Social Constructs and Disease: Implications for a Controlled Vocabulary for HIV/AIDS

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ABSTRACT

The body of knowledge associated with the human immunodeficiency virus (HIV) and the acquired immune deficiency syndrome (AIDS) represents complexity not present in any other disease. HIV infection is not only an extremely complicated disease process, but it also transcends the boundaries of biomedicine. Various domains shape the construction of HIV/AIDS as chronic disease with the societal construct circumscribing the body of knowledge concerning the pathological, mirroring the complexities of the malady itself. Disease, and the respective body of knowledge, co-exist within a social reality; consequently, a controlled vocabulary designed to facilitate knowledge organization and access relative to HIV/AIDS must reflect the complexities of this socially constructed reality.

INTRODUCTION

Social constructionists posit that reality is constructed through dynamic socialization and that the sociology of knowledge must examine the process in which this reality construction occurs (Berger & Luckmann, 1966, p. 1). Sociology of knowledge deals not only with empirical knowledge relative to various societies but also with the processes by which bodies of knowledge become established as social realities. In essence, reality evolves through continued socialization, yielding outcomes that result from

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social interactions, negotiations, and power. Where the human immunodeficiency virus (HIV) and the acquired immune deficiency syndrome (AIDS) are concerned, social construction of reality is grounded in the spatialization and politicization of the pathological.

The body of knowledge associated with HIV/AIDS represents a complexity not present in any other disease. Furthermore, the epidemic has altered the model of information production and consumption and has spawned its own vernacular, one representative of a diverse population of information producers and consumers. Further compounding this complicated communication picture, the body of information surrounding HIV/AIDS continues to grow at an epidemic rate, often in tandem with the numbers of reported cases. Finally, HIV infection is not only an extremely complicated disease process, but it also transcends the boundaries of biomedicine. Various domains shape the construction of HIV/AIDS as chronic disease, including the political, social, economic, legal, philosophical, psychological, religious, and spiritual ramifications associated with the illness. The societal construct within which the body of knowledge concerning HIV/AIDS exists mirrors the complexities of the malady and the various controversies associated with it. This diseased body of knowledge—a body of knowledge that breathes life into the pathological by providing it visibility—exists because of HIV/AIDS. Disease, and the respective body of knowledge, co-exist within a social reality, a social reality that binds and circumscribes. Consequently, the organizational schema of a controlled vocabulary designed to facilitate knowledge organization relative to HIV/AIDS must be broad in coverage yet specific in terminology so that the multidisciplinary and interdisciplinary nature of the epidemic is reflected. In representing the dynamic nosological record of HIV/AIDS, the controlled vocabulary captures the societal construct circumscribing the pathological.

**BACKGROUND**

*Complex Nature of HIV/AIDS*

Infection with the human immunodeficiency virus results in a complex chronic disease process, complicated by various nonbiomedical factors. The disease itself is characterized by a constellation of signs and symptoms that culminate in a diagnosis of acquired immune deficiency syndrome. Ultimately, most individuals infected with HIV die of AIDS-related causes. From a biomedical perspective, what differentiates HIV from other chronic disease processes is the variety of opportunistic infections and cancers commonly associated with AIDS as well as HIV-related wasting and dementia and the wide variation in the dying trajectory. Although there have been numerous therapeutic advances where HIV is concerned, drug regimens, when available and accessible, have not proven uniformly effective. Combination therapy involving antiretrovirals and protease
inhibitors, while greeted with much fanfare, has proven to be a great disappointment to the many HIV-infected individuals who have failed to improve while taking the drug cocktails. Moreover, of the 612,078 AIDS cases reported to the Centers for Disease Control and Prevention (CDC) through June 1997 in the United States, 379,258 have died (Centers for Disease Control and Prevention, 1997, p. 14).

Further exacerbating the medical complexities of the illness, HIV is complicated by myriad factors outside the biomedical arena—economic, legal, political, psychological, religious, social, spiritual—that compound disease chronicity. These components of an individual’s psychosocial reality exist in tandem with the biophysical illness with stigma trajectory corresponding to disease course progression (Alonzo & Reynolds, 1995, p. 306). Although the spatialization of disease has been plotted along a historical continuum that forms the foundation for modern medicine (Foucault, 1975, pp. 3-20), the politics and stigma associated with HIV/AIDS prevents the illness from advancing to its ultimate position in the sequence (Huber, 1996, pp. 6-9). The pathological continues to exist within a socially defined set of spaces. As well as affecting the emotional, mental, and physical well-being of the HIV-infected individual, these nonbiomedical complications dramatically impact education and prevention efforts, treatment advances, and coping mechanisms. The repercussion of infection and disease manifestation is much more than an individual life event. In fact, given the multifarious nature of the pathological, HIV transcends the boundaries of life and death (Huber, 1993a, pp. 230-31).

