Attitudes and Trends: Public Perception of AIDS

Stephen Mills

The public’s response to the AIDS crisis has captured the attention of a diverse audience including public health officials, health care workers, and politicians. While AIDS information campaigns focus on prevention and fears of contagion, the epidemic has catapulted a host of related concerns into the public arena. Questions about civil liberties, public health measures used in the past, and public acceptance of diverse lifestyles abound in everyday conversations as well as in policy discussions among health officials around the world. Mandatory testing for HIV infection, confidentiality, tracing of sexual contacts, rights to insurance, housing, school attendance, and employment—all these issues hinge on the public’s understanding and beliefs.

Public opinion is a measurable “thermometer” of trends as well as a reference for policy makers and legislators. For the last several years, polling organizations have surveyed the public to determine levels of AIDS awareness, fears of contagion, support for federal spending, and a variety of related issues. A look at the survey results dispels several myths about current public attitudes and pinpoints where information campaigns have succeeded and failed.

AIDS Awareness and Fears of Contagion

By 1983, the year the AIDS virus, HIV, was discovered, a Gallup survey revealed that 77% of the adult population in the United States had heard of AIDS. Two years later, following considerable news coverage of AIDS, the public’s awareness had reached 98%. In California where nearly 25% of all AIDS cases in the country have been diagnosed and where the recently-defeated “LaRouche Initiative” stirred much controversy, the level of awareness is an even higher 99.6%.

However, this high awareness of AIDS does not translate into extensive knowledge of contagion and modes of transmission. While more than 90% of Americans are very much aware of the primary means of transmission, a considerable segment of the population believe that casual association with a person with AIDS can lead to infection.

Studies have shown that relatively high percentages of surveyed individuals believe that AIDS can be contracted from a toilet seat (28%), a shared glass (47%), handling money (10%), and shaking hands with someone who has AIDS (7%). The data strongly suggest that information campaigns and media reports have not successfully educated the public on how AIDS is not spread. Even among residents of large metropolitan cities (500,000+ population) where access and exposure to AIDS information is more plentiful, the same misconceptions prevail.

More specifically, higher percentages of women and older adults are ill-informed about how the virus is transmitted.

This seemingly bleak portrayal of the public’s level of knowledge is improving, however. Compared to a year ago, the public is better informed about questions of viral transmission. In 1985 a CBS News/New York Times survey reported that 49% of respondents knew that AIDS was not transmitted by toilet seats. In a similar survey conducted by CBS in October of 1986, that figure had risen to 57%. That same trend is apparent with kissing; 51% now believe that AIDS cannot be transmitted by kissing, up from 42% last year. Support for one misconception has dropped by one-half during the year: only 6% of the respondents now believe that a person can get AIDS by working in the same office as someone with the disease.

Most people think that others (and this can sometimes be an entire nation) think the same as they do. This “false consensus effect” or “looking glass perception” can greatly hamper attempts to educate the public or to change already existing opinions.

Another question revealed that the public is quite aware of its lack of knowledge. More than half of the respondents in one survey said they knew hardly anything or nothing at all about the disease. Almost one-third mentioned transmission when they were asked what it is about AIDS that they would most like to know.

Public Fear and Its Consequences

The misconceptions of the public have led to considerable fear. Surveys have indicated that fear of contracting AIDS lies between 17% and 25% of the general public (question wording across surveys has produced varied results), a staggering amount considering the relatively low probability of the general public contracting AIDS compared to other diseases. When respondents were asked which two or three serious diseases or medical problems they are most concerned about getting, 13% said AIDS, placing it third behind cancer (59%) and heart disease (31%).

This fear of AIDS, combined most certainly with the extensive media coverage of the disease, has also caused biased perceptions of the scope of the disease. Many respondents believe that AIDS is far more pervasive than it really is. Almost three in ten said in an ABC News/Washington Post survey that continued on page 2
they thought the number of AIDS cases was closer to a million than to 10,000 (the Centers for Disease Control tally as of December 1985, the time of the survey, equaled 15,000).6

Given these fears, it is not surprising that 22% have reported changing their daily behavior patterns in one way or another because of AIDS. Of those who report making changes, more than 10% mention that they are doing at least one of the following: avoiding public restrooms, avoiding gay people, socializing less, limiting sexual intercourse, avoiding blood transfusions, and sticking to one sexual partner.6

