

AIDS AND NEEDLESS DEATHS: HOW EARLY TREATMENT IS IGNORED

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INTRODUCTION

[Mention length of talk]

[Discussion afterwards with:

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What is this talk about? Our argument is that early intervention in HIV disease (including antibody testing) has become crucial. We will describe certain obstacles that hinder the individual from getting this care. The main difficulties are the lack of a public health campaign around this issue, the lack of appropriate services, and problems that have to do with the relationship between the nature and course of HIV disease, the social construction of "AIDS," and the construction of the individual's experience of being seropositive or ill with HIV.

In this talk we will be mainly concerned with the issue of services for people with asymptomatic HIV infection. Some might argue that resources for HIV disease are too scarce to divert any from caring for those people who are currently ill. We completely agree that no resources should be so diverted. We are not asking that asymptomatic people be given a share of the existing pie. Instead, we are arguing for a bigger pie for everybody. We will not accept a zero-sum game which pits HIV-infected people against each other.

EARLY INTERVENTION

The first thing we need to establish is what is early intervention and why it's crucial.

Advances Provide Hope of Controlling HIV

At some point in the future, HIV infection will probably be a controllable disease — a very serious, life-long disease, but manageable, as diabetes is now. Significant steps in this direction have already been taken: *Pneumocystis carinii* pneumonia (PCP), heretofore the most frequent cause of death from HIV disease, is now widely regarded as *preventable* with certain antibiotics. Expert physicians report that PCP prophylaxis has virtually eliminated both first instances and recurrences of this deadly complication of HIV infection from their practices. Advances have also been made in the treatment and prevention of other opportunistic infections. The introduction of AZT, the first federally-approved drug for HIV infection, has paved the way for more anti-HIV therapies. The life expectancy and quality of life of people with HIV disease has been increased

through more accurate diagnosis and prompt, aggressive treatment of opportunistic infections. One study in New York City found that 15% of people survive at least five years after a diagnosis of CDC-defined AIDS, a survival rate better than many common cancers.

Significance for Asymptomatic Seropositives

It is important to realize that advances in the treatment of HIV disease have not been limited to people with symptomatic illness (such as CDC-defined AIDS), but are increasingly relevant to those infected people who have as yet experienced no symptoms. Recent evidence indicates that a high proportion of HIV infected people will, if left untreated, go on to develop life-threatening symptoms. One authoritative study gave a figure of 42% within 9 years, with the likelihood that a much higher percentage would eventually become seriously ill. Responsible medical opinion now suggests that if you are at some risk of having been HIV infected, you should be anonymously HIV antibody tested so that, if infected, you can be protected from developing PCP. If you are HIV-infected, it is important for your physician to monitor your immune system, since you may have serious immune deficiency and be at high risk of developing PCP in the near future even if you feel completely healthy. → T4

As a general strategy, if HIV infection is treated before serious symptoms develop, it may be possible to control or limit the infection's damage. Also, treatment early in the course of HIV infection may produce fewer side-effects. Treatments are increasingly available for HIV-infected people who are asymptomatic or only mildly symptomatic.

Difficulties With Evidence for Early Intervention

At this point the value of, say, PCP prophylaxis for asymptomatic seropositives has not been definitively proven with large double-blind, placebo-controlled clinical trials. It is unethical to do such trials at this point, and besides, the window of opportunity for such trials is past. Researchers would have a real problem accruing subjects for such a suicidal trial. Yet without formal proof HIV-infected people face myriad obstacles in learning about and getting access to PCP prophylaxis. Is it ethical to continue holding our medical, health educational, and insurance reimbursement systems to the standards of proof we have required so far? In many situations having to do with early intervention, it is a distinct failure of empathy to ask HIV-infected people to wait for formal proof before taking action.

INDIVIDUALS ARE NOT BENEFITING FROM EARLY INTERVENTION

Don't people already know about this?

Lack of Knowledge

Surprisingly, no! Most HIV-infected people in New York City have not heard this message, including a surprisingly large portion of well-educated, middle-class, out-of-the-closet gay men. We presented eight seminars on this topic for GMHC last summer on Fire Island. Audience comments and

questionnaire responses were revealing: many audience members were not aware of the value of PCP prophylaxis; many did not know whether they were HIV infected; many were not under the care of a physician; and some had no health insurance. This is corroborated by our clinical experience at the HIV counseling and testing service at Columbia University that we have operated for the past three years, and is confirmed by opinions canvassed from the medical and AIDS service communities. For example, contacts at gay Alcoholics Anonymous meetings held in Manhattan indicate that many attending such meetings have not been tested for HIV infection despite significant risk. We know that many people only discover that they are HIV infected when they come down with their first episode of PCP.

