Abstract: In response to a cultural imperative evoked by the AIDS pandemic, the authors have developed a controlled vocabulary specific to HIV/AIDS—encompassing the biomedical, legal, psychosocial, educational, historical, and literary domains—and accessible to communities heavily impacted by the epidemic. The work reflects both knowledge organization systems and environmental perspectives evidenced by the disease. It is intended to serve as a record of the lexicon—past, present, and future—and as a tool to organize the body of knowledge associated with the pandemic.

1. Introduction

Circumscribed by the same complexities as the malady itself, the body of knowledge that encompasses HIV/AIDS is diseased. Indeed, the vocabulary specific to the AIDS arena is riddled with signs and symptoms unique to this modern plague. The nature of the information devoted to the disease prohibits the use of existing organizational tools to describe effectively the multi-faceted concepts central to the epidemic. The work discussed in this paper represents an example of what has been called a defining role of information science: the organization of knowledge, or "knowledge work" (Florance and Matheson, 1993).

2. Background

The body of knowledge associated with HIV/AIDS is arguably more complex than that of any other disease. Moreover, the epidemic has altered the model of information production and consumption. In addition, HIV/AIDS has created its own vernacular that is representative of the diverse population of information consumers. Further compounding the intricate milieu, the body of information surrounding this malady continues to grow at an epidemic rate.

All information associated with biomedicine is complex; however, HIV infection is not only an extremely complicated disease process, but it also transcends the boundaries of biomedicine. In fact, HIV/AIDS transcends the boundaries of life and death themselves (Huber, 1993a). Included in the concerns associated with the disease are political, social, economic, legal, philosophical, psychological, and religious ramifications that go far beyond those encountered in other ailments. Consequently, the organizational schema must be broad in coverage yet specific in terminology so that the multidisciplinary, interdisciplinary, and cross-disciplinary nature of the epidemic is reflected.

In response to a perceived lack of support from the scientific community, the HIV/AIDS arena has fostered a non-traditional communications model where information is produced and consumed at the individual, local, national, and international level. Typically, information...
has been produced by the scientific community; forwarded to peer reviewed, clinical publication sources; and applied to greater or lesser degrees across the spectrum of care. The epidemic has changed this traditional model in that it is no longer the sole responsibility of researchers to produce information and of clinicians and administrators to apply that information (Michal-Johnson and Bowen, 1989). Rather, traditional consumers (i.e., patients) are often active producers of information within the AIDS arena, while traditional producers of information (i.e., researchers and clinicians) are often consumers of the information found in non-traditional sources such as underground newsletters and electronic bulletin boards. Yet, the traditional roles continue to exist as well. This paradigmatic shift confounds efforts to collect, organize, access, manage, and disseminate information concerning the illness and all its constituent elements.

Owing to the diverse—and unique—population of HIV/AIDS information producers and consumers, vernacular specific to this arena has arisen (Huber, 1993b). This vocabulary consists not only of scientific and biomedical terminology (Bierbaum, Brooks, and Brooks, 1992) but also includes language representative of the disciplines of education, anthropology, sociology, psychology, theology, and philosophy. Further differentiating the vernacular, terms common among communities affected by the disease are included. Partly because of the breadth of subject matters involved in the epidemic, yet the specificity required of the language used to describe it, traditional resources do not presently reflect the diversity of the vernacular.

Parallel to the number of documented cases of AIDS worldwide, the literature continues to grow at an epidemic rate. Several bibliometric studies have documented the rate of growth over time and compared it to the growth in numbers of cases (Forney, 1990; Gillaspy, 1995; Pratt, 1992; Self, Filardo, and Lancaster, 1989; Sengupta and Kumari, 1991). An organizational scheme useful for describing this literature and making it accessible to the producers and consumers of information across all boundaries is a helpful management tool when confronted with such a rapidly growing literature.

3. Statement of Problem

HIV disease and its end stage, AIDS, encompass a vast array of issues and concepts, crossing multiple disciplines. Furthermore, the language of HIV/AIDS has been produced by consumers of that body of knowledge. Existing vocabularies, while adequate for the areas they serve, do not reflect the full spectrum of the discourse engendered by the pandemic. Some examples serve to illustrate the variety of concepts specific to HIV/AIDS that are not explicitly represented in currently available lexicons. Two of these resources are general ones, while two are specific to some aspect of AIDS.