Perceptions Among Blacks

Fear of personally contracting AIDS is significantly higher among blacks; thus leading a greater percentage of black respondents to report making behavioral changes similar to those noted above. In an ABC News/Washington Post telephone survey of 1512 individuals during late September of 1985, 36% of the blacks feared that they would someday get the disease compared to 26% of whites. Also, whereas a September 1985 poll conducted by the New York Times and CBS News showed that the general public ranked AIDS third behind cancer and heart disease as a disease they feared most, AIDS was second only to cancer as a disease blacks were most concerned about getting (cancer — 37%, AIDS — 35%, heart disease — 22%).5 This is particularly significant in light of the high rate of heart disease among blacks in the United States. A full 65% of blacks feel that they know little or nothing at all about AIDS, a figure 16% higher than the general population. Blacks are also concerned about different aspects of the disease. Whereas transmission is the major concern for the general public, blacks voice most concern about the origins of the AIDS virus. A probable cause of this concern among blacks is the theory that the AIDS virus originated in Africa.4

Support for Federal Funding

An encouraging and important by-product of the public's fear is a willingness to see the federal government spend more money on research and prevention. Historically, citizens have rejected anything that would bring an increase in taxation. However, almost four in ten (39%) in a Los Angeles Times poll said they would favor in principle an additional one cent a dollar sales tax to be used for AIDS research. Furthermore, the ostensible public outcry against the distribution of sexually explicit material for safe sex educational purposes appears to be limited to a small, albeit vocal, segment. Of the respondents, 74% support the production and distribution of such pamphlets.7

Conflicting Public Values?
The perceived urgency of the AIDS crisis among Americans has pitted the civil liberties of people with AIDS and others against control measures which the public feels are necessary to halt the spread of the disease. In fact, the extent of support for civil rights seems to depend greatly upon whether those rights will spread the disease.8

Since the majority of the public harbors several misconceptions about AIDS, it is not surprising that such draconian measures as quarantine and tattooing have been discussed. However, a solid majority do not favor these actions: 65% are against quarantine and 84% are against tattooing a person with AIDS.9 In fact, despite the public debate over allowing a child with AIDS to attend school, more than two-thirds said that they would send their own children to school if they knew another child in the school had AIDS. Once again, very vocal minorities have greatly exaggerated support for their actions.

However, the quarantine measure illustrates the conditional nature of public support for the civil rights of people with AIDS. It also serves as a lesson on how question wording and order can drastically affect survey results.

In a Los Angeles Times poll, people were asked if they supported "adding AIDS to the list of diseases that must be quarantined in order to control the spread of AIDS." Not only does "quarantining a disease" dehumanize and negate the very human effects of quarantine, but the phrase "in order to control the spread of AIDS" adds a very strong condition to the measure. In this survey 51% of respondents favored quarantine.

Contrast that situation with the question "Do you think people with AIDS should be quarantined?" from an ABC News/Washington Post survey. Though still discouraging in terms of support, only 28% answered in the affirmative. This second formulation of the question is more concise, less conditional, and accurately speaks of quarantining people rather than a disease.6

Public Views on Homosexuality

Since a majority of the individuals in the United States with AIDS are gay and bisexual men, and even more importantly, since this fact is well-perceived by the public, many social observers expected a backlash of increased public intolerance of homosexuality.

Although acts of discrimination and violence against people with AIDS and gays in general are increasing, several data sources indicate that liberalizing trends in public acceptance of homosexuality over the past decade have not reversed, but have, in fact, continued. Comparisons in public opinion from 1977 through 1985 indicate more favorable attitudes toward gay people and their lifestyles with regard to laws about employment, housing discrimination, free speech, marriage, and child custody. However, measurements of opinion change taken in two-year increments indicate a gradual deceleration in support for gays as college teachers and for free speech rights; suggesting that AIDS may be responsible for the slowdown. A September 1986 Gallup Poll found that 54% of the public were opposed to the legalization of "homosexual relations," the largest reported percentage since Gallup began measuring public opinion on this issue in 1977.

Conclusions

Formidable challenges exist for communication campaigns aimed at educating the public. While most of the public perceives AIDS as a serious national health problem, individuals do not feel personally threatened. However, as the epidemiological profile of AIDS changes in the United States and in other Western nations, the need will become even greater for a public better informed about AIDS and one that embraces all demographic sectors.