Denial

But, distressingly, even those people who have heard this message often are not able to act on it, for a complex of practical and psychological reasons. We have an acquaintance who has been very active in many AIDS organizations, and who saw his lover die of AIDS: this man was not monitored and developed PCP last year. We know of many AIDS activists who have not been antibody tested. It is not enough to communicate this information about early intervention passively. There is a compelling need for a public education campaign that can create a consensus towards action among infected people and help the individual overcome denial.

LACK OF ADVOCACY FOR EARLY INTERVENTION

Governments and Institutions

What have the government, medical institutions and physicians, AIDS service and activist organizations and gay organizations done so far to get the message out about early intervention?

Answer: virtually nothing.

There have been no public health campaigns by government agencies at the federal, state, or municipal levels around the issue of early intervention. Neither have major hospitals or other medical institutions done large-scale patient education about this.

Past calls for widespread antibody testing have been at heart based on its symbolic value to the currently seronegative (essentially to separate the sheep from the goats, to enforce the difference of the "other"). Advocates of widespread testing usually either ignored the viewpoint of the seropositive or preemptively assumed that those at significant risk would "naturally" want to be tested. The true message behind these calls for testing was not lost on those at risk, and is remembered tenaciously now. The perception by those at risk that antibody testing is inherently hostile interferes with the acceptance of testing for the purpose of early intervention. So, not only has there been no public health campaign to promote early intervention, but the past public health campaigns for testing have actually alienated the audience for this message.

AIDS Organizations

Groups doing AIDS work have had various responses to this issue. With very few exceptions, change on the testing message has been glacially slow. Project Inform of San Francisco has worked almost alone to promote early intervention so far. Major service organizations such as GMHC and the San Francisco AIDS Foundation have only recently changed their lines. Some national gay activist organizations continue to discourage testing for the sake of treatment. The issue seems a natural one for ACT UP, given that group's pioneering work on the issue of access to treatments, but we aren't aware whether ACT UP considers this issue a priority. Staff and volunteers of many AIDS organizations are often themselves at risk, or have seen many friends and acquaintances die from the disease. This understandably might increase resistance to getting antibody tested, or indeed to crafting organizational policies advocating testing.

LACK OF MEDIA COVERAGE OF EARLY INTERVENTION

How has the mass media covered the issue of early intervention?

Answer: we suspect hardly at all, and usually with ~~total~~ distortion. It would be interesting for someone to do a thorough review of media treatment of these new developments. We can say informally that, for example, The New York Times has run only a small handful of pessimistic articles on early intervention, generally down-playing its significance, and often containing errors of fact.

The Problem of Science As News

Partly this may be attributed to ignorance of new developments because of lack of contact with clinical situation

Early intervention is often seen as not newsworthy. Reporters think there isn't enough drama in incremental steps towards controlling this disease, no human interest. Just as the best is the enemy of the good, the reporter's hunger for a cure obscures the reality and importance of early treatment. Because of the obsessive focus on finding a cure versus developing chronic care, the media tend to report on treatments that attack the underlying disease process (such as antivirals) rather than treatments for OI's (which are usually seen as trivial or beside the point, although they have a tremendous impact on life expectancy and quality of life). This is, of course, a radical failure of empathy. This bias is also seen in funding, by the way, as if the institutions are less interested in serving the currently threatened than in protecting some projected at-risk population.

Media treatment of AIDS is affected by the relationship of doctors and scientists to reporters. There is an institutional bias among medical professionals towards specialty care and acute care. Also, the public standards of proof used in research don't reflect what's actually going on in the offices of expert doctors. Researchers and physicians may be reluctant to go on record as advocating or even using unproven treatments, where the standard of proof is the large, double-blind, placebo-controlled clinical trial.

Media attention to scientific/medical issues has usually been driven by reports from scientific journals, which often have publication delays of six to eighteen months, and which require the same standard of proof.

The Construction of the Reader in the Media

The reader is never seen as being at-risk or as being infected or ill. For instance, although this disease affects a large segment of the New York Times readership, there are no Jane-Brody style articles on how to take of yourself if you may be infected. What is the responsibility of the media to tell their readership of important medical information? Articles are often brutal in their pessimism, as in the incessant drum-beating that AIDS is necessarily fatal (is this a fact or, in some complicated way, a wish?). What is the responsibility of the media to protect the sensibilities of their audience? Many PWAs feel outraged and marginalized by media reporting on HIV disease, for example.

