

# **“HIV Exceptionalism”: Putting HIV/AIDS in the Context of *Universal* Public Health Ethics**

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**Clinical Ethics Grand Round**

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# 30 Years of HIV/AIDS – Die Hard

**Died Once in 1996**

**Died Twice in 2006**

**Yet, still alive now, die harder.**

**BEGINNING OF  
THE END OF AIDS  
BY 2015**



# Or, are we losing it?



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November 10, 1996

## When Plagues End

By Andrew Sullivan

I.

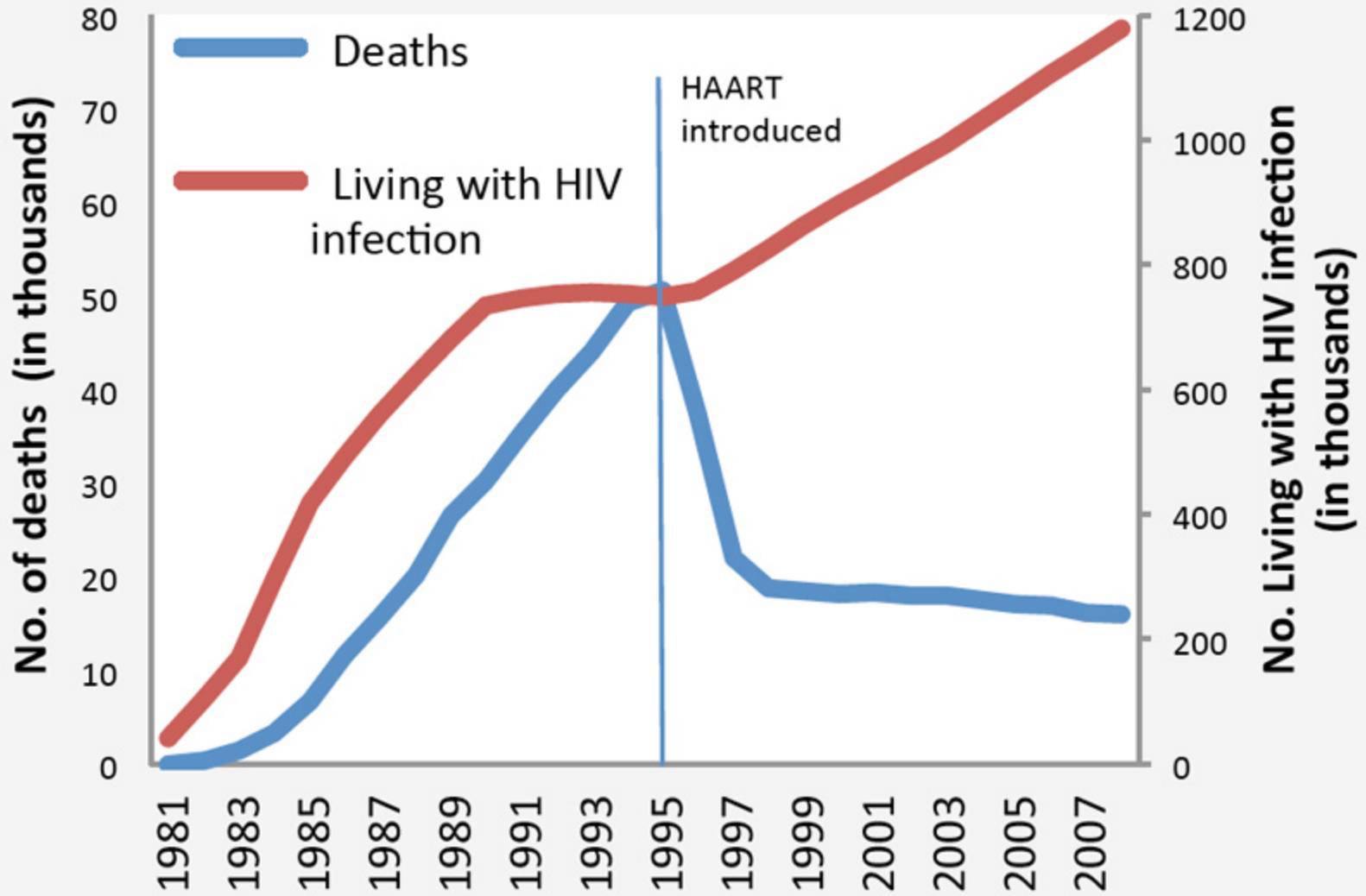
FIRST, THE THINGS I RESIST REMEMBERING, the things that make the good news almost as unbearable as the bad.