**HIV/AIDS Information and Communication**

Since the beginning of the epidemic in the early 1980s, information has been viewed as a key resource in efforts to prevent HIV transmission, manage various disease complications, and ultimately prolong life. As HIV/AIDS-related information was initially limited, however, in size, scope, and availability (SantaVicca, 1987, p. 115), underground press networks, supported largely by affected individuals and community-based organizations, began emerging within the first few years of the epidemic. These networks subsequently have evolved into recognized legitimate information resources with many AIDS service organization newsletters now being indexed by the National Library of Medicine for inclusion in its HIV-specific bibliographic database, AIDSLINE.

The AIDS pandemic, in effect, has witnessed a confluence of roles regarding information creators, seekers, and providers (Ginn, 1987, p. 333). This paradigmatic shift has resulted in a nontraditional scientific communication model where traditional consumers of information are very often producers, and traditional producers are consumers. In a traditional scientific communication model, information is generated by researchers, disseminated, accumulated, distilled, and applied in the clinical arena (see
Figure 1). Practical information, when made available, is watered down into lay terms for public consumption (Patton, 1990, p. 5). However, in this nontraditional model, traditional consumers are active contributors to the discourse (see Figures 2 and 3). As a result, HIV-related information is currently produced and consumed at virtually every level—individual, institutional, organizational, community, local, regional, national, and international.

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Figure 1. Traditional Scientific Communication Model.

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Figure 2. Nontraditional Scientific Communication Model.
Figure 3. Nontraditional Scientific Communication Model

Consumers
- PATIENTS, LAYCAREGIVERS
- HEALTH CARE PROVIDERS, RESEARCHERS, EDUCATORS
- AFFECTED COMMUNITIES, POPULATIONS
- ACTIVISTS

Producers
- HEALTH CARE PROVIDERS, RESEARCHERS
- PATIENTS, LAYCAREGIVERS
- AFFECTED COMMUNITIES, POPULATIONS
- EDUCATORS
- ACTIVISTS

DISCOURSE
MULTIPLE VERNACULARS
- BIOMEDICAL
- EDUCATIONAL
- LEGAL
- POLITICAL
- PSYCHOLOGICAL
- SOCIOLOGICAL
- THEOLOGICAL
- LAY PUBLIC
- ET AL.

DISSEMINATION & INTEGRATION
- ELECTRONIC NEWSGROUPS
- WORD OF MOUTH
- HOTLINES
- NEWSLETTERS
- WORLD WIDE WEB
- CONFERENCE PRESENTATIONS
- JOURNAL ARTICLES

COMMUNITY RESOURCES
- DISCIPLINES, APPROACHES
- CONFERENCE PRESENTATIONS, JOURNAL ARTICLES
In addition to HIV-related information being produced and consumed at multiple levels, the epidemic has spawned its own vernacular, one representative of the diverse group of individuals infected with the virus and those working within the AIDS arena (Huber, 1993b, p. vii; Huber & Gillaspy, 1996b, p. 1). The language of the pandemic embodies cultural predispositions. This vocabulary consists not only of technical, scientific, and biomedical terminology but also includes verbiage germane to the lay population directly affected by the malady as well. The lexicon also reflects the various disciplines touched by the disease.

Further complicating access to HIV-related information, the body of knowledge concerning the epidemic is growing exponentially. The literature continues to increase in volume parallel to the rise in the number of documented cases of AIDS worldwide (Huber & Gillaspy, 1996a, p. 297). In addition, HIV-related information is currently produced in every conceivable format—audiovisual, electronic, print, realia—and is present in all discipline-specific bodies of knowledge affected by the pandemic.

Societal perceptions and individual perspectives fashion the pathology of the HIV/AIDS epidemic with the course of disease progression marred by politics and stigma. Complexities associated with both the pathological condition and the body of knowledge concerning HIV/AIDS exist within, and because of, social constructs circumscribing the pandemic. Illness, information, and intricacies are all entwined, evolving relative to both scientific advances and social interactions.

