Language, Conceptions of AIDS, and Mental Health
Robert Marks and James W. Dilley, MD

Language reflects our understanding of the world. But the relationship is reciprocal: the world takes on meaning from the words we use to describe it. Language also plays an important role in mental health. The “stories we tell ourselves”—how we describe the world and our responses to the world—have an important impact on how we feel about ourselves and our relationship to others. From early on in the epidemic, language has played a central role in the way people conceive of and emotionally respond to HIV disease. Perhaps the best example of this dynamic is the Centers for Disease Control’s (CDC) AIDS definition.

The CDC first defined AIDS in 1982. In terms of the incomplete scientific and epidemiologic understanding of the time, AIDS was an immune dysfunction of unknown origin that led to the development of specific life-threatening opportunistic conditions. As time passed, the CDC added other conditions to the list of AIDS-defining diseases and made a distinction between less severe and more serious conditions. Basically, however, the foundation of the definition, and what became the popular conception of the disease, remained the same.

Despite revisions in 1985 and 1987, the CDC definition has not kept pace with scientific, epidemiologic, or linguistic realities. Society and the CDC have continued to conceive of AIDS in terms of the serious conditions from which most people die rather than in terms of the actions of the virus itself. In August 1991, however, the CDC proposed a new AIDS definition, one that was clearly tied to the direct role of HIV in disease development.

It is in the light of this proposal—now withdrawn—that this article explores conceptions of HIV disease and the mental health implications of these conceptions. Further, this article attempts to reconcile the apparent contradiction between fundamental medical and psychological approaches to HIV disease: “early intervention,” which requires treatment action early in the course of infection; and “adaptive denial,” which enables people with HIV disease to cope with the full psychological impact of facing a life-threatening condition. Ultimately, this article is about the distinction between being HIV antibody positive and having AIDS, and the language we use in the stories we tell ourselves about HIV disease.

The Proposal and Its Genesis

The CDC AIDS definition was designed to track the spread of the epidemic in the U.S., and to a great extent in the world, and worked well despite changes in scientific knowledge. Since 1982, it has also been used to define the clinical identity of HIV disease for physicians, to determine access to Social Security and other financial benefits, and to determine eligibility for services by AIDS agencies throughout the country. The 1991 change—whose effective date was postponed from January 1 to April 1 and finally to July 1, 1992 before being “postponed indefinitely”—would have maintained the 1987 definition and its focus on AIDS-defining opportunistic diseases, but would have added to this list a T-helper cell count of 200 or less. Epidemiologists predicted that by using the new definition, the number of people with “AIDS” would double.1

It is important to examine briefly the genesis of the proposed change. Because of its use as a criterion for distributing disability-related financial benefits and
AIDS—The term is only 10 years old, and much of what it connotes is still a mystery. But its grip is spellbinding.

For a little more than a decade, the term AIDS has been a powerful label to describe something that is not easily explained. It evokes a grim chill in all parts of society: intense anger is expressed by both those who view it as a scourge on society and intense pain by those who have felt directly the sting of the epidemic. And it has been used to determine, ever so coldly, who qualifies for government assistance and who goes without.

Little wonder then that the process of trying to redefine, narrow, or discard the term has proven difficult. By watching the failed attempts of the Centers for Disease Control, we’ve seen that its meaning has become too established—and its ownership too much in contention in the public and political domain— for even its inventors to regain control and officially assign it a new meaning.

On some practical levels, however, its meaning is slowly evolving, as Robert Marks and James Dilley describe in this month’s FOCUS. The authors place the term AIDS in a context by tracing its history and then describing its diminishing applicability. They argue that the term’s value is diminishing as scientists gauge the direct effects of HIV on the immune system rather than relying on the HIV-related physical manifestations that comprise AIDS and occur late in the course of disease.

As a result, the meaning of “HIV disease,” a term that is less overwhelming than “AIDS,” is becoming better understood and receiving more emphasis. This has both mental health and medical implications. Marks and Dilley explore the first of these.

HIV-related services, the AIDS definition has become particularly important to traditionally underserved populations. Advocates for these diverse groups—noting that the definition was based on research focusing on White men and that serious HIV-related conditions affecting women and children had not been included in the AIDS definition—had demanded changes to reflect the extent of advanced HIV disease in these populations. Their actions emphasize the importance of language: access to care is determined by who is included and excluded by the language defining AIDS.