And for a precious short time, like so many other positive people, I also sensed that the key to living was not a concentration on fighting the mechanics of the disease (although that was essential) or fighting the mechanics of life (although that is inevitable), but an indifference to both of their imponderables. In order to survive mentally, I had to find a place within myself where plague couldn't get me, where success or failure in such a battle were of equal consequence. This was not an easy task. It required resisting the emotional satisfaction of being cured and the emotional closure of death itself. But in that, of course, it resembled merely what we all go through every day. Living, I discovered for the second, but really the first, time, is not about resolution; it is about the place where plague can't get you.

Only once or twice did I find that place, but now I live in the knowledge of its existence.

So will an entire generation.

# With the Advent of HAART, More People Are Living with HIV Infection (red) as Rates of AIDS-Related Deaths Decline (blue)



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### **PUBLIC HEALTH POLICY AND THE AIDS EPIDEMIC**

#### **An End to HIV Exceptionalism?**

IN the early and mid-1980s, when democratic nations were forced to confront the public health challenge posed by the epidemic of the acquired immunodeficiency syndrome (AIDS), it was necessary to face a set of fundamental questions: Did the history of responses to lethal infectious diseases provide lessons about how best to contain the spread of human immunodeficiency virus (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 so treated, what would justify such differential policies?

Were the end of HIV exceptionalism to mean a reflexive return to the practices of the past, it would represent the loss of a great opportunity to revitalize the tradition of public health so that it might best be adapted to face the inevitable challenges posed not only by the continuing threat of AIDS but also by threats to the communal health that will inevitably present themselves in the future.

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**RONALD BAYER, PH.D.**

# HIV has been exceptional

*Due to socio-political-cultural systems which have potentials to violate human rights for (humane) healthcare and social justice...*

- Testing and screening
  - Voluntary and specific consent?
  - Movement towards routine and mandatory testing
  - Routine testing for pregnant women (recommended by IOM in 1998 and considered by US CDC In 2001)
- Reporting names in confidential registries of public health departments
  - Disease control approach?
- Notification of partners
  - Breach of confidentiality or duty to warn or inform?
- Quarantine and criminalization
  - Impose control over *disobedient* persons for reasons of public health?

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# Changing the Paradigm for HIV Testing — The End of Exceptionalism

Ronald Bayer, Ph.D., and Amy L. Fairchild, Ph.D., M.P.H.

The Centers for Disease Control and Prevention (CDC) is poised to issue new recommendations for testing for HIV in adults, adolescents, and pregnant women. Frustrated that more than 25 percent of Americans with HIV infection are unaware of their status and that almost 40 percent of

those with newly diagnosed AIDS discover that they are infected less than a year before diagnosis, officials have proposed that HIV screening be routinely offered in all health care settings.

The CDC already recommends routine testing among high-risk groups and in high-prevalence set-

tings. The radical departure is the extension of routine testing to the entire population and the reconceptualization of the requirements for consent. Patients would be told that HIV testing was a routine part of care and given the opportunity to opt out. According to the CDC, specific signed consent would no

N ENGL J MED 355:7 WWW.NEJM.ORG AUGUST 17, 2006

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- “[According to CDC,] specific signed consent would no longer be required, because general consent for medical care is sufficient to encompass consent for HIV testing” (p. 647)
- “I am going to perform xxx and do an HIV test. Do you have any questions?”
- *Fear of compulsory... vs. making it more difficult to say “no” justified by public health goals concerning preventable opportunistic infections*



# End or Revival of HIV Exceptionalism

*Open access, freely available online*

The PLoS Medicine Debate

## Is the “3 by 5” Initiative the Best Approach to Tackling the HIV Pandemic?

Jim Yong Kim, Arthur Ammann

**B**ackground to the debate: The World Health Organization (WHO) and its partners aim to treat 3 million people infected with HIV in poor and middle income countries with antiretroviral treatment by the end of 2005. The ambitious “3 by 5” initiative has had its supporters and its critics since its announcement in 2002.

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### Jim Yong Kim’s Viewpoint: 3 by 5 is a Point of Entry, Not an End in Itself

Those who object to 3 by 5 must address this question: what would be the likely cost if it were never attempted? We can work exclusively to prevent the further spread of HIV, or aim to improve treatment access more slowly, but in the meanwhile high-burden countries will collapse at our feet. Or we can aim for 3 by 5 and move ourselves that much closer to the ultimate goal: preventing all unnecessary deaths from HIV.