The Construction of People With AIDS in the Media

Who has "AIDS" in eyes of the media?

In the media AIDS becomes a rather fluid category. So, when seropositive female prostitutes are incarcerated in Florida, all the women are described as having "AIDS." Yet, when it comes to reporting on issues of resource allocation to provide services around HIV disease, only those with CDC-defined AIDS are thought of as having "AIDS." Translation: when the latent wish is to separate the subjects of the article from the general population, the "AIDS" category is enlarged as much as possible; when the subjects must be included under the societal umbrella, the category of "AIDS" ends up being as small as possible.

LACK OF SERVICES

99 *Do services exist to provide this kind of care for asymptomatic seropositives in New York?*

We suspect this question is what has plagued AIDS organizations and prevented them from initiating the kind of education campaign we advocate. Many AIDS organizations in New York, which typically originated among a middle-income gay-identified population, are struggling with issues of working with other populations, particularly lower-income groups with less access to health care.

Answer: Services *are* inadequate, especially considering how demand will increase in future. We feel that there is no chance of improvement of services without political action, which requires that the affected population be informed. Many of the problems we will describe concerning access to adequate health care in HIV disease are common to all ambulatory care services in this country. These problems are the result of inherent problems with the United States health care system as well as having aspects peculiar to HIV. However, this is no reason for inaction. For an HIV-infected person facing a reduced life-expectancy, "first, the revolution" is not an acceptable philosophy.

The most recent New York City Department of Health estimate is that between 125,000-235,000 New Yorkers are infected with HIV. These

controversial estimates were reduced from a previous estimate of 500,000, but in any case it is clear that (even accepting the lowest new estimate) there are not 125,000 people getting followed for asymptomatic HIV infection in this city.

Funding Problems Are Local, Not National

It's beyond our scope to talk in detail about sources of funding for this kind of care, but a few points can be made briefly. Direct costs for adequate health care for AIDS would probably be under \$5 billion yearly for the next few years. [Vladeck] This represents only 1% of the national yearly expenditure on health care, and only one-sixth of the average annual increase in health care costs. The problem funding reasonable health care for HIV-infected people stems not from the amounts involved (the cost of AIDS is dwarfed by the cost of rescuing the S&L's) but from the fact that the cost of AIDS is not distributed evenly. A few localities will bear a strikingly disproportionate share of the cost of providing these services. [In contrast, a large proportion of the failing S&L's are in a single state: Texas.]

Even if no new services are funded, education is needed to tell those people who do have access to care to go and get it. Remember, even those HIV-infected people with adequate insurance coverage are for the most part ignorant of the benefits of early intervention.

Services for Those With Health Insurance: Private Physicians

Those with adequate private health insurance can usually find a physician expert in the diagnosis and treatment of HIV disease, *if the individual realizes that this special physician expertise is necessary*. Expert physicians can provide the individual with early intervention as appropriate.

However, the number of expert physicians is still small. A recent editorial in a major journal commented that most private physicians are not aware of the rudiments of proper care for patients with symptomatic HIV infection. "Unfortunately, most primary care physicians have not yet [developed] the knowledge and skills needed for diagnosing and treating problems associated with HIV infection." [Annals of Internal Medicine, 15 Nov 1988; 109:773-775.] The same editorial lists priority areas for routine care of ambulatory patients with AIDS:

- How to evaluate common AIDS-related symptoms
- How to treat AIDS-related mycobacterial infections
- How to treat AIDS-related protozoan infections
- How to administer antifungal therapy for AIDS-related infections
- How to select prophylactic regimens against *P. carinii* pneumonia
- How to administer antiretroviral therapy
- How to manage complications of pregnancy associated with HIV infection
- How to assist patients with decisions about the aggressiveness of treatment
- Community resources for patients with AIDS

- Which conditions in patients with AIDS will require referral to subspecialists

This editorial goes on to list areas of importance for all HIV-infected people (including those yet asymptomatic):

- How to counsel patients about HIV antibody testing
- How to obtain a sexual history
- How to provide sexual counseling
- How to care for homosexual patients

Interestingly, the authors do not mention T4 cell count monitoring for any patients, much less for early intervention with asymptomatic patients. Most physicians are probably even less aware of the need for testing for patients at risk, and immune monitoring, and PCP prophylaxis of asymptomatic seropositive patients.