It is less useful to try to fully fathom the government’s motivations for changing the definition: the goals of the CDC, other executive departments, and the Congress reflect complex economic, political, and legal agenda hidden beneath a veneer of public health policy. Suffice it to say that the process of developing, reviewing, and implementing the proposal was sloppy and irresponsible, and has only contributed to confusion about the meaning of AIDS.

Richard DiGioia, MD examines the second in an article that discusses “early intervention,” a term that came into popular use in the late 1980s.

While once viewed as little more than visiting a doctor to evaluate whether illnesses had developed, early intervention is now used to describe a variety of therapeutic approaches related to the source of infection. DiGioia outlines practical approaches to early intervention.

For instance, he states that zidovudine (ZDV; AZT) used in combination with zalcitabine (ddC) is recommended for people who, at the time of their HIV diagnosis, have T-helper cell counts below 250. Even a year ago, there was little to substantiate such a suggestion.

The practice of early intervention doubtless will continue to change. But, officially or unofficially, the meaning of AIDS is likely to be more resistant. Changing this meaning will require overcoming outdated images as well as dealing with the political and emotional charge surrounding the term.

In response to claims that HIV may not, after all, be the cause, or the sole cause, of what is called HIV disease, some researchers have begun to refer to the condition as “HIV/AIDS,” maintaining a connection to the more generic “acquired immunodeficiency syndrome” in case the focus retreats from HIV.

The New Conception

The details of its scientific genesis, however, may offer the most significant commentary on the CDC proposal. Scientific research quickly progressed far beyond the limits of the initial CDC definition. Over a relatively short period, researchers isolated HIV, described the virus’s life cycle, and defined the latency period during which HIV infection progresses silently. All of this research led to a critical conceptual and linguistic change: in response to calls from physicians like Paul Volberding, the scientific community began to refer to “AIDS” as “HIV disease,” acknowledging that the designations “asymptomatic seropositive,” “ARC,” and “AIDS” were not wholly different entities but, in fact, stages along the continuum of HIV infection. Two scientific events have been particularly significant in changing the focus and conception of HIV disease. First, advances in medical treatment of the disease—like zidovudine (ZDV; AZT), didanosine (ddI), and zalcitabine (ddC), and the spectacular success of preventative treatments for
Whatever its effect on medicine, the distinction between “AIDS” and “HIV disease” has been essential to the mental health of people with HIV disease.

In light of their findings, Yarchoan et al. warned of the danger of using T-helper cells to predict the timing of an individual's HIV-related death. “Even when the CD4 [T-helper cell] count fell below 50 CD4 cells/mm³, the median survival was at least 12 months, and some patients survived three or more years. These results indicate that substantial CD4 depletions can be tolerated without a markedly increased hazard of dying... Moreover, our results suggest that restoring CD4 counts to normal levels in HIV-infected patients may not be necessary to reduce the mortality rate.

References

Pneumocystis carinii pneumonia—have propelled the early intervention movement forward. These advances have dramatically strengthened the argument for HIV detection through antibody testing, and have effectively shifted the treatment focus from the late stage of disease—specifically AIDS—to earlier and earlier stages, perhaps eventually to the time of seroconversion.

Second, antiviral drug studies are increasingly using laboratory parameters—so-called surrogate markers—as standards to judge drug efficacy. Studies focusing on the T-helper cell count have shown it to be a useful, although somewhat imprecise, marker to guide clinical decision making and monitor disease progression. Perhaps most notable in this body of research is a National Cancer Institute study that found that in a cohort of 55 patients treated with ZDV-based therapy for as long as four years, nearly all of the 44 deaths occurred in patients with T-helper cell counts of less than 50.

By focusing on the T-helper cell count as an indicator of viral activity, and by emphasizing the ability of early intervention to slow activity and disease progression, research has pushed the popular conception of AIDS away from the actions of opportunistic microorganisms and towards the actions of the virus itself. This is the scientific justification for the CDC definition change and the crux of the evolution in the conception of AIDS: attention focuses on the virus's direct effects on immune system health rather than on the physical manifestations of these effects.