Library of Congress Subject Headings (LCSH) provides access to a variety of subjects. However, LCSH is not intended to describe biomedical concepts specific to HIV disease. For example, otorhinolaryngologic disorders—including otitis media, mastoiditis, rhinitis, and sinusitis—are a growing medical complication and serious concern among HIV-infected individuals; many publications assist physicians with managing these inflammations. Describing these works in such specific terms is not possible using LCSH.

While the National Library of Medicine’s Medical Subject Headings (MeSH) does allow for this degree of detail with regard to biomedical concepts, it does not provide the level of specificity necessary to describe various psychosocial and service-related aspects of the disease and its management. Services to HIV+ individuals and those living with AIDS constitute a significant component of the discourse associated with the epidemic. For example, buyers’ clubs, a concept not represented in MeSH, facilitate access to medications for the HIV-
infected. (Thalidomide—once prescribed as a sedative for pregnant women but found to produce deleterious side effects among their offspring—is currently a valid, approved treatment option for HIV-associated wasting syndrome, yet was until recently available only through buyers’ clubs.) As services to HIV-infected persons proliferate, this portion of the discourse continues to expand.

Even though two existing lexicons are HIV/AIDS-specific, they do not represent the entire breadth and depth of the discourse. The strength of the AIDS Information Network’s (AIN) controlled vocabulary lies in its focus on HIV/AIDS, but the bulk of the terminology concerns aspects of the epidemic void of biomedical concepts. Likewise, the National AIDS Clearinghouse’s Educational Materials Database Thesaurus provides access to only one domain of the body of knowledge.

Whether general or specific, all existing controlled vocabularies lack terminology representative of the entire spectrum of the global HIV epidemic. For example, one concept central to present understanding of HIV management is category of disease progression. Currently, patients who do not progress through the disease continuum (HIV infection, HIV+ and asymptomatic, HIV+ and symptomatic, AIDS) as it is currently understood today are classified as long term survivors, non-progressors, rapid progressors, or cleared. These specific terms, ubiquitous in the epidemic, are not found in other vocabularies. Yet another concept that transcends all boundaries of the epidemic is that of disclosure within the context of the disease: HIV infection itself, mode of transmission, sexuality, mortality. HIV/AIDS and HIV/AIDS-Related Terminology: A Means of Organizing the Body of Knowledge represents an effort to bridge the many disciplines, facets, and concepts included in the discourse specific to the pandemic.

4. Literature Review

Scientific communication has long interested information scientists and bibliometricians. Through the twentieth century, information science has matured as a discipline concurrent with an explosion in scientific knowledge and the vocabulary used to describe and document it. As the body of information has expanded, once-specific disciplines (e.g., biology and chemistry, astronomy and physics) have overlapped or even merged, creating entirely separate fields of study (i.e., biochemistry, astrophysics). Specialization has in some cases actually contributed to the dissolution of borders between disciplines (e.g., medical anthropology). As science informs increasing portions of human existence, disciplines from the social sciences and humanities have overlapped with scientific fields (e.g., philosophy of science). Griffith (1990) goes so far as to describe the aim of scientific study to be deciphering, comprehending, and interpreting human behavior.

At times, various aspects of a scientific problem are being dealt with in multiple disciplines. Theoreticians reflecting on the social study of science note that “building a commonly recognized body of knowledge is seen as the ultimate goal of scientific research” (Pierce, 1990, 52). McInnis (1995) asserts that as knowledge is organized, principles and theories—concepts—emerge. Increasingly, the bodies of knowledge, and therefore the concepts central to them, emerge from interdisciplinary foundations. As insights into the problem are gleaned from a multidisciplinary perspective, researchers in the information professions have the responsibility to synthesize the findings and package them for dissemination. Indeed, such packaging is essential for the information to be made available to a broader audience, so that work on the scientific problem may be further integrated and refined (Pierce, 1990).

