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Medical Humanities Collection Development: Policy Guidelines for Indian Hospital Libraries

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ABSTRACT

A special library needs to respond to the changing boundaries of the disciplines of concern as well as the shifts in the research fronts. These changes and newer directives of the national policies are reflected in libraries through their collection development and services. The field of medicine has undergone several major changes – some due to the increased depth of knowledge in specialty areas and others due to closer interaction and better understanding of the context in which the field is practiced. Among the comparatively newer areas to come within the fold of medicine is what has been broadly termed as "medical humanities" (MH).

This paper seeks to explain the term and trace its scope and growth as reflected in literature. With developments surrounding medical practice and research in India, it is essential that collection development policy of hospital libraries in India should be redefined to incorporate the collection on humanities. Based on a small survey, guidelines have been suggested for including in policy and developing such a collection.

Introduction

The effectiveness of a library is critically dependent on its collection. Built over a period of time, it is a huge investment. A proper policy is needed to ensure that users needs are met (Every reader his or her book), and the collection is optimally used (Every book its reader) to emphasize the return on investment. At the same time the library has to strike a balance between the information requirements and

the budget available to evolve a balanced collection for all faculties of the organization. But collection development; if not implemented correctly and with an unbiased view, results either in over or under collection of resources on the different subjects.

Collection development in a special library needs to respond to the changing boundaries of the disciplines of concern as well as the shifts in the research fronts. The field of medicine has undergone several major changes – some due to the increased depth of knowledge in specialty areas and others due to closer interaction and better understanding of the context in which the field is practiced. Among the comparatively newer areas to come within the fold of medicine is what has been broadly termed as "Medical Humanities" (MH).

This paper seeks to explain the term and trace its scope and growth as reflected in literature. It reviews the status of the collection in this subject in major medical libraries in Mumbai (India) and reports on the views and perceptions of librarians about MH. Based on these inputs, the author suggests guidelines for developing a collection development policy for MH.

Medical Humanities

The field of MH developed in 1970s and included ethics, literature, history integrative medicine, and other topics, most often described from a physician's perspective. It was believed that, the approaches of medical humanities, particularly those drawn from philosophy and literature, would deepen and broaden understandings of healthcare. Thus the core subject of medicine would be supported by all other subjects on the periphery such as bioethics, religion, communication skills, theology, anthropology, forensic medicine, etc. and give new dimensions to medicine and medical practice. MH also includes many aspects relating to technological developments; for example test tube baby, surrogate motherhood, CT scan, PET scan etc.

A new focus on the importance of interdisciplinary education and collaborative experiences emerged enabling the medical fraternity to fully understand the patients, their diseases, sufferings and perceptions in relation to their culture, religious beliefs, values, feelings, fears and sufferings.

Communication skills are at the core the patient – physician relationship. In earlier days there was a strong bond between the family physician, the patient, and his family. He was involved in every family event and was well acquainted with the family issues related to health or other wise. Such practicing family physicians are now becoming rare probably due to the development, varied specializations, and the need for each individual to grow professionally and economically.

Specialized physicians are now, more involved in clinical research along with their routine of patient care. Much of clinical research is interdisciplinary in nature and

is based on social aspects and follows social science research methodology such as, cohort studies, where collecting data without disturbing or hurting the individuals' psychology and feelings is of extreme importance.

MH in Literature

There are different views about MH in relation to medicine. One view is to regard medical ethics as one of the sub disciplines of medicine, while the other view believes that MH has a larger perspective. Medical Humanities educationists have argued that MH has two basic functions –a critical and analytical function and an educational function of enriching and developing the character. Ethical issues emerge from it as part of interdisciplinary approach to medical practice and theory. A third approach is to regard the medical humanities as a sustained exploration of both theory of knowledge (epistemology) and value-inquiry, as these are embodied in clinical medicine [1].

Literature suggests that humanities might offer several benefits to clinicians. It would help by developing their abilities to communicate with patients, dwell deep in to their detailed narratives of illness, and eventually seek more diverse ways for patient's wellbeing and care. The recording and exploring human (patient) experiences, as in humanities, would help in better understanding of patient's illness, may help in treatment.

