

Health literacy for all- an investigation into consortia and partnership amongst libraries to promote health care information in India

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Abstract:

In this paper efforts have been made to analyze the present state of health information literacy in India. Health literacy is an empowerment strategy to increase people's control over their health, their ability to seek out information and their ability to take decision. Quality information and the understanding of the information are essential for the development of health literacy. The author discusses healthcare divide in India- high-quality medical care is made available to elite-class Indians and the India in which the majority of the population have limited or no access to medical care. It is proposed that through awareness and use of digital technology health related information must be widely available and effectively used through Public libraries- the people oriented institutions. Today's thrust is the use of distance learning models/e-learning to provide health information to empower the unprivileged populations. Various projects and initiatives undertaken by government as well as NGO's to spread preventive health care information are highlighted.

Keywords: Community health care, Information Therapy, Health Literacy, Health informatics, consortia and partnership in health care.

1. Defining health literacy

Health literacy is the capacity to make sound health decisions in the context of everyday life- at home, in the community, at the work place, in the health care system, and in case of emergency. Health literacy implies the achievement of a level of knowledge, personal skills and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions.....poor literacy can affect people's health directly by limiting their personal, social and cultural development as well as hindering the development of health literacy*

A working definition of health information literacy is "the set of abilities needed to: recognize a health information need; identify likely information sources and use them to retrieve relevant information; assess the quality of the information and its applicability to a specific situation; and analyze, understand, and use the information to make good health decisions" (MLA Net, 2003)[#]

India needs to focus on preventive healthcare and information on it must be provided by the Indian health care sector..."**.

To improve literacy rates, 2003-2012 has been designated as the United Nations Literacy Decade and UNESCO has developed partnership with UN agencies and other organizations to promote literacy and teach basic health literacy, through formal and informal educational programs in many countries.

2. Public Libraries, epidemic diseases and information needs of the local community

It is somewhat surprising, that little research has been carried out and very less literature is available on how public libraries and community centers can help in disseminating health care information to unprivileged community with special reference to rural community. Today deadly AIDS and other communicable disease are wide spreading only to make it essential to redefine the role of libraries and information professionals to improve health information literacy to combat the pandemic. Paiki Muswazi (2000) made a survey of fourteen public libraries in

[#]<http://www.mlanet.org/resources/healthlit/define.html>

*Health promotion glossary (http://whqlibdoc.who.int/hq/1998/WHO_HPR_98.1.pdf)

** Sheila Dikshit, Chief Minister, New Delhi, in 2nd India health summit- Emerging India Opportunities in Health care: Enhancing quality, safety and affordability, organized by CII, November 2004.

Swaziland regarding the availability of HIV/AIDS resources and found out that information resources are lacking in appropriateness and limited in number, not updated frequently.

Sidda (2005) mentioned that in the context of health literacy, there are two kinds of information: Prescribed information to a particular patient and General information about the facility, procedures and preparedness including technical information about the ailment etc. Doctors and their supporting staff concentrate on first category; libraries and health education professionals need to concentrate on second category in providing printed relevant materials in the local language or the language user understands.

The factor driving the growth of India's healthcare sector is a rise in both infectious and chronic degenerative diseases. While ailments such as poliomyelitis, leprosy, and neonatal tetanus are possible to be eliminated, some communicable diseases once thought to be under control, such as dengue fever, viral hepatitis, tuberculosis, malaria, and pneumonia have returned in force or have developed a stubborn resistance to drugs. In addition to battling infectious diseases, India is grappling with the emergence of diseases such as AIDS as well as food- and water-borne illnesses. The physical infrastructure is woefully inadequate to meet today's healthcare demands. Although India has several centers of excellence in healthcare delivery but there are problems of excess in urban India, with deprivation in the rural areas. The UNESCO Public Library Manifesto defines the public library as the local gateway to knowledge, provides a basic condition for lifelong learning, independent decision making and cultural development of the individual and social groups. Awareness programs aimed at common people are normally attempted in India through local government bodies, NGOs and primary health centres and public libraries are normally kept out of these initiatives. As the nerve centre for improving literacy, awareness, welfare and cultural awakening, the author is trying to put public libraries/ health care libraries in the right perspective to arrive at an integrated single window environment for health information access and dissemination to attain health literacy and empowerment. Previously health care information was guarded by healthcare professionals and rationed out only when absolutely necessary but the outbreak of AIDS and other communicable diseases demanding widespread availability of preventive health care information. It is the presumption that the very act of providing people with health information leads to a better health outcome and prevent diseases; as awareness could improve the dialogue between patient and health care professional, which might then lead on to better treatment.