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### Arthur Ammann’s Viewpoint: The Intentions Are Good, the Approach Is Wrong

The HIV epidemic is the worst pandemic in history. Why, then, is the international public health response so disparate from public health responses to other life-threatening infectious diseases? The 3 by 5 initiative, with no requirement for contact tracing, does not ensure the right of uninfected individuals to be protected or of infected contacts to gain access to treatment. It is time to acknowledge that the severity of the epidemic requires universal offering of HIV testing and counseling, contact tracing, and integration of sound public health prevention and treatment principles into all health-care delivery systems [8,10].

# HIV Testing Without Consent in Critically Ill Patients

JAMA, August 10, 2005—Vol 294, No. 6 (Reprinted)

Scott D. Halpern, MD, PhD, MBioethics

When Bayer first described “HIV exceptionalism” in 1991, he noted that “the effort to sustain a set of policies treating HIV infection as fundamentally different from all other public health threats will be increasingly difficult. Inevitably, HIV exceptionalism will be viewed as a relic of the epidemic’s first years.”<sup>4</sup> Nearly 25 years since the epidemic began, this prediction remains unrealized with regard to HIV testing.

Except for tests for heritable genetic disorders, HIV is the only laboratory, radiographic, or pathologic test for which specific consent is broadly required. For all other tests, there is widespread belief that either implicit consent, or a general consent to medical care, is adequate to protect autonomous choice.<sup>5</sup>

**Table.** Laws of the 53 US States and Territories Regarding Nonconsented Human Immunodeficiency Virus (HIV) Testing of Patients Who Are Incompetent\*

Cases in Which HIV Testing of Incompetent Persons Is Permitted Without the Patient’s Specific Consent	States or Territories*	No. (%)
Whenever physician expects the test result would improve the patient’s immediate medical care	Alabama, Arizona, Arkansas, Colorado, Connecticut, Delaware, Hawaii, Illinois, Indiana, Kentucky, Mississippi, New Hampshire, Utah	13 (25)
Only in an “emergency” and/or “life-threatening” situation	Georgia, Pennsylvania, New Mexico, Ohio, West Virginia, Wisconsin	6 (11)
If next of kin or legal guardian provides surrogate consent	California, Florida, Maryland, Montana, New York, North Carolina†, North Dakota, Rhode Island†	8 (15)
No cases specified	Alaska, District of Columbia, Idaho, Iowa, Kansas, Louisiana, Maine, Massachusetts, Michigan‡, Minnesota, Missouri, Nebraska, Nevada, New Jersey, Oklahoma, Oregon, Puerto Rico, South Carolina, South Dakota, Tennessee, Texas§, Vermont, Virginia, Virgin Islands, Washington, Wyoming	26 (49)

\*Includes all 50 US states, District of Columbia, Puerto Rico, and the Virgin Islands.

†Nonconsented HIV testing is only allowed if authorized surrogates are unavailable.

‡Health facilities may perform nonconsented HIV testing if it “informs the patient in writing upon admission that an HIV test may be performed without written consent.”

§General consent to medical procedures and tests covers HIV testing, but general consent is also required of patients who are incompetent.

# (Against) Nonconsented HIV Testing

- Stigma and discrimination
  - Being diagnosed or even being suspected to being HIV infected
  - What about other diseases like syphilis, TB, hepatitis...?
  - If so, should there be more restrictive consent for the diseases or,
  - Should there be fewer restrictions for HIV?

# Nonconsented HIV Testing

- No fear, but simply do not wish to be tested for HIV
  - Testing a patient against his or her wishes may be ethically wrong and legally negligent
  - Should not be considered as “routine”
  - Without consent, clinicians depends on “T-cell counts” as a proxy to HIV infection
- Most patients who are incompetent would desire any serologic testing that could improve their care if they were competent and aware of their clinical circumstances.
- Therefore, difficult to justify the exceptional treatment of HIV in the case of patients who are incompetent.