Also, even those with insurance may not be able to afford early intervention with drug therapies that have not been approved and so are not reimbursed by health insurance. The standard of proof rides again.

Services for Those Without Adequate Insurance

What about those who do not have insurance that pays for private ambulatory care?

There are two groups of people in this situation. The first group is those who are under-insured, that is, those who have some kind of health insurance, but it doesn't pay for ambulatory care. TKTK Tim Sweeney. The other group is those who are dependent on Medicaid. You have to be very poor to qualify for Medicaid. You must have income below \$440 per month, and savings of no more than \$3500 (plus a special \$1500 to bury yourself).

In a certain way those who merely under-insured are in the worst situation because there are virtually no clinics in New York that charge affordable fees for people with source of reimbursement (the exceptions are Mt. Sinai and the Community Health Project, which both often have long waiting lists).

Service for the Medicaid-Dependent

What about the HIV-infected person on Medicaid? Why can't somebody with Medicaid just go to a private doctor and have the doctor reimbursed by Medicaid?

Most private doctors do not take new Medicaid patients because of the unrealistically low reimbursement rates of Medicaid and the huge amount of paperwork required.

AIDS Clinics

The HIV-infected person on Medicaid is almost always required to fall back on clinics for ambulatory care. Clinic services specific for HIV infection are nowhere centrally listed and exist only as a fluctuating patchwork. A number of hospitals in New York City will provide relatively adequate services for HIV-infected Medicaid-eligible patients. At the moment, it is still usually possible to obtain services somewhere, but the quantity of such services available is grossly inadequate even for the near future. Even AIDS-designated treatment hospitals

do not necessarily accept asymptomatic patients in their AIDS clinics — e.g., New York Hospital and Columbia-Presbyterian Medical Center. To illustrate the nickel-and-dime level at which services are appearing, the head of the AIDS program at Presbyterian is currently struggling to get funds for a single nurse-practitioner to serve asymptomatic HIV-infected patients.

Other Clinics

What does the asymptomatic HIV-infected person on Medicaid do if he or she cannot get into a hospital AIDS clinic?

Two possibilities are to use either the general medical clinic or the infectious disease clinic at hospitals. There are two problems with these approaches. At a general medical clinic you are likely to run into the same problems described with private physicians — that is, the staff may not know how to take care of HIV-infected people. Infectious disease clinic staff are specialists, and do not provide primary care. *Rona*

This is why public education for patients is crucial. The more people know what kind of care they need, the better their chances are of wrenching it out of these systems.

Lack of Medicaid-Funded Clinics for Early Intervention

Why don't hospitals provide treatment for asymptomatic seropositive patients in their AIDS clinics?

It has to do with funding. The AIDS Institute (part of the New York State Dept. of Health) sets Medicaid reimbursement rates. They have provided a higher rate of reimbursement at AIDS-designated centers for ambulatory care visits by patients with AIDS than for ambulatory care visits by asymptomatic seropositives. Even the higher rate is too low for hospitals to recoup the expense of treating HIV-infected patients. The NYS Dept. of Health published a "Criteria Manual for the Treatment of AIDS" in order to set standards of care at AIDS-designated centers. These criteria include a protocol for an initial assessment visit for an asymptomatic seropositive patient. One expert doctor estimated that this work-up might cost \$1000, and a hospital could realistically hope to get about \$100 in reimbursement for the visit. TTKK psychosocial.

When Medicaid pays the bills, they set the terms. The terms are: non-Medicaid patients must pay, there is lots of red tape, innovative programs are virtually impossible to implement, and the whole system suffers from general rigidity. Basically, Medicaid was designed for in-patient acute care services and not for ambulatory primary care. This problem is not special to HIV disease, but is a problem for all Medicaid-funded ambulatory care.

Lack of Non-Medicaid Services for the Poor

in the past, there have been other sources of ambulatory care for the poor besides Medicaid. For example, community health centers, which were Federally-funded by block grants from the federal Public Health Service. Although some of these clinics still exist, they have been systematically starved under Reagan. As Bruce Vladeck, the president of the United Hospital Fund, has written,

Once upon a time, the federal government played a major role in supporting a wehole range of specific health care services through direct grants to providers, or to state governments acting as intermediaries, but that role has eroded significantly in the past decade... Once upon a time, when confronted with a public health problem of anywhere near the magnitude of the AIDS epidemic, it would be taken for granted that a part of the public policy response would be block-grant support for service delivery from the federal government. By an unhappy coincidence of fate, however — unhappy at least from the perspective of state and local governments and persons with AIDS and those caring for them — the HIV epidemic has coincided almost simultaneously with the Reagan Revolution in American social policy. In general there is less help from the federal government for human services of all sorts. At the same time, it must be emphasized, with the signal exception of the short-lived ADAP program to pay for AZT for non-Medicaid eligible persons with AIDS, the very significant proportional growth in federal spending on the AIDS epidemic in the last three years has been comprised entirely of funds for research, education, and surveillance, along with the federal share of Medicaid expenses — worthy activities all, but of little help to people who are actively ill.