The CDC proposal was not momentous because it would have solidified this evolution, but because it would have ultimately made popular usage of the term “AIDS” obsolete. Unlike earlier calls for a change in terminology—which were published in medical journals for a professional audience—the CDC change would have delivered this message to the general population.

Following this lead, future conceptions of HIV disease may move further and further away from defining HIV disease as a spectrum of conditions toward seeing it as a single entity, the result of a viral infection. Opportunistic conditions and their severity, of course, will remain clinically significant, but they will recede in importance in terms of defining a primary medical response: treating the infection at its source using Western or alternative approaches or a combination of these. This change will seem proactive: “early” intervention before the development of symptoms. In fact, it will simply be a more timely and effective reaction to laboratory indications of disease, which are more insidious than physical symptoms but no less dangerous.

The Mental Health Challenge

Whatever its effect on medicine, the distinction between “AIDS” and “HIV disease” has been an essential one for those infected with HIV. For many, the language they use to describe their condition has profound implications on the stories they tell themselves. “AIDS” has equated death, but “HIV infection,” that hazy period of months or years before AIDS, has often meant hope. The CDC proposal, and the series of false starts that followed, allowed many people to discover how it would feel to go to bed one night a healthy, hopeful, seropositive person and wake up the next morning a person with AIDS.

After testing antibody positive, the primary task for many people is creating a psychological distance from AIDS. AIDS is the beast that must first be vigorously denied, then bargained with—"I'll change my diet; I'll take these drugs"—and then, after a process taking time and effort, accepted. By using denial adaptively as a shield during this process, by embracing the “positives-being-positive” philosophy, many people protect themselves from horror and despair. This allows them to continue caring for themselves, leading fulfilling lives, and ultimately adjusting to the idea that their lives are threatened.

In this way, failing health acts as a rite of passage through which people with HIV disease must pass on the way to becoming people with AIDS. Psychologically, the experience of repeated and worsening medical problems enables people with HIV disease to adjust incrementally to disease progression, to change the language of their internal stories and to ease themselves into the realization that they are seriously ill.

The CDC proposal would have ensured that some HIV-infected people would forego this psychologically protective “dosing” of information and, instead, might find themselves without the emo-
tional preparation to deal with AIDS. When T-helper cell counts are 200 but a person feels well, an AIDS diagnosis has no physical parallel. The medical condition is serious; the physical condition is healthy; and it is the psyche that must reconcile this apparent contradiction—an inconsistency bound to become more common as “HIV disease” becomes the operative term and early intervention the rule.

The image of a rite of passage also implies a point of no return. Having AIDS is seen as irreversible, while being seropositive is less rigid, and may, in fact, appear as a tentative situation that could go either way—towards sickness or health. On one level, the CDC proposal would have sent many more into this psychologically and linguistic cul de sac.

Reconciling the Contradiction

Is there any way to support the adaptive denial that people require in order to live with HIV disease and, at the same time, reinforce medically accurate messages that encourage early intervention? The scientific reality of HIV disease is clear. Despite the fact that it remains “incurable,” more than ever researchers are glimpsing a light at the end of the tunnel. Advances in developing new drugs and preventive vaccines, and in the use of “alternative” treatments suggest that HIV disease will become a chronic, manageable condition. For people who choose to pursue medical care, this optimistic vision of early intervention can instill hope.

It is important to note that it is not necessary to believe that early intervention is the perfect solution. Instead it is necessary for clients and providers to act as partners in exploring treatment options. The key is for clients to be involved in the process, to face the questions in order to make responsible decisions. On a psychological level, the specific outcomes are less important. What remains crucial is the sense that clients are mobilizing their energies on their own behalf and that clinicians are their allies.4

Unlike the scientific reality, the linguistic or conceptual reality of HIV disease remains in flux. Stabilizing the language we use to talk about HIV infection, and the meaning we impart to that language, will help people develop realistic plans and attitudes about HIV disease. Acknowledging the new scientific reality rather than clinging to an obsolete one is the surest way to achieve this stability.

The CDC proposal reflects the new conception of AIDS: disease starts at the time of infection, physical symptoms may not be apparent but the virus is nonetheless active, and early intervention can inhibit progression. But it may be easier to communicate this new reality, not by changing the definition of AIDS so that it encompasses more of the HIV disease spectrum, but by changing the definition of HIV disease to repudiate “AIDS.” In this way, the sense of an irreversible condition—AIDS—is negated rather than expanded.

