
The Development of Specialized Biomedical Information

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ABSTRACT

SPECIALIZED BIOMEDICAL INFORMATION comprises most of the information found in hospital and academic health sciences libraries and has also become the focus of a growing number of specialized information services and centers. The trends we see in the development of biomedical information have been duplicated, and sometimes extended, in the development of specialized information. The emergence of AIDS during the past decade has created a complex set of information dynamics, which has led to the development of new sources, services, systems, and modes of dissemination. These new information dynamics have been accompanied by, and are the result of, the involvement of new participants in the AIDS information equation. The solutions and strategies brought to bear on the AIDS information problem have demonstrated the progress made by the biomedical information community over the past two decades. However, AIDS has also demonstrated the challenges we face in striving to participate effectively in an information environment which is increasingly complex.

INTRODUCTION

Over the last two decades, several trends have characterized the development of biomedical information and its management. These trends include the proliferation of information, production in new formats, rising costs, and new methods of dissemination and transfer. The specialized information found in biomedical libraries and

information centers and the growing number of libraries, information centers, and services which collect, provide, and disseminate specialized biomedical information also show evidence of these developments. Beyond their ability to demonstrate these changes and trends, an examination of specialized biomedical information may also provide a better understanding of the complex interactions and dynamics between biomedical information and the many and varied participants who produce, seek, share, disseminate, and manage that information.

Specialization in care and treatment, and the focus of organizations and populations on specific health-related concerns, have created the need for, and spawned the development of, libraries and information centers which address a more specialized subject matter. Specialized information centers and services may concentrate on a specific health concern or disease such as alcoholism, Alzheimer's disease, cancer, or otitis media. These centers and services may also focus on solutions to health concerns such as biotechnology; on a specific drug such as lithium; on a category of diseases such as rare disorders; on education or prevention such as cesarian prevention; or on a particular population such as retired persons. Specialized information centers and services frequently support the internal information needs of the organizations they serve, while providing information services to the external population(s) most concerned with the focus of their organization. These information services may be concerned with disease advocacy, may serve as research centers, may be provided by or serve health care professionals, or may be government affiliated.

No specialized health concern in the last two decades has challenged both the biomedical and information communities as much as acquired immune deficiency syndrome (AIDS). The emergence of new information sources and formats, of new producers and users of information, of new methods for dissemination of information, and of new dynamics among the various professions and persons concerned with the disease, have all been a critical part of the AIDS information equation. AIDS information has reflected, demonstrated, and, in some instances, caused the present trends in biomedical information and information handling. The complexity and richness of the AIDS information environment makes it the ideal health concern to use in an examination of the development and evolution of specialized information centers and services and of their coping strategies.

PARTICIPANTS IN THE AIDS INFORMATION EQUATION

Any analysis of the development of AIDS information and the strategies devised to cope with it must necessarily include a discussion of the participants involved in the production, seeking, sharing, and

management of that information. The advent of AIDS has seen multidisciplinary extended to another level where medical information is produced, shared, and disseminated not only by the clinician, psychiatrist, neurologist, and sociologist, but also by those outside of the medical field. The "Medical News" section of *JAMA* acknowledged, in 1985, that: "Homosexual and bisexual men, who account for approximately 75 percent of reported AIDS cases in this country, were the first—and remain among the most active—organizers of resource centers for information, counseling and support for persons who are in high-risk groups for AIDS" (Goldsmith, 1985, p. 2522). The development of AIDS information and literature has been characterized by an increase in sources outside of the traditional biomedical literature and produced by those who are outside the biomedical establishment (Ginn, 1987; Huber, 1991).

This active involvement in the information equation by nonhealth professionals may be most closely related to the consumer health movement. Still, the information involvement in AIDS differs in its intensity if not its cause. The support organizations which assumed responsibility for the collection, organization, dissemination, and, in some cases, the production of AIDS information, did so in direct response to the perception of a vacuum in the traditional biomedical community. This perceived vacuum initially related to care and treatment but was extended to the provision of information. Two factors probably contributed to this "pre-empting" of the central information role of health care professionals. The first was the stigma attached to the populations most directly effected by the disease—homosexuals, Haitians, and drug abusers. The conviction that the affected groups would need to provide for themselves was particularly prevalent in the early 1980s. Another factor was the concentration of AIDS knowledge in a relatively small number of cities by a relatively small number of "AIDS experts" with the largest caseloads. While a small number of these "AIDS doctors" were being overwhelmed with both treatment and information demands, they may have felt minimal discomfort in yielding the information provider role to the support and service organizations. Related to these factors was the reality that a large percentage of the AIDS focus was on education, prevention, and the provision of information as primary weapons in dealing with the disease. These were arenas in which nonhealth professionals, particularly those in the gay community, considered themselves to be at least as effective as the medical community.