**SOCIAL CONSTRUCTS**

*Reality Construction*

Although a person's conception of reality—fear and danger, abnormality and stigma, health and beauty—may be very individual, this perception, to a large extent, is culturally patterned (Ferrante, 1988, p. 224). Events, actions, attitudes, and beliefs are mediated by historical and cultural factors. Individual reality is a social construction and not necessarily an absolute truth. Personal conceptions are reflective of a much larger construct, one that transcends any individual. The relationship, however, between individual perception and social construct is an integral one in that dynamic socialization shapes the construction of reality.

Reality is constructed within three realms—social, physical, and individual—and is composed of societal definitions and interactions (Charon, 1992, pp. 37-38). Social, physical, and personal realities operate in conjunction to construct and define an individual's reality. Social reality is molded within the context of societal circumscription of the individual bounded by his or her culture. This spatial reality is grounded in social action and interaction. A physical reality also exists, independent of social reality, as a paradigmatic structure present at the instance of every situation. Physical objective reality consists of an individual's surroundings...
and current set of circumstances. Social reality responds, in part, to physical reality where physical reality is the existing situation. The situation, however, is defined by one's social reality. In addition, each individual possesses a personal reality based on that person's unique perspective. Personal reality, consciously and unconsciously, is shaped through socialization. Social reality, physical reality, and personal reality interact simultaneously to form one's cumulative perception of what is real. This cumulative perception then, when combined with other individuals' realities derived from a similar perspective, forms the basis for defining social constructs. Social constructs, however, being created from societal perceptions, may lack scientific foundation. In fact, political and economic elites very often generate media images and other forms of discourse to influence social construction of meaning and reality (Gamson, Croteau, Hoynes, & Sasson, 1992, p. 374). Social ideologies and political interests, in essence, shape the construction of reality. Where HIV and AIDS are concerned, the social construct within which the pathological exists is built upon the politics of bodies and disease.

**Bio-Politics Versus Bio-Power**

Within the historical development of civilization, bio-politics, or politics of the body, emerged as a result of the "proliferation of political technologies [that] ensued, investing the body, health, modes of subsistence and habitation, living conditions, the whole space of existence" (Foucault, 1978, pp. 143-44). Prior to, and in parallel with, the development of bio-politics, there was an "explosion of numerous and diverse techniques for achieving the subjugation of bodies and the control of populations, marking the beginning of an era of bio-power" (Foucault, 1978, p. 140). Both bio-politics and bio-power continue to mold reality construction today. Bio-politics relates to the empowerment of individuals, while bio-power may be thought of in terms of power over bodies by bodies—i.e., corporal and social, individual and collective. Within the AIDS arena, politics of the body and the body politic are inextricably intertwined and often diametrically opposed.

Nowhere perhaps is the strife between bio-politics and bio-power more obvious than in the debate between public health and individual rights, with regulation of individual sexual practices possibly being the best illustration (Gillaspy & Huber, in press). Societal normalization of sexuality is an instrument of power (Hewitt, 1991, p. 229). By defining what is normal, the body politic creates a tool that can be applied to control individual sexual behavior. Discourse—psychiatric, legal, moral, ethical—binds physical actions by rendering normative behavior. Social discourse is used and applied to define the rules of sexuality. The various standards, models, exclusions, limitations, and perversions of sexuality are derived from a particular discursive practice, based not on scientific discourse but on a
system of values and prohibitions (Foucault, 1972, p. 193). Organized religion’s stance on homosexuality, the continued existence and enforcement of sodomy laws, the legal position concerning prostitution, the lack of inclusion of homosexuality as a legitimate sexual orientation in sex education curricula, and promotion of “just say no” campaigns regarding safe sex are a few examples of the establishment’s efforts of regulating or administering sexual practices.

Given that gay men continue to constitute the largest affected population in the United States and a significant portion worldwide, along with the fact that engaging in unprotected sexual intercourse—heterosexual or homosexual—is the primary mode of transmission, issues involving sexuality cannot be cleaved from the complex discourse defining HIV/AIDS. In fact, where sexual practices are concerned, the struggle between politics of the body and the body politic extends well beyond the traditional establishment and into the gay community. Even within organized sexual communities, individual sex acts and identities vary widely (Vance, 1991, p. 878). For the gay community, this variation is often a source of conflict, given the difficult nature of striking a balance between maintaining sexual liberation gained in the wake of the Stonewall riots and seeking wider social acceptance among the heterosexual population. The relationship between sexuality and the AIDS pandemic has further exacerbated this debate. Prominent gay journalists advocating reduction in promiscuity as a means of HIV prevention have come under fire by gay theorists who counter that this position engenders “gay positive but sex negative” posturing (Crain, 1997, p. 28).