This integration of disciplines and approaches was examined hypothetically by Karl
Popper. Popper theorized the existence of three worlds: World 1, composed of material, physical objects; World 2, composed of subjective, individualistic ideas; and World 3, composed of what he called "objective knowledge," which he defined as various products of the human mind expressed through artifacts of languages, the arts, and technologies (Popper, 1972). Brookes built on Popper's work and applied some of the concepts to the world of library and information science (LIS). He maintained that the theoreticians in LIS have the responsibility to (1) study the interaction between subjective ideas and objective knowledge; (2) describe and explain the interactions; and (3) organize the content rather than the containers of information, so that knowledge can be more effectively used (Soyibo and Aiyepiku, 1988). Florance and Matheson (1993), writing about the roles of health science libraries and librarians, emphasized the necessity for meeting information needs effectively in an environment of scientific communication, which they argue "revolve around the retrieval, creation, manipulation, management, and dissemination of new knowledge."

HIV/AIDS presents an exemplary model reflecting the synthesis of diverse social and scientific discourse. The body of knowledge concerning this disease continues to grow commensurate with the spread of the epidemic itself. The convergence of multiple disciplines, populations, and sociopolitical issues combine to form a discourse (and vocabulary) unique to this disease and its scientific and social constructs.

5. Description and Methodology

This controlled vocabulary was developed in response to a need identified within the AIDS service community for a means of organizing and making accessible the rapidly growing body of knowledge about the epidemic. Compounding the issue was the variety of formats in which the information was appearing, ranging from newsletters, to serials and monographs, to audiovisual materials, to Internet support groups. A further complication was the variety of users needing access and at the same time attempting to provide access to the information. This organizational scheme was designed for the latter group of individuals, most of whom are not trained librarians.

A test bed for creating and refining this work was provided initially by a large, community-based AIDS service organization. This field environment provided information services directly to health care providers, educational staff, care givers, and patients. The organization's resources included vertical files, videos, various serials and newsletters, and monographs. An iterative approach was employed, wherein alpha testing on each section took place; the system was refined; and the analysis was then repeated. As development progressed, gaps in coverage were identified and filled. From this ongoing effort, the vocabulary evolved.

Certain decisions made at the beginning of the process guided the development of the vocabulary. Central to the entire work was the notion of making the scheme as flexible as possible to suit the varying needs of potential users and to reflect the changing nature of the pandemic. It is anticipated that this tool will allow for the amorphous state of a vocabulary that is in constant flux. Within this context of a body of knowledge growing and changing at an epidemic rate, the following guiding principles were articulated:

1. Be specific yet general. Concepts should be specific to HIV or AIDS, yet broad in terms of illness, bodies of information, and approaches to organizing knowledge.

2. Use hierarchical system. Hierarchical arrangement allows for visual representation of the relationships of concepts within the domains. Further, since this vocabulary differs from other HIV-specific thesauri in its emphasis on biomedical terms, Medical Subject Headings (MeSH) provided a logical model for arrangement.
3. **Be all-inclusive in terms of the various ramifications and implications of the disease.** HIV disease is a multi-faceted condition that confounds efforts to define its boundaries. Therefore, the domains and hierarchies within them include broad concepts that cross disciplines including social science, religion, education, arts and letters, and biomedicine.

4. **Provide for growth of the vocabulary.** Many authors (Bierbaum and Brooks, 1995; Bierbaum, Brooks, and Brooks, 1992; Brooks, Bierbaum, and Brooks, 1990; Self, Filardo, and Lancaster, 1989; Sengupta and Kumari, 1991) have documented the epidemic growth of the vocabulary specific to HIV infections. Such growth continues unabated. Consequently, where possible, concepts such as "drug therapy" provide space to include names of specific pharmaceuticals as they become available. For purposes of consistency, no names of medications are provided in the work; rather, the "Instructions for Use" tell the target audience to add terms at their discretion.

5. **Do not include names.** Names of specific organizations and projects, historically or currently associated with the epidemic, are numerous and change frequently. As is true of drug terms, they may be added at users' discretions.