The same conditions which coalesced around AIDS to create a new health information equation and new participants in the information process may not be reproduced exactly in other disease

or health concerns. Still, the levels of involvement by participants in the AIDS information crisis have provided both the professional and nonhealth professional communities with some valuable lessons. The most obvious lesson is that those most affected by a disease or health concern are willing and able to provide leadership in the development, provision, and dissemination of information about that disease or health concern. It is likely that this more aggressive approach to participation in the information equation will be seen in the future. Both the medical and information professions will need to work within this expanded framework or environment in which health care information is available and used beyond the traditional biomedical collection.

SERVICES TO A SPECIALIZED CLIENTELE OR USER GROUP

Specialized information centers necessarily serve a specialized clientele and user group, but that clientele and user group may also be extremely diverse. Most AIDS information centers provide information to a wide spectrum of different users, regardless of who they define as their primary user group. Most of the largest community-based support organizations, such as Gay Men's Health Crisis in New York, San Francisco AIDS Foundation, and Health Crisis Network in Miami, provide information services to anyone interested in AIDS information. This includes the general public; those who are HIV positive; people with AIDS; family, friends, and spouses of those with AIDS; health care workers, ranging from clinicians, to sociologists, to psychologists, to health care financial advisors; and to the vast cadre of nonprofessionals who work for, or are affiliated with, the organization, providing care, treatment, and support for those concerned with AIDS. Both the newness of AIDS and the diffusion of AIDS information makes any AIDS information provider a potential resource for much of the population.

In spite of this diversity of clientele using the larger AIDS information centers, there has also been a splintering of services, including information services. In the larger cities, in particular, several groups have split off to form specialized services, including information services. AIDS organizations which focus on women, African-Americans, Haitians, and Hispanics are examples of the specialized groups that have formed separate organizations to provide information services.

Specialized populations have received considerable attention regarding their AIDS information needs. Researchers have examined the importance of language and culture in the dissemination and seeking of AIDS information, reaching the conclusion that information for Hispanics, African-Americans, and other racially or

culturally diverse groups needs to be culturally and linguistically appropriate to be effective (Aruffo et al., 1991; Hu et al., 1989; Marin & Marin, 1990). Others have examined information dissemination, seeking and behaviors in the workplace (Barr et al., 1991; Farnham, 1991), or the AIDS information-seeking patterns and behaviors of college students (Cline & Engel, 1991; McDermott et al., 1987; Shelnett, 1989). The literature indicates that specialized populations do exhibit information needs and behaviors specific to those groups, affecting the design and provision of information services appropriate to these populations.

The diversity in specialized information center users may be based on their demographics or interests but may also be based on their knowledge or reading level. Many of the individuals belonging to high risk populations (adolescents, IV drug users, minorities) are not well-educated about AIDS or may lack the ability to read at a level sufficient to educate themselves (Huber, 1992b). A study presented at the Sixth International Conference on AIDS (Halleron-Tweedley & Ranieri, 1990) asserted that reading levels of materials are too high for many target audiences and that translations and cultural sensitivity of materials are inadequate. Greenblatt (1990) asserts that, "considering the disproportionate representation of racial and ethnic minorities and youth among AIDS victims, couching information in such technical terms is tantamount to supplying no information at all" (p. 175).

Health professionals are among the specialized groups for whom AIDS information centers and services have been designed. The Regional AIDS Education and Training Centers (E.T.C.s), are administered by the Health Resources and Services Administration (HRSA), Bureau of Health Professions, Division of Medicine, and have the responsibility and mission of improving the education of health professionals in AIDS health care and support. The seventeen E.T.C.s provide training and information for health professionals in their particular service area. The Pennsylvania AIDS Education and Training Center has targeted primary care providers—physicians, dentists, nurses, nurse practitioners, and dental hygienists. In addition to providing collections of materials, educational programs, and conferences, the Pennsylvania E.T.C. focuses on programs which support clinical training.

Specialized information services provide many of the same challenges seen in more general collections. These services and centers also have to determine or define their primary clientele and mission, keeping in mind that the services they provide need to be responsive to those of varying cultures and backgrounds or varying levels of knowledge, intelligence, or reading ability. With an increased

understanding and recognition of the multidisciplinary and multifaceted nature of most diseases or health concerns, these concerns will likely be manifested in diseases other than AIDS.