Cultural factors do influence people's health decision, and response to medical issues. Psychological social, spiritual and cultural taboos may differ with cultural variations and would need different approaches [2]. Discussions on end of life or serious illness may be very challenging due to emotional and interpersonal intensity. For instance, decision on type of treatment in serious illness maybe taken by patient himself /herself, but in India the decision is often taken by the family members; or by spouse or jointly by the family, patient and the treating physician.

Although, whether patients demonstrably benefit from their practitioner's study of medical humanities is yet to be formally determined, there are strong theoretical reasons (as derived from literature) to believe that a practitioner with a broader understanding of medicine will be more effective.

Considering that all medical students should be humanists while practicing medicine, countries have felt it necessary to provide a broad based medical education. The aim of providing a broader medical education, covering humanities subjects, has been to produce kinder and more reflective practitioners. Medical Humanities teachers use literature while teaching medical students, to try to enliven discussion of medical ethics, discussion of religious issues, particularly surrounding bereavement [3]. Ethics, health economics and medical anthropology have been considered by many schools as important peripheral subjects of medicine.

A series of articles on end of life and religious beliefs in Lancet 2005[4,5,6,7,8] is a testimony of the need of knowledge about MH in medicine. These articles focused on the end of life and issues of bereaved family members, and the religious beliefs of several faiths. The authors have suggested that if the care taker is knowledgeable about these beliefs, taking care of patients and supporting the family members is much easier, and acceptable. It is observed that serious illness or in cases of imminent death, patient and family members pursue spiritual ways to come to terms with life and near death situations. Similarly, the December issue of Indian journal of Palliative care published two articles on end of life and spiritual perspectives[9,10]. Both the articles emphasize the challenging issues surrounding the end of life care especially related to psychological, social and cultural dimensions. They suggest that palliative care practitioners must be sensitive to and have appreciation of different religious perspectives and rituals to meet unique needs of their patients and families. There are world wide variations in the perspectives on life, suffering, death, and after life. It is therefore suggested that better understanding of the traditions, common rituals surrounding the death and rebirth, ritual after death, and bereavement can improve care for patients and their family members. This avoids practitioners from imposing their convictions and faith and be proactive in their spiritual needs and help patient in achieving 'good death' and at the same time help family members to deal with the grief. Providing a culture sensitive care is extremely essential. Cultural variations, values and attitudes have important practical implications for individuals responsible for making critical medical decisions. Articles on holistic approach for elderly care in Indian situations [11]; an overview on Palliative care / home care[12] on beliefs and end of life [13], on spirituality and end of life [14] and many other articles, all point towards the need to understand these issues for better and satisfactory care of patients.

There are other situations such as 'labeling patients' or 'labeling persons' either during care or when diagnosing. Each patient has different perceptions related to his/ her health. Keeping this in mind, the care taker should carefully handle the 'labeling' of patient, as it can cause a long term psychological impact. Understanding human behavior and the different human personalities should help medical practitioners in handling situations with care and positive impact. This concept is not limited to individual health care personnel or clinicians, but is extended to organizations as well. Literature has indicated that organizational systems have to be sensitive to cultural diversity and variations and also should have linguistic competency, to be able meet patient's cultural, social and communication needs [15,16].

MH knowledge is applicable, to address effectively, the disclosure of bad news, informed consent, confidentiality, dishonesty, research ethics, end-of-life care, resource allocation and the like. The doctor must recognize situations as an ethical dilemma; possess the relevant knowledge of cultural norms, laws and policies; analyze how this knowledge applies to the situation at hand; and demonstrate the skills needed to communicate and negotiate this situation in practice [17].

It is well known fact that most of diseases are locality and region oriented. The health care centers situated in these areas are aware of the regional features, local people, their cultures, religions and customs, are prepared with required kits (diagnostic and treatment drugs) and health care programme are designed, depending upon the community it serves. The knowledge of MH would also help in education, application and promotion on issues with social impact like cryopreservation.

Relevance of MH in India

India is a diverse country in terms of religion and faith, culture, languages, beliefs, life styles, eating habits, rituals, superstitions, economic status, etc. It is sometimes found that this diversity has resulted in an integration of traditions between cultures. It is expected of clinicians to be aware of cultural diversity and beliefs and to provide culturally sensitive care especially in end-of life care practices. In cancer hospitals, palliative and / or end of life care is offered as an integral part of patient care. To support such information needs, which presently are not clearly defined, but are taking shape indirectly through efforts of Institutional Review Board (IRB) activities, Non Governmental Organizations (NGOs), patient and consumer education, and consumer courts, the hospital libraries have to be well equipped with collections in MH.