6. **Adopt specific subheading system.** In keeping with the use of MeSH as a model, terms that would clearly need to be used across domains are called "Universal Subdivisions." While not necessarily secondary in importance to other concepts, they may be appended to any term in the hierarchy to reflect a particular aspect of that idea. For example, age range categories serve to differentiate information about pediatric AIDS from adult AIDS.

7. **Prefer plural forms of nouns, Anglicized rather than Latin terms, and normal word order.** A desire for consistency, coupled with the needs of the intended audiences, determined these choices.

8. **Provide large numbers of cross references.** SEE and SEE ALSO references were included throughout to facilitate access to specific concepts.

Developing a tool for organizing the body of HIV/AIDS information involved numerous sequential tasks. Since the decision was made to create a hierarchical structure, the initial step involved identification of broad categories, or domains, representative of the concerns manifested by the disease. Domains served as the highest level in the hierarchical structure. Using the Dewey Decimal Classification as a model, ten inclusive classes were chosen. These domains were selected based on apparent foci within the body of knowledge concerning the disease. Domains were confirmed as the most important broad aspects of the body of knowledge by reviewing various HIV-specific resources, including medical textbooks, education curricula, personal narratives, and emerging electronic sources of information. Choice of the domains demanded adherence to certain criteria. Each domain had to be an "umbrella" concept that would succinctly encompass one aspect of the entire body of knowledge; be separate and distinct from all others; and be broad enough for categorical division.

Domains include Generalities; Epidemiology and Transmission; Education and Prevention; Clinical Manifestations of HIV and Complications, Malignancies, and Infections Associated with AIDS; Treatments, Therapies, and Medical Management of HIV Disease; Psychosocial and Religious Issues, Case Management; Legal, Ethical, Economic, and Political Aspects; Organizations, Funding Opportunities, and Health Policy; Fine Arts; Belle Lettres and Non-Fiction. Brevity of domain nomenclature was sacrificed for clarity, given the target audience and intended use. Domain groupings were consistent with the reality of the epidemic. For example, the three entities in the seventh domain—Organizations, Funding Opportunities, and Health Policy—are related in that most AIDS service organizations are dependent upon many levels and sources of funding and are bound by current health policy, policy and funding.
that are often influenced by the very organizations they circumscribe.

Having discerned the highest levels of the hierarchical structure, the content within each domain was developed. HIV-specific concepts were identified using standard medical references including The AIDS Knowledge Base (Cohen, Sande, and Volberding, 1994), the Textbook of AIDS Medicine (Broder, Merigan, and Bolognesi, 1994). AIDS: Etiology, Diagnosis, Treatment, and Prevention (DeVita, Hellman, and Rosenberg, 1992), Dictionary of AIDS Related Terminology (Huber, 1993b), and HIV/AIDS Curriculum (Mountain-Plains Regional AIDS Education and Training Center, 1992). Specific terminology representing concepts was mapped to the domains and arranged hierarchically. At this time, the emerging vocabulary was compared to one of the only existing HIV-specific schemes. This early arrangement was developed by librarians from Philadelphia’s AIDS Information Network (AIN) and is non-hierarchical in structure. Concepts from the AIN vocabulary were added where appropriate. The National Library of Medicine’s Medical Subject Headings (MeSH) was used to supplement biomedical content development. The Thesaurus of Educational Descriptors, developed by information specialists at the National AIDS Clearinghouse, was used to verify completeness of the third domain, Education and Prevention. Subject specialists assisted with clarifying terminology in both the Religious Aspects and United States Government components of the scheme.

As work progressed, it became obvious that some concepts applied to more than one domain. Therefore, standard subdivisions (in this work, called Universal Subdivisions) were created. Some, such as age ranges, are generally applicable; while others, such as stages of infection, are HIV-specific. These terms reflect varied facets of main concepts and may be attached to them as needed. Categories of subheadings include Age Ranges, Sexual Orientation, Gender, Stages of Infection, Ethnic Groups, Geographic Names, At-Risk Populations, Religious Faiths, Signs and Symptoms, and Special Populations. (At-Risk Populations are groups of people whose behaviors or workplace tasks may place them at risk for HIV infection. Special Populations refer to groups of individuals directly affected by the epidemic.)