The contention that the struggle between politics of the body and the body politic occurs where HIV and AIDS are concerned is important because it exemplifies societal regulation—overt and covert—of the HIV-affected individual and community. Social policy and processes have been, and continue to be, used to shape the politics of the HIV-affected body, both individual and collective. These politics, supplemented by medical complexities and exacerbated further by the nonbiomedical complications of the disease, frame the social construct within which HIV exists as a chronic disease. Within the United States, this socially constructed platform is built largely upon individual perceptions and societal perspectives involving homosexuality, drug abuse, race, and gender.

Construction of Marginalized Populations

The complex nature of this chronic disease cannot be examined without considering the social construction of homosexuality given the close affinity of AIDS with the gay community in the United States. Homosexuality has been constructed socially in much of the world as a negative label, stigmatized largely because of perceived deviation from a broader societal norm. Moral entrepreneurs have toiled tirelessly in attempting to
persuade society that homosexuality is abnormal and immoral. "It is beliefs that homosexuality is evil, sick, or undesirable—and the corresponding efforts to punish, cure, or prevent it—that make homosexuality deviant" (Greenberg, 1988, p. 2). This conception of deviance has resulted in discrimination against, and repression of, individuals seeking to engage in same sex unions. There has been tremendous effort from within the gay community, however, to liberate gays and lesbians from the psychosocial stigma associated with their respective sexual orientations. "It was a historic step to have homosexuality changed from a medical anomaly to a psychological impairment in the early part of the century, and an equally significant step to have homosexuality removed from DSM-3 and ICD-9 in the early 1970s and later 1980s" (Patton, 1990, p. 3). The close association of HIV and AIDS with homosexuality, though, has threatened to unravel social tolerance extended toward gays and lesbians, with the stigmatization of one fueling the stigmatization of the other.

While the gay community has borne the brunt of the AIDS pandemic in the United States, other socially marginalized populations have been, and increasingly are being, woven into the disease-related web of devastation. Drug injection has been determined as the mode of exposure to HIV in 26 percent of reported AIDS cases among adolescents and adults in the United States with an additional 6 percent attributed to men who have sex with men and inject drugs (Centers for Disease Control and Prevention, 1997, p. 8). Moreover, of the adolescent and adult cases reported to the CDC from July 1996 to June 1997, 43 percent were black and 20 percent Hispanic (Centers for Disease Control and Prevention, 1997, p. 3). Further, incidence of AIDS among women in the United States now accounts for 15 percent of total reported cases (Centers for Disease Control and Prevention, 1997, p. 3). These groups live within social constructs that bind and circumscribe just as homosexuality is stigmatized by society.

Although men who have sex with men continue to constitute the greatest portion of the HIV-infected population in this country, injection drug users contribute significantly to the total number of AIDS cases. Like homosexuality, substance abuse has been modeled around issues involving morality and disease. Drug abuse has been constructed as a societal taboo and criminal problem, imposing a certain degree of forced invisibility upon members of that community. Moral panics and crusades relative to illicit drug use foster the perception that this is yet another disposable population devoured by demonic deviant behavior.

Perhaps one of the most visible forms of deviation, though, in a predominantly white culture, is that of race. Race is employed as a social concept to differentiate populations based on physical traits, blood types, genetic code patterns, and inherited characteristics. However, race also is applied to ascribe psychological and moral attributes, facilitating the justification of a discriminatory system exhibiting ethnocentric biases. In this
way, race categories support destructive social labeling, founded in societal perspectives rather than scientific fact. "Race categories are social constructs, that is, concepts created from prevailing social perceptions without scientific evidence" (Witzig, 1996, p. 675). Unfortunately, the continued use of race taxons, despite scientific evidence repudiating the validity of racial constructs, fosters the application of race as a negative descriptive social label. This is particularly poignant where HIV infection is concerned, given that the number of documented cases of AIDS is rising disproportionately among people of color. Blacks constitute approximately 13 percent of the U.S. population and roughly 35 percent of CDC documented AIDS cases, and Hispanics account for about 11 percent of the American populace but close to 18 percent of the documented AIDS cases (World Almanac and Book of Facts, 1997, p. 133; Centers for Disease Control and Prevention, 1997, pp. 9-11).

