

The Challenging and Critical Role of Information Professionals in Combating AIDS in India

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Background and Context

- Indian society is at high risk – it has second largest number of HIV infected people after South Africa.
- Rural and remote area population are ignorant or very less informed about HIV/AIDS
- Educating rural and illiterate masses is a challenge because there are many major languages and hundreds of different dialects.
- India's diversity – a challenge in adopting strategies that are socially and culturally appropriate

AIIMS study on Indian AIDS situation:

- More vulnerable to AIDS
- More likely to contract disease than other people
- Lower immunity to the virus – genetic cause

The Indian National AIDS Control Organization (NACO) estimates that 5.134 million people were living with HIV in 2004. The spread of the epidemic in rural areas presents a need to disseminate HIV/AIDS related knowledge for health protection rather than waiting for knowledge to follow the appearance of the disease in communities



2003	
Adults	5,000,000
Women	1,900,000
Children	120,000
Total	5,120,000

Health literacy and HIV/AIDS

Health Information Literacy is “ the set of knowledge and skills needed to recognize a health information need identify likely information sources in all formats, and use them to retrieve relevant information analyze, understand and Synthesize the quality and content of information and its appropriateness to a specific situation; and, to apply the information in making health decisions- with an aim toward improved health outcomes” (MLA Task Force, 2003)

There are three different types of health literacy:

Functional health literacy- represents the cognitive and social skills which determine the motivation and ability of individuals and communities to gain access to, understand, and use information in ways which promote and maintain good health.

Interactive health literacy- focuses on personal and social skills development, such as self-confidence, negotiation, and assertiveness, and the resulting individual health-related behaviors associated with these attributes.

Critical health literacy- refers to the development of specific higher level cognitive and communication skills, such as accurately interpreting and evaluating media reports, navigating health care systems, and the capacity to effectively access and use health information

(Kickbusch & et. al, 2002)

Collaborative initiatives to promote AIDS literacy

- New York Online Access to Health (NAOH <http://www.noah-health.org/>) is a collaboration of a number of New York libraries, including the New York Public Library, provides full-text HIV/AIDS related information to consumers.
- Consumer Health information network (CHIN) project at Massachusetts- a collaboration of a hospital and six public libraries in the surrounding community.
- Philadelphia's AIDS Information Network have staff training program and cooperating with local AIDS service agencies, also acting as referral centre
- Visual AIDS is a project working very closely with New York public libraries <http://www.thebody.com/visualaids/about.html> and increasing public awareness of AIDS through visual arts.
- Detroit Community AIDS Library (DCAL) is a partnership of Academic health sciences, medical hospital and public libraries
- Kenya National Library Service (KNLS) introduced HIV/AIDS awareness program in response to the Government's appeal for multi-sect oral approach to combat HIV/AIDS.

E-learning through Libraries

E-learning modules

General Information

Differences between HIV and AIDS

Living with HIV/AIDS - why it is important to be tested, testing process and where to get tested...

How to survive with HIV/ AIDS - understand the Complexities of the HIV virus and how to live a healthier life with it

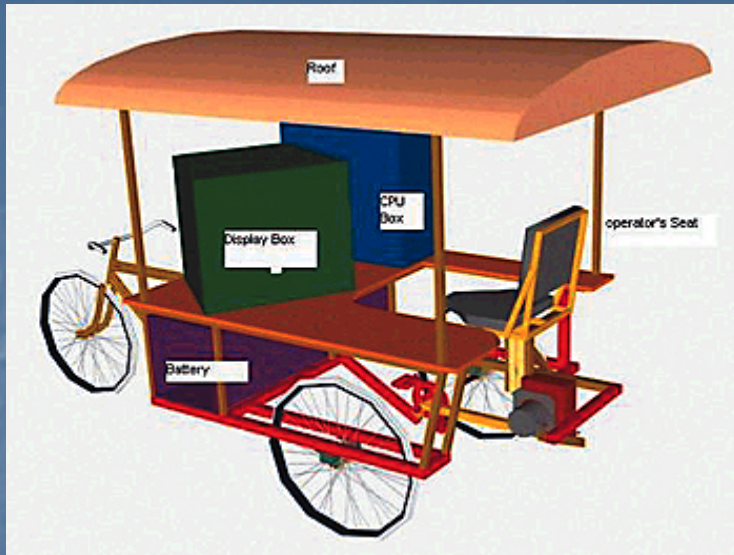
“Info_thela” Project at IIT Kanpur:

Scientists at the Indian Institute of Technology at Kanpur, an industrial town about, 500 km from New Delhi, India have developed an innovative concept "info-thela", or cyber cafe on wheels. It is a battery operated IT services on tricycles which can reach even the remotest of areas. The mobile cyber café enabling village people to get information about weather forecasts, health care, Diseases etc.

Medical Application of the Info-thela:

Info-thela is a comprehensive module to improve health standards in rural India. The major objectives are:

- To empower the rural women through information and understanding of health related issues by quicker, easily accessible, and cheaper diagnostic facility for treatment and aftercare.
- Improvement of health and hygiene of villages.



