

HIV Illusions

Ralph R. Frerichs*

Disease causes great discomfort, both in individuals and societies. To avoid such discomfort, people often hide their illnesses from view. Manic depression is seen as nothing to be proud of, nor is breast cancer or infection with the human immunodeficiency virus (HIV). When faced with such disorders, doctors, family members and friends sense that confidentiality and privacy must be maintained, keeping the disease hidden from view. Governments also are reluctant to admit the presence of disease, citing economic or political concerns as reason for their hiding actions. Some nations will not buy meat from countries where cholera is present and thus avoid reporting cholera cases. Other nations fail to report typhoid outbreaks for fear that tourists will avoid coming to their resorts or communities. Still other governments will not look for signs of HIV infection for fear that religious leaders will accuse them of not cherishing or promoting high moral standards.

Such fears are rarely addressed until some prominent figure is identified who has the disease. In the past, mental depression affected such luminaries as Edgar Allen Poe, Herman Melville, and Vincent Van Gogh, knowledge of which helped people to accept the disease. Betty Ford, wife of United States President Gerald Ford, had breast cancer and was forthright in sharing her discovery, pain and resolve with the nation. On learning of his HIV infection, basketball player Earvin "Magic" Johnson was open enough to hold a press conference and let others know of his disease. Through their public identification or pronouncements, such prominent figures have helped people understand the distinction between the diseased body and the soaring human spirit, and the value of realistically facing and accepting their illness. Yet the battle between reality and illusion continues, and is especially evident with the HIV epidemic.

Minor Illusions

In his book on mental illusions that distort our reasoning power,¹ Piattelli-Palmarini cites a finding in a French study of happiness done several decades earlier. A well-designed opinion poll reported that good health was considered last as an important determinant of happiness, but *not* having good health was cited first among factors causing unhappiness. Piattelli-Palmarini views this as a mild instance of *intransitivity of preferences*, a thought process that distorts our way of reasoning.

Instead of good or poor health, the opinion poll in modern times might have asked about the absence or presence of HIV infection. When thinking of reasons for unhappiness or despair, many might rank highly being infected with HIV, because they have heard numerous bad accounts of the disease. Besides being a life-shortening condition, most have also learned that HIV infected persons face additional hardship from discrimination or social rejection. Thus thinking of HIV seems reasonable when considering reasons for unhappiness.

Happiness, however, taps a different dimension. Here we think of events or occurrences that typically give us joy, and not the avoidance of unsettling events considered terrible but uncommon, like HIV infection. But how uncommon is HIV? Several years ago, a United States household survey found that 72 percent of young adults reported there is *no* chance they are infected with HIV.² When asked if they are currently working near someone infected with HIV, 94 percent responded that it was *unlikely* or *definitely not possible*. Given these findings, it seems reasonable that most younger Americans would not view as a primary determinant of their happiness, *not* being infected with HIV. They might, however, view HIV infection as a major determinant of unhappiness, thereby experiencing the *intransitivity of preferences*.

Major Illusions

Another illusion that creeps into the conversation of many people is the notion that HIV infection is more a social condition than a viral disease. As the epidemic continues to expand throughout the world, many health officials have preached the importance of learning to live with HIV, and have placed less emphasis on avoiding HIV infection. They feel that once infected, there is nothing people can do to ease or extend their life, and little they can do to avoid transmission. Thus knowing you are infected holds little practical value and can only upset the mind. Furthermore they see many social injustices that plague HIV infected persons and reduce the quality of their already-limited life. With such reasoning, some health officials recommend hiding the identity of HIV infected people from public view by avoiding HIV testing altogether, or by keeping secret the results of testing. Yet such thinking overlooks that HIV is a virus which, once adequate contact is made, moves relentlessly from person to person. The illusion that not knowing of HIV is better than knowing eases transmission and makes winners of the virus and losers of humans.³

Prenatal testing. The disparate view of the rights of HIV infected persons and the reality of a virus becomes most apparent in the debate on HIV testing of pregnant women or of newborns. If a woman is infected with HIV, she will transmit the virus to about one-fourth to one-third of her offsprings. Some transmission occurs during the pregnancy, some during the delivery process and some via breastmilk.⁴ Recent studies have shown that transmission of the virus from mother to infant can be reduced by nearly 70 percent if treated with zidovudine (AZT) during and after pregnancy, and the child is not breastfed.⁵ Since harm from discrimination or ostracism may come to the pregnant woman if people learn she is infected, there are undesirable consequences to her being tested and identified. Yet if not tested, harm from the virus may beset her offspring. The illusion that alters the reasoning of many social activists is that discrimination toward HIV infected mothers causes greater harm than the death of some infants, and that the right of the mother to avoid such harm transcends the right of the infant to a virus-free life.