The image of the beast at the door is transformed into the image of a single virus, cunning yes, but ultimately manageable, and so much the more manageable because early intervention has provided a head start in controlling infection. Just as the term “AIDS” carries with it historically negative connotations, “early intervention” evokes positive and hopeful associations. Using this language in the stories we tell ourselves helps promote mental health among people learning to live with HIV disease.

Clearinghouse: Early Intervention

References


Books


Early Intervention for HIV Disease
Richard DiGioia, MD

The development of relatively effective antiviral treatments has led to the “early intervention” approach to HIV disease. Early intervention is defined as starting therapy before the onset of AIDS so as to prolong survival and quality, disease-free time. This article examines current early intervention standards and focuses on antiviral treatment. It also briefly discusses the use of preventative treatments for HIV-related opportunistic diseases.

It is important to note, before discussing drug strategies, that the variability of the natural course of HIV disease itself—both in terms of the timing of serious symptoms and the course of disease after AIDS diagnosis—makes it inherently difficult to evaluate early intervention strategies. Furthermore, prophylaxis against Pneumocystis carinii pneumonia (PCP), which came into widespread use starting in 1987, altered this natural history. In doing so, it markedly decreased the most frequent cause of HIV-related death and the most common indicator of the passage to the AIDS phase of HIV disease. Up to this point, antiviral researchers had used the timing of PCP onset and PCP-related death as the primary measures of drug efficacy.

Antiviral Treatment
Despite these difficulties, both controlled studies and clinical experience have shown that the use of zidovudine (ZDV: AZT) at some point in the course of HIV disease prolongs life. It also has been proven that taking ZDV before symptoms appear delays the onset of symptoms, thus prolonging quality time. This is not to say that ZDV benefits all HIV-infected patients, just a large majority. Also, it is unclear how long ZDV prolongs life and delays the onset of symptoms; the gain probably ranges from six months to three years.

Early intervention—including antibody testing as a first step—is currently the best hope for HIV-related care.

It is still considered unclear whether taking ZDV before the onset of AIDS prolongs life more than taking it after onset. Most physicians feel that extra time is gained by starting earlier. This practice, however, must be balanced by the distress caused by side effects and the negative psychological impact of taking medication regularly especially when feeling well.

The current standard of care is to start ZDV at a dose of 200 milligrams every eight hours when T-helper cell counts fall below 500. Ongoing studies are seeking to determine if patients gain survival or quality time by starting at higher T-helper cell levels, and if starting earlier leads to more drug toxicity and to the eventual emergence of ZDV-resistant strains.

Clinical studies have indicated that

References
**didanosine** (ddl) is an acceptable substitute if patients cannot tolerate ZDV.

If at the time of diagnosis of HIV infection, the T-helper cell count is less than 250, data suggests that using ZDV in combination with *zalcitabine* (ddC) is preferable to ZDV alone. However, these studies have not been continued long enough to show an increase in quality or survival time. In addition, ZDV plus ddl may work as well as ZDV plus ddC.

Numerous questions about antiviral therapy remain. What is the best course if, while on therapy, T-helper cell counts decline, symptoms develop, or an AIDS-defining condition occurs? Is it better to add ddl or ddC to ZDV or to substitute one of them for ZDV? If combination therapy is used, is it better to use both drugs simultaneously or in alternating months?

To answer these questions, new criteria for drug effectiveness need to be developed. Using the clinical course of disease to judge effectiveness is no longer practical both because it is variable and because it lengthens the time needed to collect data. Surrogate markers, that is, laboratory tests—most frequently T-cell counts and HIV p24 antigen levels—are being used in clinical trials. Unfortunately, these are not totally reliable, and other tests, such as serum neopterin and beta2 microglobulin levels have proven much less satisfactory. Tests currently in development may eventually respond to this need.

**Prophylaxis**

The occurrence of opportunistic infections greatly affects the course of AIDS. Once limited to PCP prophylaxis, researchers are investigating preventative approaches for other infections. However, since these diseases are much less common than PCP, the evaluation of prophylaxis is difficult.