# Nonconsented HIV Testing

- Under the policy of “nonconsented or routine” HIV testing, they would avoid access to health care
  - Limited contact would lead to public health loss
  - Lose opportunity to be treated effectively
  - Further alienation and limited acceptance of future public health intervention
  
- Such consequences are less likely if nonconsented HIV testing is limited to critically ill patients

# Support Nonconsented HIV Testing

- Support nonconsented HIV testing among critically ill patients
  - Improve the quality and efficiency of their care
  - Because most patients would likely choose to be tested if they were competent and aware of their clinical circumstances, allowing such testing may respect patients' autonomy even when they cannot voice it.
  - Exceptionalism, once existed in the first decade of the epidemic, is over, rather facilitating stigmatization and limiting the quality of care for at-risk populations

# Surrogate Consent

- Surrogate consent from health care proxy, court-appointed guardian, or relative or friend of patients who are incompetent
  - *Assuming that most patients who are incompetent would wish to be tested for HIV if they were competent and aware of its clinical importance*, surrogate consent is unnecessary because proceeding with testing is itself an enactment of these patients' autonomous choice
  - Critically ill patients with HIV lack surrogates with sufficient insights into patients wishes to provide meaningful consent
  - Very difficult for “proxy” to assess patients risk for infection
  - Surrogates will not be free from their views towards HIV

# Nonconsented Human Immunodeficiency Virus Testing Among Critically Ill Patients

*Arch Intern Med.* 2007;167(21):2323-2328

## *Intensivists' Practices and the Influence of State Laws*

Scott D. Halpern, MD, PhD, MBioethics; Thomas S. Metkus, MD; Barry D. Fuchs, MD; Nicholas S. Ward, MD; Mark D. Siegel, MD; John M. Luce, MD; J. Randall Curtis, MD, MPH

- Of 2333 potentially eligible intensivists, 1026 completed.
- 77.0% of intensivists believed that HIV testing among decisionally incapacitated ICU patients should be allowed whenever the physician believes the test would influence immediate care
- 21.8% believed such testing should only be allowed in medical emergencies
- 1.3% believed such testing should never be allowed
- 62.6% believed they should be able to test for HIV without first obtaining surrogate consent.

**Table 3. Regression Models of Variables Associated With Pursuit of Nonconsented HIV Tests (vs Obtaining Surrogate Consent)**

Independent Variable	Odds Ratio (95% Confidence Interval)	
	Unconditional Model <sup>a</sup>	Conditional Model
Belief that nonconsented testing was ethical	3.8 (2.1-6.5)	3.4 (2.0-5.6)
State law makes exception for nonconsented testing	0.8 (0.6-1.2)	<sup>b</sup>
Belief that state law makes exception for nonconsented testing	2.3 (1.6-3.4)	2.3 (1.5-3.6)
Medical specialist (vs surgery or anesthesia) <sup>c</sup>	1.4 (0.9-2.1)	1.5 (0.9-2.4)
Practice duration > 19 y <sup>d</sup>	1.5 (1.0-2.1)	1.5 (1.1-2.3)

Abbreviation: HIV, human immunodeficiency virus.

<sup>a</sup>Hosmer-Lemeshow  $\chi^2=6.09$  ( $P=.64$ ), indicating adequate fit of the model.

<sup>b</sup>This variable drops out of the conditional model because there is no variance in state laws among intensivists within the same state.

<sup>c</sup>We combined surgeons and anesthesiologists for this analysis because they often practice in the same intensive care units and, therefore, their practices were hypothesized to be more similar to each other than to medical specialists' practices. Indeed, surgeons and anesthesiologists did not differ in their probability of pursuing nonconsented testing ( $P=.40$ ).

<sup>d</sup>Physicians were dichotomized at the median practice duration of 19 years.



# Follow-Up w/ Patients after Testing

- Confidentiality
- Patients should still be given the option to know whether they are infected because they would have had that option if they had been competent at the time of testing.
- Partner notification

# Disclosure to Surrogates

- Ethical duties to provide surrogates of critically ill patients with complete and accurate information on which to base their decisions.
  - What and how are duties
  - Under what circumstances

		HIV is a primary cause for critical illness	
		Need of Anti-retroviral Therapy	No Need of Anti-retroviral Therapy
Surrogate may be harmed by failure to HIV disclosure	Spouse or Sexual Partner	Yes	Yes
	Non-Spouse (e.g., offspring, relative)	Yes and No	No (?)

# Direct and Indirect Duties

- Disclosure may repair surrogates, who would be upset and resentful, ability to make decisions on the patient's behalf.
- Balanced consideration of the direct duties of physicians to patients, and their indirect duties to surrogates and third-party contacts...