DEVELOPMENT AND EVOLUTION OF AIDS INFORMATION

AIDS information has been produced in a variety of formats, by a variety of producers, in prolific amounts. The media, government, health care profession, consumers, and support organizations have all contributed substantially to the information and knowledge base on AIDS (Ginn, 1987).

The nontraditional information sources have come primarily from support organizations and consumers, including those who have AIDS, are HIV positive, or are in high risk groups. In the first years of the epidemic, particularly from 1982 to 1984, information hotlines, newsletters, and publications from the alternative press, such as *The Advocate* or *The New York Native*, were among the first to provide information about the disease. These nontraditional information sources have continued to serve as a primary information source for many.

The proliferation of AIDS information over the past ten years has been clearly visible and documented through research. Sengupta and Kumari (1991) observed that the number of AIDS cases doubles every ten or eleven months, with the body of literature concerning AIDS doubling in volume every twenty-two months. This dramatic increase was also explored by Roberts, Shepherd, and Wade (1987), who found annual increases in the number of MEDLINE articles published in the mid-1980s to be as high as 75 percent in 1984. The explosion of the AIDS biomedical journal literature is further evidenced by the National Library of Medicine's *AIDS Bibliographies*, which were first published semiannually, then quarterly, and then monthly. It has been estimated that, from 1983 through mid-1991, more than 200,000 MEDLINE entries were AIDS-related, that almost 60 percent of the journals indexed in MEDLINE published at least one article on AIDS during the past ten years, and that the literature of AIDS has grown to encompass at least twenty-nine languages and sixty-five countries (Pratt, 1992). There appears to be no research, bibliometric or other, which compares the growth of this literature to that of literature for other diseases or medical topics. Still it is clear that those providing AIDS or other specialized information services will likely have to cope with ever-increasing amounts of information.

AIDS specialty journals proliferated during the 1980s (Gluck, 1989), but the scattering and seepage of the AIDS literature to a wide range of biomedical journals continues to be significant (Sengupta

& Kumari, 1991). Specialized AIDS-related databases also proliferated during this time period (Branch, 1988; Rosenthal, 1990). The development of AIDSLINE from the National Library of Medicine in 1988 provided a bibliographic database that brought together citations from multiple disciplines and databases such as BIO-ETHICSLINE, POPLINE, CATLINE, AVLINE, and others (DuPont & Dutcher, 1990).

Centers and services providing AIDS information face a difficult task. The task extends beyond coping with the volume of information, to the evaluation of the information, and to the problems inherent in the organization and management of information in multiple formats.

SELECTION, COLLECTION AND EVALUATION

Librarians have alternately embraced and shunned the role of information evaluator (Kuller et al., 1993). Reasons for this reticence range from a lack of subject expertise to the very small number of information malpractice suits directed toward librarians or information specialists. The dynamics involved in the development and production of AIDS information have added to librarians' and information specialists' responsibilities in collecting, selecting, and evaluating AIDS information.

The criteria typically used by librarians in evaluating medical information and information sources may also be used in evaluating AIDS information; they include audience, coverage, scope, timeliness, accuracy, source credibility, purpose, cost, and organization. In the evaluation of AIDS information, some of these criteria assume a new meaning and present a more difficult challenge than other medical topics.

Between 1982 and 1987, timeliness was particularly crucial in selecting, evaluating, and weeding AIDS information. The first five years of the epidemic saw a rapid curve in the identification of the syndrome, its opportunistic diseases, its modes of transmission, the retrovirus that caused it, and the first drugs that could slow or control it. Since 1987, the information has stabilized somewhat, but timeliness of AIDS information remains an important criterion.

The accuracy of AIDS information presents perhaps the greatest challenge to evaluation. In spite of epidemiologic data to the contrary, mosquito transmission of AIDS was strongly suggested in the mid-1980s (EIR Biological Holocaust Task Force, 1986). In spite of a lack of substantive evidence, the theory that HIV was introduced by the government as a form of genocide is still being suggested (Snead, 1992). Somewhat more subtle controversies surround the issue of whether HIV is really the "cause of AIDS" or whether AIDS is actually

a form of syphilis (Adams, 1989). For librarians and others evaluating AIDS information, determining what constitutes misinformation and what constitutes an "interesting theory" will continue to be problematic.