Part 1: Providing Primary health screening at the doorstep

The diagnostic devices being made available in the village itself and performed medical tests with less cost. This is to encourage more people to get tests done, which would definitely lead to improvement in overall health. The referral for the clinical examination is likely to come from local doctors and health workers.

Part 2. Introduction to the World of Microbes

This is an educational package designed for the village woman includes information in a multimedia format on microorganisms, especially those causing disease. Preparation of slides on the spot from blood samples and showing slides of various disease causing microbes are the main activities.

Part 3. Health related information package:

A multimedia version including simplified text and visual content on medical specialists, availability of medical facilities, specialist hospitals in Uttar Pradesh; commonly used medicines and existing government health programs.

Part 4. Iconic/voice Based User Interface to Access and navigate the disease and Health Information Base

The icons will be developed with the active participation of the village women themselves.

The Challenges....

- The lack of knowledge of AIDS, its modes of transmission and ways to avoid infection is a major challenge. Limited information literacy increase demand for more information processing to add value to information and services to promote information awareness, accessibility and usability.
- Educating people about HIV/AIDS and prevention is not a simple rather complicated task, as India has many major languages and hundreds of different dialects.
- The dynamics of the epidemic raise the need to keep abreast with new developments thus the need to actively collect, synthesize and disseminate information. This is however constrained by lack of adequate resources (human, financial and material) to initiate and sustain efforts.

Challenges

- Lack of ICT related training for staff and low levels of penetration of the infrastructure and supporting environment necessary to effectively use ICTs
- The multiplicity of demand for consistent, relevant and timely information on HIV/AIDS, and existence of factors at various level, and in different settings also poses the challenge of processing and packaging the same information for different level of users.
- HIV is too complex and too multifaceted for any one stakeholder constituency to deal with. Meeting the HIV/AIDS information needs of diverse communities in a vast country like India is a challenge for librarians.

Emerging role of Information Professionals

Information professionals can play dual roles as both advocates & educators; they can provide dedicated services to the society by helping to access AIDS information not only in urban setting but also in rural environment. Professionals serving in different libraries/ potential information dissemination centres are expected to :

- Empower adolescents to protect themselves from HIV infection
- Create documentation of the AIDS epidemic using convergence technologies
- Make information relevant, realistic and acceptable to the local community

Emerging role of Information Professionals

- Reduce the stigma of HIV/AIDS increases infection
- Form partnerships with marginalized community groups, such as AIDS orphans, widows and the aged.

Literature on role of librarians in disseminating health-care information:

The interactive online services will provide a service to those prefer privacy, but human interaction of the librarian could become an even more essential piece in the health information seeking process

(Dorothy Warner and J. Drew Procaccino, 2004).

A study carried out by NCLIS (US National Commission of Libraries and Information Science; report available in

<http://www.nclis.gov/news/pressrelease/pr2005/2005-12LibrariesAfrica.pdf>)

on new roles for libraries in HIV/AIDS information dissemination in Africa makes three recommendations:

- 1. Libraries' role in disseminating HIV/AIDS information is strongest when they establish partnerships with other organizations already involved in dissemination and education activities.
- 2. Libraries in Africa should expand the scope of information resources they collect and distribute to include sources outside the role of traditional libraries, including taking a leadership role in using ICTs for sharing digital materials, and providing information in formats that are accessible & interesting to young adults who are making decisions about their own sexual behavior.
- 3. An opportunity for African librarians now exists to redefine their traditional roles and take a strong lead in the dissemination of HIV/AIDS information

Suggestions and Recommendations:

There are insufficient number of libraries and information centres to meet the needs of culturally and linguistically diverse population in India.

The Health Resource Center/ Knowledge centres should be created to provide preventive health care information to the general public, specially women who are responsible for the health care of the entire family.

Public libraries should work in closely with medical libraries and NGOs and develop health information website for communicating HIV/AIDS information, and have a national information infrastructure to bring consumer health information to the broadest possible female population in the country.

Suggestions and Recommendations

- Governments in India should take libraries and provision of HIV/AIDS information seriously, hence should avail reasonable amount of money to libraries, specially, public libraries/ Knowledge Centres to develop HIV/AIDS collection. Prevention should be a key area of focus and prime concern that can be brought about by awareness.
- At a time when infection rates among women are rising because they are powerless, ordinary female population must be sensitized to change their behavior. Reduce the risk through awareness should be priority if India is not to face an epidemic.

Concluding Remarks

India has an emergency in terms of treatment but if the preventive aspects are ignored, then we will face a crisis in coming years, which will use up our resources. There is a need for strong advocacy and political support at the national level. Educating the users in libraries how to access health information on the internet has the potential to give them knowledge to maintain more healthy life styles, provide them with reliable information about their problems and make them aware of possible treatment options. One of the keys to successfully combating the HIV/AIDS epidemic is the creation of an infrastructure that concurrently develops healthcare networks, education programs, and community participation.

Thank you

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