[Vladeck, Bruce C. The economics of a caring approach. Prepared for the Conference on the AIDS Patient and the Health Professional, Cornell Univ. medical College, Fifth Conf. on Health Policy, Feb. 22-23, 1989.]

Services Are Not Adequate for Current or Projected Need

In New York City, city-run anonymous test sites test 1400 to 1800 people per month, with about 200 of those testing positive. According to Robin James, Project Coordinator of a city anonymous testing site, counselors *are* currently able to find ambulatory care services for clients who test positive, but the wait for an initial appointment is about three weeks to two months. Unfortunately, informal studies suggest that half of those testing positive through the city are *already significantly immune compromised*, and therefore in *immediate* need of evaluation and care. According to Ellen Rutenber, the Assistant Commissioner for AIDS of the New York City Dept. of Health, there is indeed currently a huge lack of ambulatory care services for HIV-infected people, and said that DOH is working on proposals to increase services. The success of these proposals will depend on budget constraints. As the number of people testing positive increases, the demand for services is going to rise and the waiting time before obtaining a clinic appointment is going to get longer and longer.

So: the lack of services is real. The need to increase these services is pressing. The funds required are not large relative to national expenditures for health care. Political action is needed.

THE SYMBOLIC MEANING OF EARLY INTERVENTION FOR THE INDIVIDUAL

We have two purposes to advocate: 1) we want to convince individuals who can get care to do so: because there are many psychological barriers even if you do have access to health care; and 2) we want to enable a political movement around the development and acquisition of these services in order to get institutions to respond.

Unless the experience of the individual affected is understood, we'll always be ten steps behind. Montefiore conference story TKTK expand: safer sex campaigns ignoring those groups who need them most. Most safer sex education in NYC for gay men came from the gay community. As has been widely discussed, the notion of the "other" interferes with planning of rational programs. So planning programs and allocating resources rationally require empathy: it needs to be done by thinking from point of view of individual most affected.

We need to study the interaction of three things: the nature and course of HIV disease, social construction of the illness, and the construction of the experience of the individual. No one of these suffices to explain the observable problems. First of all, we cannot ignore the realities of the disease, and the particular problems it imposes on those it affects. But beyond this are less tangible factors. This illness exists in a social context with powerful effects. Yet people are not just blank slates on whom the media and government write things — the social construction view is not enough. People bring their own characters and conflicts to the experience of HIV disease. These psychological reactions are crucial determinants of the individual's ability to use medical care. Of course, their psychological reactions are *mediated* by the social construction, the context of how AIDS is discussed. We need to understand the relationship between these three issues.

Some of these points may be of practical use, but some will of course not be solvable within a practical program. (We will not even mention the psychological stress of not being able to get medical care at all.)

Parenthetically, the source of our experience is our clinical work, friends, reading, study, etc. there are definite limitations to our experience. We have observed a university population, which means that there is probably much that we have missed that affects other groups. Our points should not be seen as all-inclusive. But the psychological observations we make should apply across the board, such as they are, since psychopathology is a right not a privilege.

A History of the "Folk Epidemiology" of HIV Disease

Over the course of the epidemic, people developed ideas to explain what was happening. These ideas constituted a "folk epidemiology" that still affect people's behavior in regard to getting tested and treated.

Risk Groups

1981-1983: When AIDS first was noticed, it was first identified among a stigmatized group in this country, i.e. gay men. AIDS became identified with this group (remember GRID?). It was unfamiliar, frightening, protean, without order. There was a tremendous need to make order out of this disorder, both for scientific and emotional reasons and so that the individual could hope to place himself or herself far from that category of people who might have or get AIDS.

Initially if you were a gay man there were two categories you could belong to: being at risk or having AIDS. Later on there came to be the idea of being at-

risk, having ARC, or having AIDS. The question of who would go from being at risk to being sick was of obsessive, powerful interest.