Finally, the authors generated an alphabetic listing of terms and wrote instructions for using the controlled vocabulary. The alphabetic index facilitates access to the hierarchical arrangement. Users unfamiliar with hierarchical schemes can go directly to the index and locate the term or terms they need to describe a given work. Cross references guide users to preferred terms within the vernacular. Instructions for use include examples for describing works using terms from the lexicon and combining them as needed to reflect various facets included.

6. Discussion

Discourse surrounding the AIDS phenomenon continues to evolve and requires that a nosological record be maintained in order to describe the collection of existing and emerging resources. Detailed description provides a key element necessary to organize the body of knowledge. As the epidemic matures, the continued accumulation and distillation of information will reflect a synthesis representative of the understanding of the disease and all its ramifications at a given point in time. This synthesis supports the depiction of accurate information that may allow for the iterative transformation to knowledge.

For example, early nomenclature used to describe the disease was tied directly to populations perceived to be most affected in the United States; i.e., gay-related immune deficiency (GRID), gay cancer, gay bowel syndrome, gay pneumonia. Eventually, the human
immunodeficiency virus (HIV) was identified as the causative agent of the constellation of signs and symptoms known today as the acquired immunodeficiency syndrome (AIDS). Over time, the pejorative terms were replaced with nomenclature descriptive of the diseases themselves rather than specific populations affected by them. This modified nomenclature is reflective of the expanded knowledge base that has developed over the course of the epidemic. Regardless of the standardization of the vocabulary, however, there is little consistency in its use (e.g., "AIDS virus" rather than HIV). This lack of consistency demonstrates that transformation from information to knowledge is dependent upon multiple factors and cannot be guaranteed.

Similarly, the legal realm offers evidence of an evolution in discourse. Since the beginning of the epidemic, legal discourse concerning disclosure issues, insurance coverage, adoption, medical malpractice, multiple end-of-life matters, and other topics has assumed a growing presence. Indeed, AIDS has generated more litigation than any other single disease in the history of the United States' legal system (Gostin, 1990). Despite the body of legal precedent regulating behaviors, practices, and procedures associated with HIV/AIDS, discrimination, abdication of responsibility, failure to adhere to guidelines, and other abuses continue to occur. Therefore, though the transformation from information to knowledge has begun (e.g., regulations governing blood donations), the process is impeded by the complex nature of the disease.

Owing to the basic science research performed as a result of the AIDS epidemic, the discourse of molecular biology, virology, immunology and other life science areas has expanded remarkably. In particular, scientists' understanding of retroviruses existed at a macro level prior to HIV/AIDS. Because of the compelling need to stem the spread of the disease, viral structures and their activity at the cellular level intrigued scientists world-wide to a new and urgent degree. While basic information about retroviruses was available, the epidemic served as an impetus to develop the knowledge base. Today scientists know how retroviruses insinuate themselves into cells, replicate, and mutate. This understanding theoretically facilitates the development of a vaccine, but the transformation from information to knowledge is not yet complete, since no vaccine yet exists to prevent HIV infection or to cure AIDS.

Indeed, no preventive vaccine exists to slow the epidemic, but prevention is possible through education (Osborne, 1989). The discourse necessary to implement this preventive measure varies from group to group, culture to culture. No matter the group or culture, however, a central tenet of the discourse focuses on what has come to be called "safe, safer sex." Since HIV is known to be transmissible through unprotected sexual activity, an entire discourse concerned with means of prevention has developed and continues to evolve. While safe sex prevention measures have been adopted by some individuals, HIV continues to be transmitted by unprotected sexual behaviors. Sadly, since the epidemic continues to claim more lives, the information available regarding this and other means of prevention has not yet been transformed into knowledge.

The body of knowledge surrounding HIV/AIDS continues to grow at an epidemic rate. Within the context of that body of knowledge, the transformation from information to knowledge has occurred in some instances, but not in others. The availability of a lexicon chronicling the evolution of the discourse facilitates maintenance of the nosological record and knowledge production. It also serves to record the social as well as the scientific constructs of the disease.
References


syndrome (AIDS) and the epidemic growth of its literature. *Scientometrics*, 17, 49-60.