In recent years, India is becoming a centre for clinical medical tourism. Clinical research, usually sponsored by pharma industry is also rapidly increasing and the country is now flooded with clinical studies both drug trials and other forms of clinical research. With the large patient base, various diseases, improving infrastructure, industry friendly regulations, strong ethical guidelines and trained workforce, India has become a centre for clinical trials for many international companies and the growth is only likely to increase in future. However, to achieve its goal of becoming a global hub of clinical trials, the country will have to overcome challenges like unethical trials [18].

The world's top ten global pharma industries are currently carrying out the largest number of clinical trials in India. It has been reported that of total trials registered in US, 8.9% are conducted in Asia, 7.4 % Latin Am., 7.1 % Central and Eastern Europe and 1.6% in Africa. If only India is to be considered, it is observed that the major players are GSK (122), U K based industry (13), Astra Zeneca (186), Johnson and Johnson (8), Pfizer (7), and many more from companies like – Wyeth, Merck, Bristol-Myers, etc. covering drugs and vaccine trials including patients and participants from all age groups and often include women of childbearing age. It is estimated that by 2011 India will be conducting more than 15% of trials conducted globally[18].

Clinical trials definitely have an advantage for outsourced developing countries. They bring in new technology and new treatments and they also sensitize the bio-medical community towards the country's need to advance medical and clinical

research[19]. Several times established drugs are studied .The whole process is viewed in Indian settings, in terms of safety of people, economics, culture, and need, to satisfy the regulatory requirements of the land (Drug Controller General of India). The study medications are often offered free to patients / participants, who might benefit from such drugs. So there is an advantage to the patients and the community as well.

There is a well developed and established Ethical Guidelines to be followed in order to ensure safety of participants; it is essential that, people who conduct trials, design trials and who administer consent and also those who review the projects for ethical approval are knowledgeable about various ethical issues. India is now facing the challenges of protecting trial participants and patient care, keeping in view the differences in cultural and spiritual outlooks to life.

While there was no registry of clinical trials and people were really not aware of how many similar studies were being conducted and by whom. Recently, the Government of India (ICMR) initiated the registration of all clinical studies including PG student research, which have to be evaluated for scientific and ethical issues. Bioethics does not simply relate to protecting participants' health – psychological, and physical; but its objective is to protect all aspects of the participants – physical, psychological, economical, religious beliefs, faith and cultural, as well. This calls for researchers who can understand these aspects. Clinicians or researchers are required to have information and knowledge not only about participants' safety but also about their socio-cultural backgrounds and beliefs. It is essential that the researcher respects the human side of medicine and research. The participants should also be well aware about the studies, their rights and responsibilities, risks and benefits that may come to them.

The need for medical professionals to understand this 'humane' aspect of patients has been long established and many of western medical / health science institutes have included Medical Humanities (MH) in their curricula. However, in India MH has not entered the medical curriculum either at the undergraduate or post graduate stage.

The fact that publications related to spirituality and patient care have appeared in national scholarly / scientific publications are indications that India too is recognizing the need of medical humanities and organizations should encourage and allow the libraries to support such activities through its collection and services. Libraries should support these activities and needs of newer directives of the national polices, through collection. But, presently the libraries are neither encouraged to collect such broad based resources nor do their budgets allow them to support collection of materials other than the main domain of the hospital requirements. With these developments in medical practice and research, it is essential that collection development policy of a hospital library should be redefined to incorporate the collection of humanities.

Queries on various aspects of MH were put to the author and the information could only be provided with help from Social science research libraries within the city. These experiences triggered interest in the field. In a cancer hospital, healing is often supported by the benefits of collaborative medicine and its enhancement through art therapy, e.g. - music therapy. It emphasizes meeting the psychosocial needs of patients, encouraging participation in treatment, and facilitating a psychologically positive hospital experience through the application of music, exchange of thoughts of patient groups, etc. It has been observed by many that psychological symptoms, such as depression and anxiety, commonly experienced by patients with chronic illness, are satisfactorily dealt through the creative arts programs. The specific physical and psychological benefits of music, in oncology treatment have been recorded in medical literature. The rehabilitation centre / unit of most of the hospitals indulge in several such activities with patients, particularly with children. It promotes drawing, paintings and even musical events, where the patients are participants. These are actually a form of therapy and give an additive effect for the response to medical treatment. These forms of activities are gaining ground in hospitals in India and when such activities are undertaken and promoted by the organization, it is necessary that the library supports the need by providing books and such other materials.