Theories were developed about who would get sick, based partially on the shreds of scientific knowledge that were available, and partially on magical ideas often unconsciously connected to concepts of morality, as can be seen in the thinking gay men used to ward off the fantasy of themselves as ill. Efforts to develop rational theories about the illness became contaminated with moralizing among both the disapproving straight society and gay men themselves: see for example theories about drug use (such as poppers), fast lane, disco bunnies, dangerous older gays, getting fucked, and effeminacy. Some gay men theorized that "political" gays were safe, pinstripe gays were safe, rich gays were safe, young gays were safe, "nice gays" were safe, straight-acting gays were safe, currently celibate gays were safe. This is analogous to what Freud in a discussion of racism in *Civilization and Its Discontents* labels the "narcissism of minor difference."

Whatever overlap some of these ideas had with scientifically defensible observations, they were never rational causal explanations. Whatever people felt guilty about began to be connected to AIDS. Bargaining with the self began, offering penance for the hope of salvation.

HIV Positive and HIV Negative

1983-1985: With the observation that transfusion recipients and intravenous drug users were becoming sick, theoried relying on co-factors and lifestyle issues began to give way to an infectious disease model. With improved observations about transmission patterns, the discovery of HIV, and the introduction of the HIV antibody test a new set of categories gained authority: "zero-risk," HIV negative, at-risk, HIV positive, ARC, and AIDS.

The specter of mandatory testing posed a real threat to the civil liberties of HIV-infected people. Mandatory testing has so far been used against certain "captive" populations: people in the military, Foreign Service, immigrants, prisoners, Job Corps, and in certain health and life insurance contexts.

Although universal mandatory testing has yet to come to pass, the encoded message of such testing has had a profound impact on people's individual fantasy/experience of being tested. This encoded message was something like: "I am afraid of AIDS. Facts about transmission don't overcome my fear. What I'll do instead is make certain people synonymous with AIDS and imagine that I can protect myself by thinking about how different I am from those people." Testing offered the perfect magic tool to foster this irrational fantasy. Society's construction of antibody testing forces individual to experience testing as risking identification with "AIDS."

Remember that original social construction of testing: our concern here is the effect of this on individuals who test positive. Of course, practical problems with antibody testing including legislative failure to protect HIV-infected people from discrimination (particularly as regards health insurance) make people reluctant to get tested. But beyond this, the mental association of antibody testing

with stigmatization and of seropositivity with AIDS interferes with the individual's willingness to use testing for medical purposes. Insofar as the test was used to symbolically separate the general population from the dangerous Others, the emotional peril of testing positive is increased.

Conversion to Symptomatic Disease

New, pessimistic, data have appeared implying that the majority of those infected will if left untreated progress from asymptomatic infection to life-threatening opportunistic illnesses. This makes early intervention even more important, but makes testing positive more frightening.

Summary: Even Valid Medical Distinctions Have Symbolic Value

There have been a variety of ways that people have made distinctions between who is "sick" and not "sick." What we can observe is the evolution of these distinctions as people attempt to maintain distance between themselves and their most frightening fantasies about being sick with AIDS.

- AIDS vs. not AIDS
- Risk groups vs. the general population
- AIDS vs. ARC
- AIDS vs. asymptomatic seropositive

These distinction may or may not have scientific/medical utility, but inevitably bring along unconscious baggage.

Identifying With the Self-With-AIDS is Difficult

When we tell people to get antibody tested and get medical care, we must recognize that we are asking them to blur exactly the distinction they most want to maintain. We believe that it is most medically useful for the individual to see HIV disease as a continuous spectrum, but this presents a emotional strain to the individual: he or she must see him or herself on a continuous spectrum with the fantasized self-with-AIDS. When we speak of the fantasized self-with-AIDS we are not talking about PWAs, and their actual lives and experiences. For an asymptomatic HIV infected person the fantasy of what it would be like to have AIDS is constructed from many factors, only one of which is their actual experience of people they know with AIDS. The lives and experiences of PWAs are, of course, not all the same.

There is a tension for the individual between enough identification with the self-with-AIDS to allow rational action, and enough distance from the worst fantasy of the self-with-AIDS to prevent crippling paralysis? What is realistic optimism for the seropositive individual? What is dangerous denial? How can the individual maintain equilibrium, given the many disruptions to this optimal balance, i.e. the awful New York Times?

Consider the magnitude of the mental and practical work that confronts the individual at risk. At minimum, the task includes:

- Obtaining and maintaining adequate health, life, and disability insurance.
- Finding a doctor.