Public opinion is often difficult to sway, especially on the penetrating issue of AIDS which taps deeply rooted beliefs about death and sexuality. These beliefs are especially resistant to change, partially because individuals are immune to information which conflicts with their existing attitudes. A common tendency is that individuals make flagrant errors in estimating the prevalence of opinions in their social environment — with a bias in the direction of their own opinions. In other words, most people think that others (and this can sometimes be an entire nation) think the same as they do. This "false consensus effect" or "looking glass perception" can greatly hamper attempts to educate the public or to change already existing opinions.

Mere information, however valid or true, does not usually penetrate the psychological barriers set up to new material. Healthcare providers, especially those engaged in educational and promotional activities, should acquaint themselves with the properties of this resistance and adopt a marketing orientation in the development of their programs. Messages and information, much like consumer products, must be sold to their audiences in order for them to be successful.

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and important to adopt low-risk behaviors.

Tertiary Prevention is concerned with preventing as many of the disabling aspects caused by AIDS as possible. This maximizes the living potential of the person with AIDS, ARC, or HIV infection. This is called the “Living with AIDS Model.” One person with AIDS explained, “You’re only dying the final week of your life. Until then you’re living with AIDS.” This helps prevent and manage some of the hopelessness for the individuals who are ill, their significant others, and for the professionals working with them.

Several recommendations for conducting effective AIDS prevention education with either individuals or groups include:

(a) Avoid information overloads; people can only absorb so much at any one time.

(b) Messages about what behaviors are high-risk and what behaviors can be changed must be repeated frequently over time.

(c) Risk reduction messages must be tailored to the targeted audience, for example, using different approaches for men who have sex with men, for I.V. users, for women, for ethnic populations.

(d) Messages about risk reduction must never be punitive but rather always empowering so that behavior and attitude changes can be adopted more easily.

(e) Targeted people must be able to identify and examine their own fears, feelings, and resistances rather than having these force-fed by a trainer or clinician.

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REFERENCES

BRIEFS

In Review

THE SOCIAL DIMENSIONS OF AIDS: Method and Theory by Douglas A. Feldman & Thomas M. Johnson (Editors), Praeger Publishers, New York, NY, 1986; 256 pages, hardbound, $37.05. This book presents 15 original papers on various social, psychological, and cultural aspects of AIDS. Six major themes are addressed: (1) social research strategies, (2) social epidemiology, (3) lifestyle and behavioral change, (4) media, (5) health beliefs and behaviors, and (6) impact of AIDS on health care delivery. While only a few of the papers are based on actual fieldwork in AIDS settings, all offer insights into the pitfalls and limitations of AIDS research.

Siegel and Bauman survey social science research methods and raise crucial issues about the validity and comparability of social science studies of AIDS. They question the accuracy of the information being gathered when selective recall and self-reports are involved. Retrospective questioning quite likely has resulted in overreporting of sexual behaviors thought responsible for the epidemic and underreporting behaviors that have been stigmatized as promiscuous or associated with contracting the disease.

Flam and Stein maintain that any attempt to define the origin of AIDS must consider co-factors, for example, exposure to sperm alloantigens and immune dysfunction, the role of re-exposure to common STDs, etc. Flam and Stein also complain about the dangers of the current rigid definition of AIDS, which
clearly lies at the end of the disease spectrum. As it stands, the definition encompasses few people who have other manifestations of HIV infection and thus results in a very high mortality rate. The authors argue that if a broader definition of AIDS were used, more people would be seen as affected and the mortality rates would appear lower.

Des Jarlais, Friedman, and Strug provide perhaps the best article with their study of AIDS in the subculture of I.V. drug users. The authors' descriptions of shooting galleries and their occupants are excellent. They document the social context for shared needle use and the vital relationships that link individuals who routinely share their "works." The researchers assert that prospects for behavioral changes in this risk group are limited, given the intense climate of suspicion and mistrust in the subculture. AIDS is but one more risk added to the daily dangers of robbery, assault, arrest, and drug overdose faced by these individuals.

The chapter by Casper considers the role that stress may play in individuals who contract AIDS. She suggests that AIDS research has much to contribute to the study of the role of patients' personality and attitude in fighting disease. She also discusses a number of problems with physicians who moralize about lifestyles and suggests ways to circumvent these obstacles to an effective doctor-patient relationship.