Tightly woven into the social fabric defining race, gender has been constructed in many cultures to portray female submissiveness and male domination as societal norm. Building on the conflict between politics of the body and the body politic, many feminists argue that the rules of sexuality have been delineated by men (Few, 1997, p. 619). In general, universalistic feminist theory views gender as being defined in terms of binary opposition—man/woman—and assumes that women are subject to gender subordination (Dugger, 1995, p. 139). Social order revolves around patriarchy, with women occupying secondary positions. While this view does not recognize the role of race, ethnicity, and nation in gender construction, it does serve to frame loosely the social construct within which HIV-infected women and those at risk for infection live in much of the world. This construct is even more binding, however, when applied specifically to women of color. Although white women are subject to societal circumscription and HIV-related prejudices, women of color are stigmatized further by individual perceptions, social expectations, cultural norms, and socio-historical development. For Hispanic women, male dominance is often typified by machismo attitudes. For black women, "womanhood was constructed not in terms of familial and domestic activities, but through black women's role as laborer in slave, colonial, and market economies, and through their roles as domestics and surrogate mothers to white families" (Dugger, 1995, p. 140). HIV-infected women of all races are at the same time "innocent victims" and "immoral carriers," further illuminating "prejudices which have long existed in medicine and law" (Van Vliet, 1993, p. 193).

Because of the biomedical complexities, disfiguring nature of the illness, and close association with death, HIV/AIDS would most likely have been stigmatized to some degree no matter who was initially infected (Herek & Glunt, 1988, p. 887). However, the American AIDS epidemic has been defined as a disease of marginalized populations with the resulting
social construct being shaped by this definition. The construct is not surprising, though, given that the construction has been based on a social response to a disease most prevalent among already stigmatized populations.

Stigma

Much of the construct circumscribing the HIV pandemic is plagued by stigma. Stigma may be thought of in terms of a language of relationships, resulting in the construction and application of deeply discrediting attributes (Goffman, 1963, p. 3). Stigma represents a deviation from some socially constructed ideal or expectation, such as adhering to an accepted sexual orientation or remaining free from a disfiguring disease (Alonzo & Reynolds, 1995, p. 304). Deviance is key to this broad multidimensional construct and acts as a negative discounting social label. However, deviation itself is not intrinsically immoral or pathological; rather, it is inferred from a culturally defined meaning. The social construct within which stigma exists allows stigmatized attributes to be discredited and tainted, resulting in prejudice and discrimination. In its extreme, stigmatization of disease withholds legitimate privileges afforded non-stigmatized maladies and imposes special obligations on those affected, thus resembling crime more than illness (Freidson, 1970, p. 236).

Blatant stigma-related rejection, prejudice, and discrimination are manifested—overtly and covertly—where HIV and AIDS are concerned. Attributes involving the disease are stigmatized because of a variety of biomedical and nonbiomedical factors, including modes of viral transmission, psycho-demographics of populations most affected, and obvious visibility of the disfiguring nature of the illness. Fear of contagion, homophobia, racism, sexuality, social perception of drug abuse, and the close association of AIDS with an unaesthetic form of death feed the stigma branding this pathological condition. The degree to which the disease is stigmatized affords the imposition of shame directly on those individuals who are HIV-infected as well as indirectly to family, friends, and partners in the form of a courtesy stigma. All too often, "existing societal fears and stereotypes quickly amalgamate with misrepresentations of medical and sociological facts" (Patton, 1992, p. 323). In fact, stigmatization of HIV and AIDS is so strong that the stigma trajectory has been conceptualized to mirror the course of disease progression, resulting in full manifestation being equated with passage to social and physical death (Alonzo & Reynolds, 1995, pp. 309-11).

The reality of the social trajectory of stigma is painfully apparent in the AIDS pandemic. Stigma and disease often outlive infected individuals through sheer irrationality and the continued politicization of the disease. "Cultural narratives of perversion and contagion seem endlessly capable of turning apparently interpretation-proof facts into ammunition for pan-
ics and discrimination" (Patton, 1992, p. 323). Social construction of the pathological condition ensures regulation of the HIV-affected, with the construct of the AIDS arena being described and recorded in the body of knowledge that has evolved since the inception of the epidemic.