The public libraries are considered the local gateway to knowledge, provides a basic condition for lifelong learning, independent decision-making and cultural development of the individual as well as social groups. UNESCO Public Library Manifesto was released first time in 1949 and subsequently revised by IFLA in 1972 and the revised version was adopted by UNESCO's Intergovernmental Council for the General Information program in 1994. There are several programs for health promotion in India including health literacy. These programs fall under various policies of the Government namely National Health Policy, National Population Policy, National Rural Health Mission, National Nutrition Policy, Health Insurance policy and others. Burnham (2005) stated "Libraries and librarians can contribute to the health of their communities through their involvement with health literacy initiatives and by keeping literacy issues at the forefront".

As stated in UNESCO Library Manifesto, the following key missions related to information literacy, education and culture should be at the core of public library services:

- Creating and strengthening reading habits in children from an early age;
- Facilitating the development of information and computer literacy skills;
- Supporting and participating in literacy activities and program for all age groups, and initiating such activities, if necessary.
- Providing adequate information services to local enterprises, associations and interest groups;
- Supporting both individual and self-conducted education as well as formal education at all levels;
- Providing opportunities for personal creative development;
- Stimulating the imagination and creativity of children and young people;
- Prompting awareness of cultural heritage, appreciation of the arts, scientific achievements and innovations; supporting the oral tradition;

Public libraries have potential to provide health information for HIV patients within the community. However, more thought is needed as to the format and quality of content; Information professionals serving in public libraries need to create tailor made information in accordance with the community need. Informational and emotional support can affect personal retrieval capacity; emphasis will be given on E-learning to provide health education through tele-

medicine which can make available specialized health care to rural women through ICT. In this digital age through mobile gadgets and social networks with 24/7 access has tremendous potential to empower under privileged group. All the public libraries/village resource centres can contribute to the development of databases and customize information according to community need. There are three types of health literacy categorized by Nutbeam (2001) viz. functional, interactive and critical health literacy.

HELP - Health Education Library for People (<http://healthlibrary.com/aboutus.htm>) is one of the free health library situated in Fort, Mumbai. It is one of largest patient education center housing more than 11,000 medical books on almost all aspect of health and diseases, along with pamphlets, health care magazines, with an exhaustive audiovisual section. The online health Care directory can be searched under the categories: Doctor, Hospital, Blood Bank, Pharmacist, chemist and so on. MyHealthPedia - the online health wiki is available in Hindi,users can share expert opinion, case histories & personal experiences.

3. Collaboration/ Consortia and use of convergence technology to promote health Literacy:

The government of India launched the National Rural Health Mission 2005-2012 in April 2005 to provide effective healthcare to India's rural population, with a focus on states that have low public health indicators and/or inadequate infrastructure. The government is working to increase the capabilities of primary medical facilities in rural areas, and ease the burden on to tertiary care centers in the cities.

A health grid is an environment that allows sharing of resources, in which heterogeneous and dispersed health data as well as applications can be accessed by users according to their level of authorization. The issues such as security and management of private data represent some of the biggest obstacles to the adoption of grid technology as the IT infrastructure for healthcare. CDAC a premier R&D institution of Government of India is working to develop Hospital Information System (HIS), one of the most promising applications of information technology in the health care sector on telemedicine, medical Informatics standard, Health Grid. Although corporate sector hospitals have managed to enable their operations, but a large number of public hospitals have been denied these state-of-the-art tools till now.

There are several examples of Academic libraries consortia in India to share resources on medical sciences, for example a consortium, Health Science Library and Information (HELINET) (www.rguhs.ac.in/HELINETHOSTCONSORTIIM/homeholinethost.htm) is the medical library consortium in India, initiated by Rajiv Gandhi University of Health Sciences (RGUHS), Karnataka.