Clinical studies are often related to social aspects, results of which may affect public health policies. e.g., behavioral studies of patients, public health surveys, etc. Several such studies are based on social science methodology and evaluated based on standard keys. e.g., perceptions of pain, scale to evaluate sexual function after treatment of gynecologic cancer, etc.

A Review

With these issues and needs in view, a study of the collection development policy of major hospitals, medical college and research centre libraries in the city of Mumbai was undertaken. Libraries of ten major hospitals (which were also teaching institutes) in the city were selected,, on the basis of their budgets and total collection, for the survey. A small questionnaire was served to the library chiefs. Of the ten major libraries, two institutes were a century old, seven had completed about 50-70 years of establishment and the remaining one was less than a decade old. In all cases the libraries were established since the inception of the institutes. The questionnaire related to the present collection and the collection development policy, (particularly in relation to collection of medical humanities). The participants were provided with a brief about the study, its purpose and possible outcomes. Following observations were made –

1. There were four under graduate teaching institutes while the remaining were post graduate institutes, MH was not included in the curricula, at either level. But two teaching institutes conducted workshops for junior doctors on ‘how to communicate with patients. These workshops covered some aspects

of MH, particularly how to ask questions for better understanding of their illness. At these workshops librarians participated.

2. All the institutes had an institutional review board (IRB), a rehabilitation centre and medical social workers to assist patients. All the institutes were engaged in clinical research – funded in-house or extramural funds or were supported by pharma companies. This showed that there was definitely a need for MH information; but hospital libraries were not approached. In any case they did not have any resources to meet these needs.
3. It was found that except for one, none of the libraries had a well defined written collection development policy. However each one of them were following some unwritten criteria and guidelines, which had developed out of situations; the suggestions and recommendations of the library committees were generally accepted. Few of the major points were -
    a. It was the practice in most libraries to equally distribute the budget amongst the departments in the hospital. This was an arrangement to make the selection and purchase a balanced one and, to some extent, to satisfy the needs of different users. However the budget always needed to be redistributed / adjusted during the year to accommodate the purchase of a series or reference volumes such as encyclopedias; the cost of these was met by drawing funds from the unused allocations of different departments.
    b. The recommending authorities were usually the department or unit heads, however the final decision lay with the library committee and the head of the institute. The libraries did not cover MH subjects, although there were departments such as preventive medicine, IRB, rehabilitation, social work, etc.,
    c. The library collections focused on all aspects of medical specialties, and criteria for selection for almost all libraries were similar, –
        i. Text books as required by and prescribed for undergraduates and post graduates, only latest edition were acquired.
        ii. Advanced research books and journals as required by faculties, depending upon their research activities.
        iii. Journals (both print and electronic) were subscribed covering all specialties and continuity in subscriptions was maintained as permissible by budget. The subscriptions were usually print plus electronic based.
        iv. Few libraries had initiated joint subscriptions to some commonly subscribed journals.
4. Almost all librarians received requests for information other than medicine, mainly on general management, engineering, human behavior, forensic law, and ethical issues. The library collection did not support such queries and the librarians had felt the need of developing MH collection.
5. The libraries, except for one, did not specifically make any attempt to add subjects related to arts and humanities but had a small collection related to forensic law, since this was usually a part of the curriculum. The single library which collected a few books on MH was fairly new. In the past two

years it had collected less than 150 books but no journals on MH. No new additions were being made.