Relationship between Disease and Body of Knowledge

Bodies of knowledge are bound by societal norms, policies, and processes, and scientific discoveries, social interactions, and personal beliefs are recorded within the containers of information that support those bodies of knowledge. Information and society are indelibly linked, as are pathology-specific bodies of knowledge and the diseases they represent. There is an integral relationship between a disease and the body of knowledge concerning that disease. In reality, one does not occur without the other. In order for a body of knowledge about a pathological condition to develop, the disease must exist and have been discovered. The body of knowledge concerning a disease, then, is generated to define and describe the malady, classify the pathological, and provide discourse regarding affected individuals. In return, this pool of knowledge breathes life into the pathological, providing it visibility. Without a representative body of knowledge, the disease remains invisible. Information concerning a disease, however, is bound by the life of that pathological condition and is circumscribed by any stigma associated with that illness. The body of knowledge is riddled with the same complexities as the malady itself, yielding a diseased body of knowledge where HIV and AIDS are concerned. Mirroring the complex nature of the epidemic and the controversies associated with the disease, the body of knowledge regarding the pandemic is circumscribed by the same societal construct as the pathological itself (Huber, 1996, p. 33).

HIV/AIDS Controlled Vocabulary

Given this societal circumscription, the controlled vocabulary and classification structure used to organize the body of knowledge associated with HIV/AIDS has been problematic. The very names first used to describe the disease reflected not only the community originally most affected but also society’s stigmatization of it. These names included gay cancer, gay pneumonia, gay bowel syndrome, gay-related immune deficiency (GRID), acquired community immune deficiency syndrome (ACIDS), and community acquired immune deficiency syndrome (CAIDS).

The controlled vocabulary referenced here, HIV/AIDS and HIV/AIDS-Related Terminology: A Means of Organizing the Body of Knowledge (Huber & Gillaspy, 1996b), was developed in direct response to a need voiced within AIDS service organizations (ASOs) across the United States—i.e., a need for a system of organization and access to the ever growing and evolving data, information, and knowledge spawned by the epidemic. Organization
and access were complicated by the variety of formats in which information was appearing and the diversity of individuals needing to use it. The system needed to be comprehensive and yet simple enough for nonlibrarians to use, as many ASOs do not employ information professionals (Huber & Machin, 1995, p. 242).

The vocabulary was tested and refined at a large community-based AIDS organization that provided direct information services to physicians, educational staff, caregivers, patients, students, and allied health personnel. Resources included the variety typical across the board: videos, monographs, vertical files, brochures, serials, and even realia. The vocabulary evolved from efforts to organize this collection.

Central to the entire development process was the conviction that the vocabulary must be descriptive yet flexible to suit the needs of users and to portray and preserve the rapidly expanding, multidisciplinary body of knowledge. Using the Dewey Decimal Classification as a model, ten "umbrella" concepts, termed domains, were identified:

1. Generalities;
2. Epidemiology and Transmission;
3. Education and Prevention;
4. Clinical Manifestations of HIV and Complications, Malignancies, and Infections Associated with AIDS;
5. Treatments, Therapies, and Medical Management of HIV Disease;
6. Psychosocial and Religious Issues, Case Management;
7. Legal, Ethical, Economic, and Political Aspects;
8. Organizations, Funding Opportunities, and Health Policy;
9. Fine Arts; and

Having identified ten mutually exclusive domains consistent with the reality of the epidemic, the content within each domain was developed. Core medical references, an AIDS dictionary, and a curriculum from an HIV/AIDS Education and Training Center were key to ensuring inclusion of all relevant concepts and terms identified at the time. Newsletters, especially GMHC Treatment Issues and BETA: The Bulletin of Experimental Treatments for AIDS, were invaluable for identifying possible future research directions and assuring space in the scheme for the addition of terms resulting from such work.

Upon completion of the first draft of the vocabulary, it was compared to several existing works, including an early nonhierarchical HIV-specific arrangement developed by librarians at Philadelphia's AIDS Information Network. Development of biomedical content using core medical texts was supplemented with the National Library of Medicine's Medical Subject Headings (MeSH). The Thesaurus of Educational Descriptors, compiled by information specialists at the National AIDS Clearinghouse, was used to
determine completeness and accuracy of the third domain, Education and Prevention. Subject specialists reviewed the sections on religious aspects, United States government components, and virology and clarified the terminology.