Source credibility may also be difficult to establish in an ever-changing knowledge base. As indicated earlier, although the number of AIDS experts is still relatively small, increasing numbers of authors are writing about the disease. Knowledge of disciplines or fields related to AIDS has not uniformly been accepted as ensuring credibility about AIDS. When Masters et al. (1988) published a work on heterosexual transmission of AIDS, his expertise on sexual behavior was noted, but his knowledge of AIDS was also questioned.

The criterion which has perhaps grown most in importance with the emergence of AIDS is that of "purpose, agenda or perspective." Those reading, selecting, or evaluating information must have a heightened awareness that AIDS information operates in the same political environment as the disease itself, and that this affects its content and presentation (Ginn & Stevens, 1988). Those who simultaneously call for quarantine of AIDS patients and cite studies that the virus can "live" in saliva, provide an example of information which may be affected (or contaminated) by purpose, agenda, or perspective.

TERMINOLOGY AND LANGUAGE OF AIDS

In addition to the proliferation of AIDS information in its variety of formats and producers, the growth and evolution of AIDS terminology has been noted (Roberts et al., 1987; Ginn & Stevens, 1988). AIDS and AIDS literature was in existence for over two years before receiving its initial Medical Subject Heading (MeSH), **Acquired Immunodeficiency Syndrome** in 1983, while other indexes or databases, such as *Reader's Guide* or *Psychological Abstracts*, assigned terms earlier. This was consistent with the National Library of Medicine's policy of waiting to ensure that a concept, technique, instrument, or disease would last more than just a year or two. Still, the National Library of Medicine did recognize the uniqueness of the situation and, deviating from its standard practice, established the AIDS heading in mid-year (March 1983).

The MeSH headings grew with the terminology of the disease, with the term **AIDS-Related Complex** established in 1987, terms for the family of **HIV Infections** in 1990, and terms for **HIV Antigens**, **HIV Antibodies**, **HIV Envelope Protein GP120** and other concepts now available. The headings available to those searching the literature have grown with the scientific and medical community's knowledge of the disease itself.

While the headings available to MEDLINE searchers have grown, those responsible for collecting and organizing materials and information continue to face a formidable challenge. Specialized AIDS information collections provide both broader and deeper AIDS coverage than general biomedical collections. They require a more extensive terminology or thesaurus than MeSH headings offer. Most support organization libraries and information centers have chosen not to use MeSH headings, developing their own headings and methods of organization instead. For example, the Pittsburgh AIDS Task Force provides its own non-MeSH heading and subheadings for information on costs:

Costs

Education
Foreign Spending
Federal Spending/Medicare
Hospitalization
Research
Insurance
State/Local Spending
Testing
Treatment

Other organizations, such as the library of the AIDS Information Network in Philadelphia, have developed a substantial number of non-MeSH AIDS and AIDS-related headings (approximately 600), which include definitions or scope notes and a classification scheme which provides for *see references* to assist in the organization and retrieval of information:

(46) **Cofactors in HIV Infection**—other than substance abuse/drug use, nutrition, sexual behavior.

SEE	97.10	Drug use/Cofactor
	181	Disease progression
	217.17	Nutrition/Cofactor
	222.55	Opportunistic infection, conditions/Vitamin deficiencies
	(277)	Sexual behavior
	(280)	Sexually transmitted diseases
	292	Stress

The organization of AIDS materials is complicated by large amounts of ephemera, including newspaper articles, unpublished reports, and internal documents. Those providing electronic versions of their AIDS information and holdings have generally been limited to using automated systems for small collections or libraries, or

bibliographic management software such as ProCite, Reference Manager, and EndNote.

No authoritative thesaurus for AIDS terms has yet been adopted for specialized AIDS collections. However, Huber (1992b) has recently published *Dictionary of AIDS-Related Terminology*. The monograph represents the first attempt to meet the need for a dictionary in comprehensible language for the layperson and seeks to address some of the complexities and unique attributes of the vocabulary. It contains approximately 1,500 terms identified through clinical and popular presentations of AIDS-related information. The definitions attempt to be as useful as possible without sacrificing medical, scientific, or popular accuracy, with lengthy technical definitions preceded by a simplified condensed version. Huber's work acknowledges one of the more important information dynamics surrounding AIDS; the vocabulary of AIDS is used by a diverse group of individuals with varying degrees of education and knowledge about medicine in general or AIDS specifically. The terminology and language of AIDS presents problems for those who need to find AIDS information and those who collect, organize, and disseminate that information.