The ICMR e-consortia (http://icmr.nic.in/icmrnews/e_consortia.htm)

Ratnakar et.al (2009) the consortium of Indian Council of Medical Research (ICMR) for sharing resources of its medical libraries among its 25 institutes....“ICMR with the help of Informatics India took the initiative to provide a common access point to its different libraries and information centres, so that they can know what the other libraries of the Council are subscribing and at the same time also increases the usage of these sources among the Councils libraries”. JCCC-ICMR is an extension of JCC for a group of homogenous consortia members of the ICMR. J-Gate Custom Content for Consortia (JCCC) is an extension for library consortia. It has shareable bibliographic database amongst member institutes. Elsevier Health Sciences and Helinet, India's premier medical library consortium for e-resources, have announced an agreement that will provide all medical students at Helinet's medical colleges with access to leading international and local medical content through Elsevier's electronic platforms: ScienceDirect(R) and MD Consult(R). The special agreement provides all students/researchers and faculty within the Consortium with access to journals and reference books.

The Ministry of Information Technology jointly with the Ministry of Health and Family Welfare has devised a framework for IT infrastructure for health in India (ITIHI). It envisages setting up a National Health Informatics Centre (NHIC) as also State Health Informatics Centre (SHIC) for Standardization of Information and Data that are prerequisites for ‘telemedicine’. Many studies have found that “higher the health literacy- more and sensible usage of health care services. Ghosh (2005) proposes a model of ICT driven public libraries for India and suggests that public libraries could offer a single integrated environment for dissemination of health care information. National Knowledge commission has recommended Indian Health Information Network Development (I-HIND) a web based network to connect all health care establishments in public and private sector, create common electronic health record (EHR) etc.

The Indian Association for Medical Informatics (IAMI) is a non-government, professional organization, at Hyderabad established in 1993 to sensitize Indian Medical

community, bring awareness and greater utilization of Information Technology (IT) in healthcare. IAMI has been holding conferences and regional meetings and has a highly vocal and vibrant online discussion group where all matters relating to telemedicine and e-health (<http://www.iami.org.in/>) are discussed.

The India pilot (<http://www.hin.org.in/>)

It is developed by a core team consisting of government, private sector and technical program staff to support tuberculosis and tobacco control programs throughout the country. This project contributes to filling gaps in the health research information system, supports electronic publishing of related Indian journals and reports, and facilitates the network of medical libraries.

The government of India is planning a mobile based information dissemination program for disseminating health promotion messages, could be sent out as and when required for maternal and child health, nutrition for children, adolescent health and population stabilization, tobacco control, information on non-communicable diseases and healthy lifestyle and HIV/AIDS. The objective is to reposition the mobile technology from a mere communication system to an instrument of empowerment of the community and take health care services at the door step. One example of effective use of mobile technology is using SMS to communicate with 3.2 million Central Government Health Services (CGHS) beneficiaries spread across India. The beneficiaries are patients who come to CGHS Wellness Centres for consultation and getting medicines for treatment. Under the aegis of National Rural Health Mission, mobile telephone based systems are being increasingly used for managing health information system.

NTR University of Health Sciences at Vijawada has a digital reference library for medical and allied sciences. In order to respond to the changing modes in the curriculum, the university had decided to focus on web-based resources and services. Staff and students of medical colleges (allopathic, dental, Indian systems of medicine, nursing and physiotherapy) affiliated to the university and staff in government hospitals and other teaching hospitals in the State were eligible for regular membership in the library.

Community Information Centres in the North East of the country has parallels in a similar joint effort by the Uttaranchal government, and the Indian Institute of Technology, Roorkee, funded by UNDP to provide e-services to dispersed mountainous populations.

Mother and Child Tracking system (MCTS) is a new initiative of the Ministry of Health and Family Welfare and one of the excellent example of leveraging ICT for delivery of full spectrum

of health care and immunization services to pregnant women and children. This system is aimed at generating a databank to validate delivery of services, ensuring ante-natal, intra-natal and post natal checkups, immunization and micro planning. These initiatives are important health indicators like Infant Mortality Rate (IMR) and Maternal Mortality Rate (MMR).

4. Observations and discussions:

In developing countries like India people continue to die from various health related complications, infection etc., due to a lack of healthcare information. On the one hand, India is a global leader in the knowledge economy and part of the nuclear world; while alongside this powerhouse live more than half the world's poor and illiterates. There are problems of excess in urban India, with deprivation in the rural areas. There is tremendous potential to offer easily accessible health care information services in India that are on par with international standards. Although the country had a diverse system of health care delivery but most of the specialized treatments are available only in the big cities, Use of convergence technologies in the health care sector, would be an answer to the lack of continuum in the three-tire health care system in the country. Crisp, 2007 stated "Trained health librarians have the potential to put knowledge management into practice and to respond to the rapid developments in the health and information environment. The need for librarians to exchange expertise with other librarians and collaborate with health care professionals and other health agencies has never been greater".