Sexual partner testing. A related illusion arises in policy discussions on testing of married persons or those committed to long-term sexual partners. Some health professionals feel that if persons are found infected, their long-term sexual partners must be informed. They recognize from discordant couple studies (one partner is infected and the other is not) that HIV transmission to the susceptible partner can be reduced by 84-100 percent,^{6,7} but only if both know of the infection and are willing to take appropriate preventive measures. Yet other health professionals argue that the decision to inform sexual partners must be left up to the infected persons, inferring that the right of the infected individual to avoid further discomfort transcends the right of susceptible sexual partners to be told of possible infection. Unfortunately, the virus holds no such illusions.

The 4-40 Illusion

The illusion that preventing certain harm to one type of person has greater value than preventing potential infection and death among other types of people is common among those working in the HIV/AIDS field. Most recently, this argument has been used to block the sale of simple HIV screening tests that can be used in the privacy of the home.⁸ Critics of home testing contend that knowledge derived from such simple tests will cause social ostracism or even suicide among some in the society. These critics, however, disregard the benefits of prevention or early treatment that comes from knowledge, specifically to those

who learn of the infection.⁹ Thus one group in time (HIV infected persons now) is valued more than other groups in time (HIV infected persons in the future, and susceptible persons now).

Another example of this differential value illusion was recently published in *The Lancet* in an article on the right not to know of HIV infection,¹⁰ along with my response.¹¹ The article addresses the sometimes desperate responsibilities of those practicing clinical medicine versus public health. This article subsequently served as the basis for a teaching exercise I created on illusions and public policy that was completed at two workshops in Asia and at UCLA in Los Angeles. The first group who completed the exercise was health professionals from nine Asian countries who were attending an HIV policy workshop in Thailand. The second group was a national group of health professionals attending a workshop in Bangladesh on HIV screening, surveillance and control. The third group who did the exercise was entering graduate students at the beginning of my epidemiology course at UCLA.

The findings reported in *The Lancet* article best describe the basis for the teaching exercise. In the Kenyan study of pregnant women, 324 of 5,274 were tested and found HIV infected. Seventy-five percent of these women returned for their test results and proper counseling. Among the 324 infected women, 19 (or 5.9%) reported a violent event after learning their HIV status. One committed suicide, male partners beat seven, and the remaining 11 were either chased away from their house or replaced by another wife. Reacting to this spousal violence, the authors questioned their policy of informing all women of their test results and if HIV-positive, having them notify their sexual partners. Their new policy was decidedly less rigorous at informing women of their HIV status. HIV-tested women were told that they must ask for their results or findings would not be forthcoming. With the original policy, the Kenya investigators could counsel 75 percent of the HIV-positive women, telling them of the disease and ways to prevent viral transmission. Counseling was less evident with the new *laissez-faire* policy, however, with only 35 percent of the HIV-positive women coming forward to learn of their infection. Yet with this reduction in notification and counseling, the authors noted a parallel reduction in spousal violence. Only six (1.9%) of 311 HIV-infected pregnant women reported a violent event, less than the 5.9 percent who reported violence with the old policy. To avoid harm in the future, the authors concluded that women being HIV tested should have the right not to know of their HIV status.

Different from clinical practice, the intent of public health is to safeguard the community. People are tested for HIV both for their own good and to protect others with whom they have intimate or blood contact. To control the HIV epidemic, public health practitioners must prevent viral transmission, not obfuscate infection. When people do not know they are infected, the virus has an easy time moving from one host to another. The new policy favored by the authors resulted in 40 percent fewer pregnant women being told of their infection. The repercussion was that none of these women knew to seek medical assistance or supportive care, to avoid opportunistic infections, or to consider alternatives to breastfeeding of their uninfected offsprings. Even more central to public health, the uninformed women could not tell sexual partners to avoid unprotected intercourse, and thereby prevent new infection. Thus a policy that benefits few in the short-term (HIV infected pregnant women), harms many in the long run (offspring and husbands).