RECENT DEVELOPMENTS IN SPECIALIZED INFORMATION DISSEMINATION

The dynamics surrounding AIDS resulted in the application of existing modes of information dissemination and the development of new dissemination modes. Newsletters produced by support organizations and others assumed new forms and levels of importance. Several newsletters, such as the *AIDS Medical Update* from the UCLA AIDS Clinical Research Center, provided editor generated abstracts or editorial comments to either supplement or replace the abstracts provided by the author. This type of external input to the analysis of journal articles is additional evidence of the desire to provide multiple and varied perspectives and interpretations of the biomedical information.

The concept of an "invisible college" among the producers of traditional AIDS literature (health professionals and basic scientists) has been studied by Self (1990). She found that the AIDS literature is written predominantly by the collaboration of two or more individuals, although the data did not allow for definitive conclusions regarding relationships between authorship and the authors' patterns of informal communications.

CD-ROMs appeared fairly early in the provision of AIDS information, with the introduction of the AIDS Compact Library from the Medical Publishing Group in 1988. This tool provided access to MEDLINE references on AIDS, AIDD (an international AIDS

database, produced in England), the full text of AIDS articles from several biomedical journals, and the AIDS Knowledge Base produced by experts from San Francisco General Hospital and the University of California at San Francisco. The knowledge base provided the ability to continuously update information (bimonthly), particularly important in a disease where information was changing rapidly.

Phone services and electronic bulletin boards have also assumed a heightened importance in the dissemination of AIDS information. In addition to providing a newsletter, San Francisco's Project Inform provides information on the availability and effectiveness of antiviral and immunomodulating drugs. Project Inform was one of the first organizations to provide information on drugs which were not federally approved. Without providing recommendations or endorsements of treatments, this organization provides information on AIDS therapies using physicians and other health care professionals as part of their organization. Electronic bulletin boards and mail systems emerged to facilitate information exchange and communication about AIDS and AIDS therapies. Huber (1992c) lists over a dozen bulletin boards or messaging systems, including AIDS Info BBS, Computerized AIDS Information Network (CAIN), FOG CITY Bulletin Board System, and AIDS Teleforum.

Beyond these new methods of information transfer, there is another phenomenon which cannot be ignored when discussing AIDS. There is an informal underground network of AIDS information which focuses primarily on therapies, some of them alternative, some unproven, and some potentially dangerous. This underground network extends beyond the provision of information about AIDS drugs, to where to get them, or even how to make them (Kolata, 1991; Richman, 1989). While many health professionals may be uncomfortable with these new roles of consumers and patients, the established biomedical community will need to acknowledge this new level of assertiveness and participation in the health and health information process and the conditions and frustrations which led to their appearance.

Computer-assisted instruction programs for AIDS have been produced to assist health professionals in managing and caring for those with AIDS. Available from the East Central AIDS Education and Training Center, *AIDS: Vignettes for Physicians*, *AIDS Vignettes for Dental Professionals*, *AIDS-Vignettes for Nurses*, and *AIDS and HIV Disease: Psychosocial Interventions for Health Care Workers* contain case-based vignettes which present health care professionals with decision-making situations and the opportunity to test their own knowledge (East Central Aids Education and Training Center, 1990). More AIDS resources of this type will likely be developed in

the 1990s as a wider range of health professionals (not just AIDS experts) are required to provide care and treatment to those with HIV and AIDS.

INTEGRATIVE SERVICES AND SYSTEMS

The difficulty inherent in providing AIDS information from multiple sources and in varying formats has created the need for integrated services and systems. These services and systems have attempted to bridge the gap between the multitude of different information sources and formats.

The first computerized information system which attempted to bring together the variety of information sources, traditional and nontraditional, in a variety of formats, was the Computerized AIDS Information Network (CAIN) developed by Delphi Inc. in 1986. Administered by the Gay and Lesbian Community Service Center in Hollywood, California, and the San Francisco AIDS Foundation, CAIN attempts to provide a database comprising a broad spectrum of AIDS information. Designed primarily to meet the needs of support organizations, health professionals, people with AIDS, and educators, the database was unique in bringing traditional and nontraditional information into the same system. The menu includes service resources, organization assistance, informational and educational resources, electronic publications, and legal information. A small number of citations from the biomedical literature are also included. CAIN is structured to allow subscribers to contribute information to the database as direct information providers, with technical information reviewed by professional advisory panels local to each information provider, also a new approach (Ginn, 1987).

The state of the art for integrated online computerized AIDS information may be the recently developed Southeast Florida AIDS Information Network (SEFAIN) and Boston's Service Providers Information Network (SPIN).