Geis and Fuller uncovered a climate of fear and uneasiness among staff dealing with AIDS patients in four midwestern hospices. The staff found great difficulty in expressing their concerns for fear that they would be regarded as unprofessional by their peers. Yet these conflicts between professional values and personal and family values are real and need to be aired.

The overall theme of this book emphasizes that AIDS cannot be fully understood from a biomedical perspective alone. These articles illustrate the need to include input from social and behavioral scientists. In addition, this book offers an overview of methodological issues for researchers interested in entering the field of AIDS research.

—Reviewed by Kenneth W. Payne, PhD

Recent Reports

Needlestick HIV Seroconversion. Few cases of seroconversion to HIV in health care workers after a needlestick injury have been reported, thus emphasizing the low risk of HIV transmission by these events. The exceptions, however, remind health care workers to take adequate precautions. A report from Martinique to The Lancet (October 4, 1986) describes the seroconversion of a young student nurse who pricked the fleshy part of her index finger with a needle used to take blood from an AIDS patient. One month later she tested negative for HIV antibody, but two months later presented with fever and a progressively spreading macular eruption (discolored spots on skin). This condition resolved in three days; but six months after the needlestick injury, the nurse was HIV seropositive. Ongoing tests have revealed little change in the nurse's healthy immunological status. This report is notable in that exposure was so minimal. Readers should also note that it is often difficult to determine whether these anecdotal reports are well-documented from an epidemiological basis. This case should be interpreted in light of much larger studies conducted by San Francisco General Hospital and the Centers for Disease Control that found there is lower risk for these types of HIV exposure.

Natural History of HIV Infection in Zaire. An international group of researchers led by Project SIDA in Kinshasa, Zaire has provided (The Lancet, Sept. 27, 1986) the first estimates for rates of progression to AIDS and ARC among healthy HIV seropositive heterosexual adults in Central Africa. The study looked at 67 healthy seropositive hospital personnel and 113 age and sex matched seronegative controls. During a 7 month period of interviews and tests, 1 seropositive and no seronegatives developed AIDS, 8 seropositives and 1 seronegative developed minor symptoms of immune suppression, and 19 seropositives and 8 seronegatives showed symptoms of minimal lymphadenopathy. These rates are similar to those reported in gay and bisexual men in the United States and Europe.

The researchers concluded, "There is no evidence that seropositive Africans are experiencing a much more aggressive clinical evolution of HIV infection than Americans and Europeans." They also observed that if the natural history of HIV infection among Zairians is similar to that of Americans and Europeans, then this could mean that the two groups are exposed to the same kinds of co-factors or perhaps that co-factors are not essential in determining the progression from HIV infection to AIDS.

This study was conducted over a relatively brief period of time; considering its purpose was to examine the natural history of HIV infection. While this and similar studies are interesting and may yield important data about early clinical symptoms, they make interpretation difficult since natural history observations generally require long-term studies.

Corrections:

The October issue of FOCUS contained two errors. In the lead article, "A Constant Increase: AIDS in Ethnic Communities" by Amanda Houston-Hamilton, DMH, a typographical error misrepresented the percentages of AIDS among ethnic women. The correct percentages are 52% of women with AIDS are Black, 25% are White, and 22% are Latina. In the same article the calculations of Peter Selwyn, MD (and the analysis of the data by author Houston-Hamilton) relating to the number of infants born with AIDS or ARC were printed as reported cases rather than as estimated possible cases. In the June 15, 1986 issue of Hospital Practice, Selwyn states, "Application of the transmission rates reported in the few existing vertical transmission studies would lead to an estimate of 6000 or more cases of AIDS or AIDS-related complex among children born to drug-abusing mothers in New York City." He notes that only 122 such cases have been reported to date.

FOCUS regrets any misunderstanding that may have resulted from these errors.

NEXT MONTH

In the January issue of FOCUS, medical specialists from San Francisco General Hospital will discuss the management of psychiatric patients with AIDS on an inpatient psychiatric ward. Jay Baer, MD, Susan Lewitter Koehler, RN, MS, and Kris Holm, RN will consider the difficulties with patient disposition, symptom management, the kinds of patients being seen, and the rate of increase of psychiatric patients on the hospital's inpatient unit for psychiatric AIDS patients. Baer is the attending physician on the ward; Holm is the acting head nurse; and Lewitter Koehler is a clinical nurse specialist.

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