Since some concepts were applicable across domains, standard subdivisions, called "universal subdivisions" in this work, were developed and may be appended to main concepts as necessary to facilitate access to the information. The categories of subheadings finally included were Age Ranges, Sexual Orientation, Gender, Stages of Infection, Ethnic Groups, Geographic Names, At-Risk Populations, Religious Faiths, Signs and Symptoms, and Special Populations.

The final tasks were the generation of an alphabetic listing of terms and cross-references, the tagging of MeSH and near-MeSH terms, and the composition of instructions for use. The alphabetic listing and cross-references are intended to be particularly valuable for users unfamiliar with hierarchical arrangements; the cross-references guide users to the preferred terms within the vocabulary but reflect the full spectrum of the vernaculars used within various communities to describe concepts applicable to the pandemic.

Participation in the Large-Scale Vocabulary Test

In 1986, the National Library of Medicine embarked on a complex research and development project designed to link various biomedical vocabularies to a single system, today known as the Unified Medical Language System (UMLS). One of the four knowledge sources for the UMLS is the UMLS Metathesaurus, a "uniform, integrated distribution format for more than 30 biomedical vocabularies and classifications" (National Library of Medicine, 1997). Between July and December 1996, individuals were invited to participate in a test of the UMLS to determine to what extent existing biomedical language schemes fulfill the needs of health information systems.

HIV/AIDS and HIV/AIDS-Related Terminology: A Means of Organizing the Body of Knowledge (Huber & Gillasp, 1996b) was one of the test vocabularies. The work as it stands contains 1,457 terms, excluding the Universal Subdivisions. Of these, 537 were identified at the time as MeSH headings while 98 were considered near-MeSH headings. (Since publication, some of the terms have been added to MeSH.) There were 822 terms that were considered unique from MeSH and approximately 336 of these (23 percent) have no equivalent in the UMLS. Such a significant number reflects not only the multidisciplinary nature of the disease but also the distinctive flavor of the lexicon itself, one that has added new terms (e.g., safe sex) to the language and increased both visibility and notoriety among the marginalized groups of people associated with the epidemic in the mind of the body politic.
Examples from the Controlled Vocabulary

The instructions for use state clearly that the evolution of the epidemic and progress on the scientific front guarantee that the lexicon will grow. Therefore, users are encouraged to add terms to the scheme as they are developed. For example, this work went to press shortly before HIV protease inhibitors, integrase inhibitors, and non-nucleoside reverse transcriptase inhibitors burst onto the scene; these are perhaps only the most obvious examples of terms that must be added for the vocabulary to remain current and useful.

Biomedical terms, however, are eventually accessible from other sources. The strength of a controlled vocabulary devoted solely to all aspects of the HIV/AIDS epidemic is that it includes terms commonly used among those affected by HIV but not reflected in other schemes. Some examples of vernacular terms that have no equivalent form or have a different meaning in other vocabularies but are, nonetheless, commonly employed within the discourse of the pandemic may serve to illustrate the usefulness of the arrangement. One series of terms, for example, describes unique individual responses to HIV infection: rapid progressors, nonprogressors, and long-term survivors.

*Rapid progressors* appear to be infected with a particularly virulent strain of HIV. Their blood counts tend to fall precipitously over a short span of time, perhaps just within two to three years, and their overall health fails rapidly (Khanlou, Salmon-Ceron, & Sicard, 1997, p. 163). *Nonprogressors* are patients who have tested positive for HIV antibodies but who retain normal blood counts and good health over a period of seven to twelve, or even more, years. *Long-term survivors* are patients at any stage of HIV disease whose conditions remain stable over several years. Even if their disease has progressed to AIDS, they tend not to be stricken with opportunistic infections but to remain relatively healthy (“AIDS Medical Glossary,” 1997, pp. 20-21). Of these three terms, only the concept of long-term survivors has roughly equivalent MeSH headings: Survivors, Survival Analysis, and Remission Induction/Methods, where methods is a subheading attached to the main heading. None of these terms, however, is common to the literature and discourse surrounding HIV/AIDS, though to experienced searchers, a relationship is evident.

With purely vernacular terms, however, no such relationship that would be meaningful in community settings exists. For example, a primary means of HIV transmission is shared needles among injection drug users. In international urban areas, a common venue for this activity is shooting galleries, often abandoned buildings or similar areas where users assemble for the specific purpose of injecting various substances into their bodies in a social setting. MeSH headings used to describe documents where shooting galleries is a text word include Substance Abuse, Intravenous, or Needles and Risk-Taking. While information professionals find such indexing logi-
cal, populations needing access at the community level to information about these behaviors are unlikely to use such terminology. Moreover, this controlled vocabulary is meant to be a record of the lexicon of the epidemic, mandating the inclusion of "street language," especially when it records a place with a social ecology that facilitates the transmission of the virus.