- Coping with being antibody tested.
- Coping with anxiety about symptoms real or imagined
- Overcoming your fear of doctor's visits and regular lab tests (e.g., quarterly T4 counts)

- Complying with medication schedules
- Reading scientific material that may be anxiety-provoking

Each of these sub-tasks implies a constant reminder of stigmatization, illness, and death. In our clinical work we see over and over again how hard it is for people simply to go to the doctor. It's not just that you have to live passively with these anxieties, but that you have to simultaneously act (and act well — the skills necessary to succeed in these tasks can be very class-bound). Doing AIDS work, subscribing to newsletters, belonging to HIV support groups are all valuable sources of information and comfort to infected individuals. However, they all require increased identification with other infected people. For the individual, this is sometimes helpful and sometimes is experienced as increasing a sense of difference and damage.

Aspects of the Individual's Experience of HIV Disease

We do not mean to suggest that there is some universal or even typical experience of being HIV-infected, since psyches and circumstances are diverse. Rather, we want to sketch some emotional dilemmas faced by HIV-infected people. Some things we will mention are not specific to HIV, but may also be found in people with other serious chronic illnesses. However, there are aspects of the experience peculiar to HIV disease that intensify the distress of the individual. What is symbolically or psychologically special for the individual about HIV disease? How does this make people reluctant to be tested? How does this make seropositive people reluctant to get appropriate medical care?

Reminders of Pain and Death

Don't forget the obvious: everything relating to HIV disease is tinged with pain and death, which are always distressing to contemplate. Many HIV-infected people have seen friends die from the disease and retain frightening pictures of the process. Also, the media treat HIV disease differently from other diseases. You don't read about other diseases in the paper every single day. There is a barrage of (mis)information in media that alternates with an eerily selective silence on certain topics. We discussed some aspects of media coverage relating to early intervention above. Much has been written elsewhere about the activity of the media around AIDS in general (cf. Simon Watney's book, *The Policing of Desire*). If you are not infected or at risk, it is a good exercise to try reading the paper from the point of view of someone who is infected or someone who is sick. What is it like to read the obituaries first every day? Simply reading or learning about the illness is difficult for many people. The very people who need the information are likely to pass it up as too depressing. Susan Sontag has written about what it is like to have the disease which has become the metaphor for danger.

Loss of Control and Autonomy

Once people test positive, and take it seriously as requiring special medical attention, there are myriad small injuries to the supportive routine of daily life. What impact do going to the doctor more frequently, taking medication, learning and thinking more about HIV have on the patient? Loss of control: What is it like to have job, housing, eating, travel options restricted by HIV? What is it like to have to keep a job you despise in order to keep your health insurance? HIV-infected people deal with many issues relating to loss of control — many required doctor's appointments (with the attendant waiting), confronting the chance that you may become dependent on medication or an in-dwelling catheter, become home-bound or require some form of life-support.

The regular use of the T4 cell count and prognostic markers generate much of the "otherness" and disruption of the antibody test, but T4 counts are done over and over, indefinitely.

Disruption of Expectations About the Future

How can HIV-infected people rationally plan for the future? Is it rational to pretend that nothing is different? Who is that for? People are unnerved by the sense of an immortal virus living inside them, "lurking" and waiting to cause trouble. HIV observes no statute of limitations — even a decade of health following infection cannot give a sense of security. The type of cautious planning that is rational for HIV-infected people is usually developmentally anomalous. It often puts young people in the situation of very old, fragile people.

Ambiguous Health Status

Sick vs. healthy: How can people understand themselves as sick if they are feeling and looking fine? Sick and healthy lose their meaning in HIV infection. If you are HIV infected, have no current symptoms, but have a low T4 cell count, are you sick or are you healthy? Neither is precisely true. What does it mean to know yourself to be sick in some way and yet not have that fact be generally acknowledged by those around you? Contrariwise, what does it mean to have others regard you as sick although you may feel as healthy as you ever have? What does it mean to take medication that may make you feel more ill than you might otherwise feel (as in chemotherapy)? This is the situation of some people who start AZT when they are asymptomatic but below 200 T4 cells: some who felt fine before taking AZT become anemic and feel sick.