While the faulty reasoning of the authors seemed clear to me, I wondered if others might view the problem in a different way. Therefore I created a teaching exercise to address this issue which I term here, "the 4-40 illusion." In successive days, three different stories were distributed to workshop or course participants. Each was asked to respond in an anonymous manner, using only an identification number to link the three response forms. The first story, titled *Husbands and Wives*,

featured infected promiscuous husbands and their wives. The story stated that only married men are automatically tested for HIV and the results are shared only with them and their wives. The content was as follows:

Imagine that a country for which you are responsible is experiencing an outbreak of HIV that has already infected 100 husbands, all of whom are expected to die in the coming decade. The microbe is believed to have been transmitted to the husbands by sexual intercourse outside of marriage. If ***policy one*** is adopted, 75 of the husbands would be informed of their disease status (the other 25 could not be contacted after testing), along with their 75 wives, thereby potentially saving 75 female lives. Yet several wives would be upset by this information and 6 would ask people in the village to punish and stone their husbands or force them to leave the community. If ***policy two*** is adopted, the husbands would not be forced to learn of their disease; only 35 of the 100 infected husbands would persist in getting their HIV test results. Like before, these results would be shared with their wives. Among the 35 infected men, 2 would be stoned or forced to leave the community. Thus ***policy two*** compared to ***policy one*** prevents the certain stoning and ostracism of 4 husbands but would also result in the potential death of 40 additional wives and others who the women might subsequently infect.

The second story was titled *Wives and Husbands* and featured prostitutes and their husbands. The story stated that only married commercial sex workers are automatically tested for HIV and the results are shared only with them and their husbands. The plot of the story was the same but the characters differed as follows:

Imagine that a country for which you are responsible is experiencing an outbreak of HIV that has already infected 100 married commercial sex workers, all of whom are expected to die in the coming decade. The microbe is believed to have been transmitted to these married women by sexual intercourse outside of marriage. If ***policy one*** is adopted, 75 of the wives would be informed of their disease (the other 25 could not be contacted after testing), along with their 75 husbands, thereby potentially saving 75 male lives. Yet we know that some husbands would be upset by this information and would beat up or abandon 6 of the wives. If ***policy two*** is adopted, the women would not be forced to learn of their disease; only 35 of the 100 infected wives would persist in getting their test results. Like before, these results would be shared with their husbands. Among the 35 infected women, 2 would be abused or abandoned by their husbands. Thus ***policy two*** compared to ***policy one*** would prevent the certain abuse or abandonment of 4 women but would also result in the potential death of 40 additional husbands and others who the men might subsequently infect

The third story was titled *Husbands and Husbands* and featured homosexual couples. The story stated that as a risk group, homosexual men are automatically tested for HIV and the results are shared only with them and their long-term male lovers. The story went on to read:

Imagine that a country for which you are responsible is experiencing an outbreak of HIV that has already infected 100 homosexual men, all of whom are expected to die in the coming decade. The microbe is believed to have been transmitted to the men by anal intercourse with strangers, not their long-term male partners. If ***policy one*** is adopted, 75 of the men would be informed of their disease (the other 25 could not be contacted after testing), along with their 75 long-term male lovers, thereby potentially saving 75 lives of long-term male companions. Yet we know that some of their long-term male partners would be upset by this information and would beat up or abandon 6 of the infected men. If ***policy two*** is adopted, the infected men

would not be forced to learn of their disease; only 35 of the 100 infected men would persist in getting their test results. Like before, these results would be shared with their long-term male companions. Among the 35 infected men, 2 would be abused or abandoned by their long-term male partners. Thus *policy two* compared to *policy one* would prevent the certain abuse or abandonment of 4 men but would also result in the potential death of 40 additional long-term male lovers, and others having anal intercourse with the infected men.

I asked the workshop participants and my graduate students to mark which of the two policies they favored. My anticipation was that most would favor **policy one** since it *potentially* benefits more people, and but recognized that some might favor **policy two** since it prevents *certain* harm to a smaller number of people. I also anticipated that the characters in the story might influence the choice of policies. This is what occurred, as shown in Table 1. In general, participants from the nine Asian countries who attended the Bangkok workshop were less supportive of policy one (the public health approach) for promiscuous men, more so for female sexworkers, and most for homosexual men. That is, they were most worried about harm from HIV disclosure coming to heterosexual men and least worried about homosexual men. This finding suggests that several participants were likely to select policy one (favorable to public health) only for those people whom they valued the least.

In Bangladesh where the epidemic is still at the early stages, the workshop participants seemed to have less exposure to the social issues surrounding HIV. In general, their policy selection showed no preference for promiscuous heterosexual men or female sexworkers, but did seem to value homosexual men less (see Table 1). Or at least, they were willing to be the most objective regarding public health when considering homosexual men.