Health literacy is a valuable tool in empowering community to improve their health status and achieve sustainable development. Public libraries/ rural information centres with their mission to facilitate access to information and resources in a variety of media should be at the forefront of assisting people, who need preventive health care information. There is a felt need for providing health information services through Community centers/public libraries located in rural areas. Women have high rates of depression after delivery, when they raise children, and to cope with the double responsibilities of having a job and a family. This is what is causing tremendous burden on working women. The awareness program on HIV/AIDS with a clearly defined concept on the part of the librarians to community needs in the way of library service with the best material collection the library can afford to fill that need. Prevention should be a key area of focus and prime concern that can be brought about by awareness.

There are projects catering to the poor and reaching to unreached; there are examples of audio-video conferencing, multi-media instructional materials being used; there are examples of e-learning, e-governance issues as well as e-services. The projects also cover the country's geographical spread. There are a variety of applications, from an Intranet e-governance portal to examples like an online teacher's forum where teachers are able to plan their classroom sessions and share and learn through each other's experiences.

India has extensive experience in the use of broadcast technologies for both formal and non-formal education. These include the use of radio and television for rural development, for non-formal education, and to reach out of unprivileged community. Satellite based teleconferencing for formal and non-formal education has been operational since 1992 at a national and regional level. These efforts have culminated in the launch of GyanDarshan, a dedicated educational satellite to cable educational television channel and GyanVani, dedicated educational radio project. The combination of educational television and radio channels have expanded to include teleconferencing and broad enrichment content for television and FM channels exclusively for education. It is now become necessary that all these channels could be effectively used for imparting health education among most vulnerable young adult. GyanDarshan-I is a satellite based TV channel devoted to educational and developmental needs of the society. The GyanDarshan-II / Edusat, is an exclusive educational satellite to provide interactive education using DVB-RCS technology. It offers distance education through Virtual Class Room mode and provides access to digital repository.

5. Recommendations:

Collaboration among multi-type organizations

Relationship can be established with a number of voluntary health organizations and NGO's and potential health information providers to reach a very broad public through new technologies. Therefore, it is of vital importance that network is to be developed amongst institutions to reach to the remotest corner of the country.

To make people aware of health related information, to help them in taking informed decision it is necessary to make the fast growing corpus of information on health related issues accessible to all. A good number of open source resources are available which can be organize/customized as per need of the community.

✚ Librarians' role in health information dissemination can be categorized as selector and Trainer and less traditional jobs are Referral, broker, advocate, IT consultant. Public libraries situated in rural areas can set up pre and post HIV pre and post test counseling so that who have been counseled took precautions to protect their partner/child from infection.

✚ Developing online health communities

To bring people in collaborative dialogue to explore social conditions that are the major influences of health and illness; generates deeper collective awareness and community driven action.

✚ At a time when infection rates among women are rising because they are powerless, public libraries must undertake the job to sensitize ordinary female population especially young and change their behavior. Reducing the risks through awareness with the help of converging technologies should be priority.

✚ A closer relationship between health librarians and social workers is required to promote a better understanding and acknowledgement of the specific needs of community.

----Conduct information needs analysis of Social workers on HIV/AIDS

----Review the gap in library and information service provision, social workers and local community

✚ During the last 5-10 years, lifestyle diseases are growing at a faster rate than infectious diseases. Wellness programs to be organized to target the sedentary job holders could help to reduce the rising incidence of lifestyle diseases.

6. Concluding remarks:

Health Literacy as a major health investment and health development strategy needs long term commitment, strong partnerships and powerful spokespersons. There is a growing movement within India to establish a health grid that connects medical institutions and practitioners throughout the country. This would allow super specialists to exchange case studies, compare experiences, and hold virtual conferences to discuss critical disease patterns and provide treatment. The free availability of health information to the growing number of people able to

access the WWW created a positive impact on the community. Medical libraries in India need to develop a very high tech information system. It is logical that Public Libraries should take a lead in developing partnerships/consortia with medical libraries to ensure that access to health care information is readily available across the country.

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