Unpredictable Transitions

"Time bomb:" People with HIV infection are sometimes ill, and sometimes well. Transition into illness can happen suddenly and without warning at any time. The perception of your own body as a "ticking time bomb" adds a very unpleasant element of suspense that might not be present with illnesses that follow a more predictable course. Minor symptoms (which in seronegative people are easily dismissed) frequently become a source of profound anxiety. In the days when ARC was a more widely used diagnostic category, studies by MSK

psychologist Susan Tross indicated that PWARCs had an even higher rate of psychological distress than PWAs.

Disruption of Social and Sexual Lives

What is the difference between establishing contact with others (social and sexual relationships) when you merely know yourself to be at risk for HIV and when you know you are seropositive? How does it change the nature of fear of rejection to conceive of oneself as "damaged goods?" There is a set of difficult issues having to do with the formation of sexual and romantic relationships when one or more partners has a known infection. Do you tell your sexual partner? When? Will you be rejected? Will your lover desert you if you become ill? Will you desert your lover if he or she becomes ill? Will you be stuck as someone's unwilling care-taker? Are you yourself looking for a lover or a potential nurse? These issues can arise even in non-sexual friendships. Even the question of whether it is prudent or desirable to tell friends of your seropositivity can be tricky. There are practical and emotional risks to discussing your infection publicly, yet how can you feel close to your friends if they do not know something so central to your life?

Sex and Guilt

Children construct illness as punishment. This idea lingers in the unconscious of the adult. Some illnesses are more likely than others to be felt in terms of this unconscious fantasy. Illness associated with sexuality is very likely to be interpreted as punishment for unknown transgressions.

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Analilty

Anal sexuality is frequently associated with HIV disease, both because of certain scientific speculations regarding transmission of the virus and because of the common equation of homosexuality, anal erotism, and AIDS. In psychoanalytic theory, conflicts regarding analty are in the course of development and in the unconscious related to feelings of shame. This makes HIV disease a powerful magnet for feelings of shame. This can be seen in the tendency to talk of HIV in the moral language of contamination. Specifically, it is both common and painful for infected people to experience their blood and semen (usually seen as life-giving fluids) as contaminated.

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People with HIV sometimes feel guilt and shame because society tells them to feel guilty and ashamed. However, these emotions derive extra power from reverberation with the individual's own inner conflicts.

[On the topic of analty, it is interesting to note that anal intercourse may not be a more efficient route of transmission than vaginal intercourse. The premature conviction this concept met in the scientific establishment may have resulted more from some scientists' fear of analty than from any objective evidence concerning HIV.]

Aggression and Danger

Over the course of the epidemic there has been an exaggerated interest in the idea of a person with AIDS purposely infecting innocent victims. See for example, Shilts portrayal of Gaetan Dugas in *And the band played on*. We call this the "malicious leper" myth. This image powerfully heightens the infected individual's internal conflicts about his or her own aggressive impulses. All people have to cope with such impulses, and it doesn't make it easier to be young and sick. Hence the terrifying image of one's genitalia as a "loaded gun" and of one's sexual fluids as poison, capable of killing with a single orgasm.

Loss of Self

"Cold, cold speck in a tiny, tiny universe." The arbitrary fate assigned to HIV-infected people is unbearably decentering to the individual and encourages magical thinking about the causality of HIV disease. Vicissitudes of fate are inexplicable and, in a certain sense, meaningless. Our best efforts do not change this. It can seem unbearable to be aware of yourself the object of arbitrary fate. There is a tendency to generate a moral system to restore the self and its actions to significance, rather than to tolerate the insignificance of the self in AIDS. This is true even if it requires categorizing the self or past behavior as "bad." At times it feels better to say, "This happened because I was bad," rather than to say, "This just happened."

"Thinking positively" ^{may} is the flip side of this type of magical thinking. It restores the self to a position of control and power by asserting that intentional acts can influence the course of the illness in some beneficial way. This can be dangerous if magical thinking keeps the individual from getting needed medical care.

[Incidentally, this dynamic may be part of the unconscious motivation of those who maintain that "lifestyle factors" are the cause of AIDS, not HIV. Certainly, Peter Duesberg's agenda is moral in tone and punitive in intent.]

CONCLUSION

So what has this talk been about? Our argument has been that early intervention in HIV disease (including antibody testing) has become crucial. The main difficulties are the lack of a public health campaign around this issue, the lack of appropriate services, and problems that have to do with the relationship between the nature and course of HIV disease, the social construction of "AIDS," and the construction of the individual's experience of being seropositive or ill with HIV.

We call for public education about early intervention for HIV disease, for increased services for this purpose, and for sensitivity to the interaction of the social construction of AIDS with the individual's psychological conflicts.