While the term "shooting galleries" or its equivalent does not exist in the biomedical literature, some other terms do but are defined differently in the community. An example of such a term is *frottage*. *Dorland's Illustrated Medical Dictionary* (1994) defines frottage as "paraphilia in which sexual arousal or orgasm is achieved by rubbing up against another person, who is unaware of the activity, as when pressed close to others in a crowd, usually without specific genital contact. Called also frotteurism" (p. 665). *The Diagnostic and Statistical Manual of Mental Disorders, 4th edition* (DSM-IV), used in constructing the UMLS Metathesaurus, employs the term *frottage* in defining Frotteurism. In the section on Sexual and Gender Identity Disorders, DSM-IV states that "the paraphiliac focus of Frotteurism involves touching and rubbing against a nonconsenting person" (*Diagnostic and Statistical Manual of Mental Disorders, 1994*, p. 527). Using computer systems, such as the National Library of Medicine's Internet Grateful Med (IGM) that incorporate the UMLS Metathesaurus in their search functions, entering the term *frottage* automatically maps to Frotteurism. However, among both heterosexual and same-sex partners, *frottage* has long been considered a consensual act, one that can lead to sexual gratification with little chance of either disease transmission or unplanned pregnancy. Educational units of some AIDS service organizations teach frottage as a safer-sex alternative to penetration. Researchers studying contraception effectiveness among married couples in Ireland noted that "about half reported using oral sex and/or frottage (body rubbing) [to achieve sexual release]" (Bonnar, Lamprecht, & O'Connor, 1997, p. 173). The equating of *frottage* in authoritative biomedical sources with a defined, deviant, nonconsensual act is a prime example of the body politic's continuing efforts to regulate sexual behavior by declaring deviance of both heterosexual and homosexual community norms. Such declarations further isolate, burden, and assign stigma to already marginalized populations.

**CONCLUSION**

As an evolving narrative, the discourse surrounding the HIV/AIDS pandemic represents the dynamic nosological record of the disease. This record, as captured in an HIV/AIDS controlled vocabulary, reflects the social construct within which the pathological condition and respective body of knowledge exists. For HIV/AIDS, examining this social construct is imperative because it sheds light on the direction in which disease and socio-scientific response have developed.
Although HIV is a complex chronic disease process, it has, to a large extent, been defined in the United States by the body politic. Discourse originating from the empowered elite fosters idealized conceptions, conjured through rhetoric, that are ultimately disseminated to the public. This discourse then becomes a tool central to constructing reality and building social constructs. However, social constructs, deriving from individual perceptions and societal perspectives, may be destructive in nature. Given the complexities associated with HIV/AIDS, the importance of this potentially negative effect cannot be overlooked. By representing HIV/AIDS as being reflective of particular socio-sexual categories and marginalized populations in public discourse, the body politic is provided the opportunity to promote the normalcy of "traditional" behavior and the abnormality of "deviant" conduct (Nzioka, 1996, p. 567). Discourse facilitates the shared construction of meaning, positive or negative, but only with socialization does the discourse yield consequences. In this way, HIV, through public discourse, becomes synonymous with promiscuity, permissiveness, and moral decadence, thus facilitating stigmatization of the disease and fostering prejudice, discrimination, and blame. By politicizing and stigmatizing the pathological, the biomedical complications of HIV/AIDS are further exacerbated.

The organizational schema of a controlled vocabulary intended to facilitate knowledge organization relative to HIV/AIDS must be reflective of the various biomedical and nonbiomedical complexities connected with the disease. Similarly, the structure needs to be flexible enough to accommodate evolution of the discourse, and the controlled vocabulary itself should be representative of the multifarious intricacies defining the body of knowledge associated with the pathological. Both disease and respective body of knowledge exist within the societal construct circumscribing HIV/AIDS, with social interactions and scientific advances delineating this construct being recorded in the controlled vocabulary. However, a lexical representation devoted to HIV/AIDS does not exist irrespective of the influence of the construct; rather, the vocabulary is affected by, just as it is reflective of, social ideologies and scientific realities framing the pandemic.

REFERENCES