Before prophylaxis, PCP occurred in 60 percent to 80 percent of AIDS patients. Prophylaxis has markedly decreased this rate. PCP prophylaxis should be started when the T-helper cell count falls below 200. The most effective of PCP prophylactic options is probably oral *trimethoprim-sulfamethoxazole* (TMP-SMX-DS). It appears that dosing three days a week is almost as effective as daily dosing and is less likely to cause sulfa-drug-related side effects. When allergic reactions develop, aerosol *pentamidine* and oral *dapsone* are good alternatives.

While preventative measures against other, less common opportunistic conditions usually occur in the late stages of HIV disease (often when T-helper cell counts are less than 50), it is worthwhile mentioning them in this overview of early intervention. Oral *fluconazole* prevents candida infection. It is suspected but not confirmed that fluconazole may also prevent activation of cryptococcosis, histoplasmosis and coccidiomycosis.

While high dose oral *acyclovir* has so far failed as a reliable prophylaxis for active HIV-related cytomegalovirus (CMV) disease, one study suggests that acyclovir may prolong life for a period of time. Studies are currently ongoing to determine if a variety of medications, including oral *pyrimethamine,* will prevent toxoplasmosis. Two large studies examining *rifabutin* for the prevention of mycobacterium avium complex disease are currently being analyzed. This drug is available through a compassionate release program.

Irrespective of T-helper cell count, anyone with a history of or a currently positive tuberculosis skin test or a chest X-ray strongly suggestive of prior exposure should receive one year of daily oral *isoniazid* to prevent TB reactivation.

**Conclusion**

Emerging clinical evidence suggests that current therapeutic programs of antiviral drugs and opportunistic infection prophylaxis can prolong survival and quality time for symptom-free patients even more than therapies available two years ago. Although there is an increasing number of HIV-infected people with T-helper cell counts of less than 50, among those receiving ongoing care, there has been a decline in the number who are sick or hospitalized. Early intervention—including antibody testing as a first step—is currently the best hope for HIV-related care.

**Comments and Submissions**

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**Recent Reports**

CDC AIDS Definition Affects Policy

A commentary on the 1991 Centers for Disease Control proposal to change the AIDS definition recommends that the CDC change the definition only to improve its primary goal of providing comprehensive surveillance data to reflect disease incidence and manifestation in various populations.

In order to evaluate the proposal the commentary reviews the various applications of the definition, including: to assess eligibility for entitlements and benefits, to determine government spending on the epidemic, to define research priorities, and to lead to the provision of appropriate clinical care.

The authors recommend that: the Department of Health and Human Services ensure that all federal agencies that use the AIDS definition—including the Social Security Administration—do so in a consistent and appropriate way; the needs of people with HIV disease be evaluated on their own merits separately from surveillance criteria; research be conducted to measure the economic, social, and medical impact of HIV-related diseases that are not included in the AIDS definition.

The authors conclude: “Consider the saying, ‘If you don’t know where you are going, any road will take you there.’ The CDC definition is one marker on the road to effective HIV/AIDS policy, but it is not the destination.”

New Jersey’s Early Intervention Program

Operating out of five ambulatory care clinics, with strong ties to community organizations and drug treatment clinics, New Jersey’s Treatment Assessment Program (TAP) is the first early intervention program in the U.S. to institute a common protocol of care accessible throughout a state, according to a brief overview article.

The program includes risk reduction education and counseling, psychosocial, family support, and financial needs assessment and referral. The clinics provide ongoing monitoring of T-helper cell counts, aggressive treatment with prophylactic drugs to patients with T-helper cell counts below 200, and appropriate medical treatment and supervision to patients with levels above 200.

TAP seeks to avoid costly hospitalization by offering improved access to treatment and encouraging early contact with the health care system. Although traditional health care financing mechanisms fail to cover all program costs, TAP estimates that the program will be cost-effective if even one person out of 300 avoids hospitalization. Estimated costs per patient per year ranged from $850 for screening alone to $7,200 for those receiving zidovudine (ZDV; AZT) and prophylactic treatment to prevent Pneumocystis carinii pneumonia (PCP).

To promote the active involvement of private physicians, the state distributes an office-based protocol for managing HIV disease that emphasizes the value of early intervention. Bilingual messages advertise the program to affected groups, and community organizations and drug treatment programs refer clients to the clinics with which they have a working relationship.

