outbreak, the primary goals of the public health and broader health care workforce are to contain the spread of the infectious agent and educate people on how they can remain uninfected. This is true for both H1N1 and HIV. H1N1 is easily transmissible through casual contact with an infected person (e.g., coughing, sneezing) or contact with a contaminated surface or object, so people may be exposed to the virus without even knowing it. In this case, vigilance on the part of uninfected individuals is paramount to avoiding disease.

While HIV is certainly not as easily transmitted, it can still be argued that it is possible for people to be exposed to the virus without knowing it. Indeed, data indicate that 25 percent of all HIV-infected persons are not aware of their infection, and someone in the United States becomes infected every 9-1/2 minutes [6, 7]. So, just as with H1N1, vigilance on the part of uninfected individuals is paramount for avoiding disease. Despite these statistics, far too many Americans continue to think of HIV as something that happens to other people.

Perhaps one of the main reasons for this cognitive dissonance lies in the fact that, unlike H1N1, HIV/AIDS disproportionately affects those who are on the socioeconomic and cultural margins of what we've been come to know as mainstream American society. To wit:

- African Americans represent only 13 percent of the U.S. population, but account for more HIV and AIDS cases and more HIV-related deaths than any other racial or ethnic group [8]. Similarly, Latinos represent 14 percent of the U.S. population, but have the second highest HIV-prevalence rates in the nation after African Americans [8]. These racial and ethnic minority communities also represent those individuals most in need of, but least likely to have, coverage for (and, therefore, access to) HIV care and other important health and social services, including addiction treatment, mental health services, and general primary care [9].
- Surveillance data from the CDC show that, in 2007, men who have sex with men represented the largest proportion of new HIV/AIDS diagnoses among American adults and adolescents, accounting for 53 percent of total diagnoses and 71 percent of diagnoses among men [5].
- In 2007, injection drug users accounted for 17 percent of newly diagnosed HIV infections. While epidemiological data usually do not include information on use of drugs other than those that are injected, research has shown that the use of alcohol and illicit substances (such as methamphetamines) are also associated with increased risk of HIV infection [10, 11]. Data from the Substance Abuse &

Mental Health Services Administration indicate that, among those persons who need but do not receive treatment for alcohol or substance use, reasons for not receiving treatment included lack of health coverage and inability to pay (36 percent), lack of transportation (10.5 percent), and fear of negative opinions from neighbors (8.9 percent) [12].

Despite the many social- and civil-rights advances that have been made to date, pervasive social forces such as stigma, homophobia, bigotry, discrimination, and disparities in access to health care have ensured that these populations remain on the outside. These social forces are still alive and deeply rooted in our society. Those seeking evidence of this fact need only visit a homeless shelter, witness public protests of gay marriage, or listen to certain members of Congress present their opposition to syringe exchange or comprehensive sex education.

Would the general public's response to HIV/AIDS be different if those afflicted were "ordinary Americans," i.e., predominantly white, middle-class heterosexuals with good health coverage, easy access to care, and no history of risk behavior? This question cannot be answered with hard data. Judging from the emotionally charged debate over a proposed health care plan that might be more inclusive of the needs of the disadvantaged, and publicly expressed fears about how the proposed legislation would affect "ordinary Americans," I would argue that the answer to this question is a resounding "yes."

If those at greatest risk for HIV infection more closely resembled "ordinary Americans," public vigilance about HIV prevention might be comparable to the response currently associated with H1N1. But, ideally, the population's response to an epidemic should not be dependent on whether or not the at-risk individual fits the "ordinary American" profile. Our nation is diverse, and its diversity encompasses race, ethnicity, socioeconomic status, sexual orientation, and health status. As Americans, we are all vulnerable to epidemics like H1N1 and HIV. And, as Americans, we all need access to the educational resources, prevention services, and medical care that are essential to staying healthy. If our policymakers could agree with this principle, we might finally achieve the establishment of a health system in which all people have equal access to care, regardless of who they are or what their illness may be.

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# Virtual Mentor

American Medical Association Journal of Ethics  
December 2009, Volume 11, Number 12: 998-1001.

## OP-ED

### **HIV Stigma and Discrimination Persist, Even in Health Care**

Bebe J. Anderson, JD

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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## Virtual Mentor

American Medical Association Journal of Ethics  
December 2009, Volume 11, Number 12: 1002-1015.

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## **Virtual Mentor**

American Medical Association Journal of Ethics  
December 2009, Volume 11, Number 12: 1016-1019.

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