Finally in the United States, the entering graduate students seemed to be most concerned with avoiding immediate harm from disclosure for females sexworkers, next with homosexual men, and least with promiscuous heterosexual men (see Table 1). When tallied by gender, the preference among female graduate students for policy two for female sexworkers increased to 30 percent (compared to 15 percent among the male students), suggesting a definite cultural bias for the protection of women from the trauma of bodily harm.

The article in *The Lancet* was written by several women from Belgium and Kenya who might have felt even more sympathy for pregnant women than did the female UCLA students for female sex workers. If this is true, then it seems plausible that the authors might have preferred policy two (avoiding ostracism and discrimination) because of a culturally-derived social preference for pregnant women, even at the expense of husbands or offspring, both of whom would potentially benefit from the prevention of viral transmission. If this occurred, then the *4-40 illusion* would have altered their reasoning, and contributed to a biased policy recommendation.

While the existence of such mental tunnels can never be proven, as observed by Piattelli-Palmarini in his book, *Inevitable Illusions*, such thinking can lead to a collective irrationality that results in great harm when formulating public policy. To be just, HIV control policies should clearly treat all people in a similar manner, favoring life over death. Such just policies, however, will only occur in the HIV field if policymakers can separate mental illusions from epidemiological reality.

* Professor Ralph R. Frerichs, Department of Epidemiology, University of California at Los Angeles (UCLA), Los Angeles, California, 90095-1772 USA

References

1. Piattelli-Palmarini M. Inevitable illusions: How mistakes of reason rule our minds. New York: John Wiley and Sons, 1994;
2. Aguilar SM, Hardy AM. AIDS knowledge and attitudes for 1991: data from the National Health Interview Survey. **Advanced Data from Vital and Health Statistics** 1993; **225**: 1-15.
3. Frerichs RR. HIV winners and losers. **Epidemiology** 1995; **6(3)**: 329-331.
4. Nicholl A, Newell M, Van Praag E, Van de Perre P, Peckham C. Infant feeding policy and practice in the presence of HIV-1 infection. **Aids** 1995; **9**: 107-119.
5. Connor EM, Sperling RS, Gelber R, et al. Reduction of maternal-infant transmission of human immunodeficiency virus type 1 with zidovudine treatment. Pediatric AIDS Clinical Trials Group Protocol 076 Study Group. **New England Journal of Medicine** 1994; **331**: 1173-1180.
6. Saracco A, Musicco M, Nicolosi A, et al. Man-to-woman sexual transmission of HIV: longitudinal study of 343 steady partners of infected men. **Journal of Acquired Immune Deficiency Syndromes** 1993; **6(5)**: 497-502.
7. Nicolosi A, Musicco M, Saracco A, Lazzarin A. Risk factors for woman-to-man sexual transmission of the human immunodeficiency virus. Italian Study Group on HIV Heterosexual Transmission. **Journal of Acquired Immune Deficiency Syndromes** 1994; **7**: 296-300.
8. Frerichs RR. Personal screening for HIV in developing countries. **Lancet** 1994; **343**: 960-962.
9. Mertens TE, Smith GD, Van Praag E. Home testing for HIV [letter]. **Lancet** 1994; **343**: 1293
10. Temmerman M, Ndinya-Achola J, Ambani J, Piot P. The right not to know HIV-test results. **Lancet** 1995; **345**: 969-970.
11. Frerichs, R.R. The right not to know HIV-test results [letter]. **Lancet** 1995; **345**:1506-1507.

Table 1. Selection of HIV testing policies for different groups, by study site.

Workshop or course respondents	Promiscuous Men (Husbands and Wives)		Female Sexworkers (Wives and Husbands)		Homosexual Men (Husbands and Husbands)	
	Policy One	Policy Two	Policy One	Policy Two	Policy One	Policy Two
	%	%	%	%	%	%
Bangkok, Thailand (n=25)	64.0	36.0	84.0	16.0	87.5	12.5*
Dhaka, Bangladesh (n=20)	85.0	15.0	85.0	15.0	95.0	5.0
Los Angeles, CA USA (n=36)	89.9	11.1	75.0	25.0	77.8	22.2
Males (n=13)	92.3	7.7	84.6	15.4	76.9	23.1
Females (n=23)	87.0	13.0	69.6	30.4	78.3	21.7

* one person was not willing to choose