Early ZDV Treatment Reduces Mortality

Initiating treatment with ZDV before progression to AIDS results in significantly reduced mortality rates, particularly among patients with T-helper cell counts ranging from 200 to 350, according to the large, prospective Multicenter AIDS Cohort Study (MACS).

The cohort included 2,568 seropositive, gay or bisexual men from Chicago, Pittsburgh, Los Angeles, and Washington/Baltimore who were enrolled in the study in 1984 and 1985. The mortality rates were calculated for men who entered the study in one of five disease states, defined by numbers of T-helper cells (ranging from less than 200 to more than 350) and clinical symptoms (asymptomatic or symptomatic). Subjects were divided into five groups depending on T-helper cell count (ranging from less than 200 to more than 350) and clinical symptoms, and were followed for six, twelve, eigh-
teen, and twenty-four months. Researchers calculated rates of death separately for those who began ZDV treatment before and those who began after an AIDS diagnosis.

After six months, early treatment was associated with a reduced risk of dying for men with T-helper cell counts lower than 350. All groups showed lower mortality after 12, 18 and 24 months of follow-up. Those who benefited most started with T-helper cell counts between 200 and 350. After adjusting for ZDV use, PCP prophylaxis was also associated with lower mortality, after 18 and 24 months. The use of ZDV alone was associated with reduced mortality after six, twelve, and eighteen months, but not after twenty-four months. Researchers could not evaluate the benefit of early treatment on subjects with T-helper cell counts greater than 350, because the mortality rates remained low in both treatment and non-treatment groups.

Public Labs and Early Intervention


An expert panel of public health laboratory directors identified as particularly important three areas of laboratory testing—to identify HIV infection, to establish stage of infection, and to control secondary spread of disease—that must undergo change in order to allow for the effective monitoring of HIV-infected people.

The panel urged the FDA to license as medical devices reagents and kits used in tests to identify HIV infection. These materials are currently treated as “biologics” and are therefore available “for research purposes only.” To better mark the presence of HIV-1 99.9 percent of the time and was specific to the presence of HIV-1 antibodies, as opposed to antibodies to other viruses, 99.6 percent of the time. These results make the Murex test comparable to other approved HIV antibody tests. The FDA recommends that positive test results be confirmed using the Western blots or immunofluorescence assay (IFA).

FDA Approves a Rapid Antibody Test

Food and Drug Administration. Rapid AIDS test licensed. Talk Paper. May 27, 1992. [Editor’s note: Talk Papers are prepared by the FDA Press Office to guide FDA personnel who interact with the public.]

The Food and Drug Administration (FDA) recently licensed an HIV antibody test that takes approximately 10 minutes to complete. The test, significantly faster than other antibody tests, is designed to be used by properly trained personnel in doctors’ offices, clinics, and other health care settings where traditional testing procedures are not practical or available.

Murex Corporation, the manufacturer of the test, conducted clinical trials at 11 sites using 8,714 blood or plasma specimens. The test was sensitive to the presence of HIV-1 99.9 percent of the time and was specific to the presence of HIV-1 antibodies, as opposed to antibodies to other viruses, 99.6 percent of the time. These results make the Murex test comparable to other approved HIV antibody tests. The FDA recommends that positive test results be confirmed using the Western blot or immunofluorescence assay (IFA).

[Editor’s note: As with any type of antibody testing, pre- and post-test counseling is an essential part of the process.]

Next Month

More than most medical conditions, HIV disease challenges every aspect of the “system,” from medical treatment, to access to care, to psychosocial and practical support. Case management has long been used to deal with such complex interactions, particularly in designing and coordinating medical care for older people. In the September issue of FOCUS, Debbie Indyk, PhD, MS, Director of Education and Prevention at the AIDS Center of Mount Sinai Medical Center, and Kathy Wade, MSW, Assistant Director of Social Work at Columbia Presbyterian Medical Center, both in New York, outline case management theory and approaches, and examine applications of case management in the realm of HIV-related care.

Also in the September issue, Clint Nix, MSW and Robert Paul Cabaj, MD—both of the UCSF AIDS Health Project—discuss the application of case management to an AIDS and substance abuse program.
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