SEFAIN (Burrows, 1992) is a community-based AIDS information system prototype developed for the 40,000 health professionals in the high incidence South Florida area, which includes West Palm Beach, Ft. Lauderdale, Miami, and Key West. The system integrates the University of Miami School of Medicine's online catalog with the AIDS Care and Service Provider database, which provides access to information on over 400 AIDS service and care providers in the region. SEFAIN includes the Research and Clinical Trials database which provides information on research in South Florida, inclusion/exclusion for participation in clinical trials, and the National Library of Medicine's AIDS databases, AIDSLINE, AIDSDRUGS, and AIDSTRIALS.

Similar to SEFAIN, the Service Providers Information Network (SPIN) (Boston AIDS Consortium, 1992) is based at the Harvard School of Public Health and designed by the Boston AIDS Consortium. The network enables direct care providers and people with HIV to access a range of information from a personal computer equipped with a modem. SPIN services include information services (newsletters, information on clinical trials, statistics, experimental treatments, job opportunities, information on drug reimbursement programs); communication services, including electronic mail, conferencing and forums; and provider referral. The provider referral is an online database of over 1,200 health and social service agencies providing services across the continuum of HIV/AIDS care (Boston AIDS Consortium, 1992; Boston AIDS Consortium, 1993).

TOWARD A COMPREHENSIVE SPECIALIZED INFORMATION COLLECTION AND SERVICE

Providing a truly comprehensive collection and service, even in a specialized biomedical area, is nearly impossible. The proliferation of AIDS information has already been discussed, together with the various formats in which it is produced. Specialized collections and information services will still need to evaluate and select information, even while attempting to be comprehensive. The two most ambitious attempts to collect comprehensively in the area of AIDS have probably been undertaken by the National AIDS Information Clearinghouse (NAIC) and the AIDS Library of Philadelphia.

Established in 1987, the NAIC is an information service provided by the Centers for Disease Control. The clearinghouse collects and distributes information on HIV and AIDS, maintains databases of AIDS organizations and educational materials, and provides telephone reference assistance. The clearinghouse also provides a funding database for HIV and AIDS service or support organization and the AIDS Clinical Trial Information Service.

While most of the specialized AIDS information centers of significant size have been associated with AIDS support organizations, the library at the AIDS Information Network in Philadelphia represents the state of the art in specialized information centers and houses perhaps the most extensive collection on the topic. Established in 1987 as the AIDS Library of Philadelphia, the network's library now houses an information file of 80,000 articles from 1981 to present, 3,000 monographs, 250 videos, 160 serial titles, 200 pamphlet and brochure titles, as well as CD-ROMs and laserdisks. In FY92, the network answered 35,000 queries. Funded by private donations, some grant funding, and special events, the network is staffed by 2.5 FTE librarians, a paraprofessional, and approximately twenty volunteers.

Other staffing includes an executive director of the AIDS Information Network and an office manager. The AIDS Information Network also publishes a monthly newsletter and provides an AIDS education and prevention program (Schmidt, 1991; J. Hofacket, personal communication, February 12, 1993).

The National AIDS Information Clearinghouse and the AIDS Information Network of Philadelphia provide information and services to the widest range of those needing information on AIDS. These attempts at comprehensive collections and services represent important resources in the spectrum of AIDS information.

CONCLUSION

As an example of specialized biomedical information, AIDS is both representative and unique. AIDS has presented the biomedical and biomedical information community with challenges that are somewhat similar in kind to other diseases or conditions, but which operate in a significantly more intense environment and which present a set of information dynamics previously unseen. New participants in the AIDS information equation have added to this complexity, with consumers assuming roles even more active than those seen in the growing consumer health movement. These new participants have produced or inspired new information sources, formats, and modes of dissemination.

Those in the biomedical information community, such as librarians and information specialists, will need to provide their expertise to assist in the development of effective information sources, services, and systems. But they will also need to recognize that those directly and indirectly involved in the provision, organization, and dissemination of information now constitute a wider sphere. This wider sphere of involvement extends the role of librarian beyond that of either information collector or gatekeeper to that of educator, consultant, and resource.

AIDS has challenged our ability to provide both effective health care and effective health care information sources, services, and systems. Some of the solutions, strategies, and technologies brought to bear on the problem have been effective, but the AIDS information crisis has also exposed some of the flaws and weaknesses in our ability to solve information problems. The development of solutions and strategies for the AIDS information crisis will help solve the challenges of the broader range of medical and health information problems.

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