6. Two major libraries reported that during the initial years the library did collect some books and a few journal titles in the areas of social and behavioral sciences. During the early 1990s, the additions and subscriptions to these were discontinued due to budget constraints. Of late due to rise in clinical research and the mandate of IRB approval, the need to develop a collection on MH was deeply felt and expressed by the library committee. However, in practice, the collection had not been developed for want of additional budget. The libraries yet maintain small collections of 'holistic medicine' under which donated items on such subjects are classified.
7. Library professionals suggested that following aspects should be addressed in the guidelines for collection of MH
    a. Special budget allocations be made for books, journals, e- resources etc.
    b. Identification of recommending authority, since the subject would be of relevance to all
    c. Coverage or scope of collection
    d. Structure on how to conceptualize and develop such a collection

Collection development of Medical Humanities has to be done objectively, since the subject would relate to all aspects of patient care and research, from local and community information to communication skills, religious beliefs and faith to ethical issues. A policy on collection development of peripheral nature of the subject needs a careful attention. The policy should aim at avoiding over enthusiasm or should not be event driven. It should be framed to support organization activity and user needs. According to the guidelines of IFLA[20], a policy should clearly define the audience for whom the collection is being developed, purpose of such collection, description of collection, levels or depths and limitations of collection and local importance.

Guidelines for policy development:

The mandate of any medical / health science library is to concentrate on medical collection covering all specialties. There are several issues to be addressed while developing a policy to cover the inclusion of MH in the collection. The following points/questions may need to be answered in order to formulate the policy. These would need to be further fine tuned, depending upon the community the hospital serves, the hospital activities and needs and the queries that are made on the library.

1. Specify the target group.
   The core group of users would obviously be the clinical faculty of the institution. In addition, should the library, cater to the needs of non-clinical staff, external consultants, patients and their families, NGOs working with patients, public health departments, and such others?

2. Decide on the Scope.
   Should all humanities subjects, which have implications for the medical profession be acquired? Specific decisions on the following areas may need to be taken - anthropology, behavioral sciences, bioethics; medical law; social issues, health economics; spirituality, religion; literature like short stories of life experiences, fictions and books with specific purposes for example “chicken soup for the soul” series may need to be taken, Books on happiness and religious customs, culture and lifestyle may also be considered. Within these broad areas, focus should be on the specific communities of the neighborhood. It may also cover other allied areas like general and hospital management, engineering – civil and biomedical engineering, ergonomics, etc.

3. Formats and languages of materials to be covered.

   Depending upon the community the library serves- clinicians and para-medics or patients the collection should cover print and electronic formats – accessible over intranet and internet, including web links, etc. Atlases, glossaries, Pamphlets, booklets, general information books in local languages, language (technical) dictionaries, etc. apart from books and journals to cater to both clinicians and patients may be needed. The continuation of serials may be based on usage.

   Music CDs – of all forms – vocal and instrumental, essentially which are soothing in nature, like Hindustani classical, folk music, religious like Sufi form, bhajans, choir, hymns, etc. People knowledgeable in Indian classical music can always recommend typical ‘ragas’ for the desired effect.

   The general collection development guidelines for electronic information resources include relevance and potential use of the information, redundancy of the information contained in the product, demand for the information, ease of use of the product, access to simultaneous users, stability of the coverage of the resource, longevity of the information, cost of the product, accessibility, equipment needed to provide access, technical support, and availability of the physical space needed to house and store the information and equipment.

   English and local language materials would be minimum requirement. It is most important that to get the real flavor of culture and understanding of the community, publications in local languages should be preferred.

4. Budget and recommending authority.

   Should MH be reflected independently in the budget? If additional budget was not available should a portion of departmental budgets be earmarked to create a special head? In such a situation, the question of who should be recommending authority would need to be answered. The answer may be institution specific

and will be based on the over all policy of acquisition. For instance, any of the faculty could recommend a purchase since MH is a subject of interest to all specialties.

OR

Should all departments be encouraged to recommend books on MH from their own budgets? Thus there would be no separate budget head for MH. The respective departmental heads would be responsible for recommendations. This option would carry with it the risk of an uneven and patchy collection.

5. Collection Maintenance

Updations of MH collection would depend upon the sub categories of the subject e.g. law, socio-economic related aspects may be updated earlier than other sub-categories, such as religion or philosophy. The frequency of updation would thus depend on the developments in these fields.

Care would also need to be taken to ensure that there is neither over nor under selection. In order to achieve this purchase of latest editions only should be considered. Publications prior to two years from date of purchase may be considered with care.

The MH collection may require a separate clause on weeding policy, since unlike medicine, the consensus on the topics and the utility of the information of MH may not change at the same pace, except for subjects like medical law where interpretations of law and their implementation also are very important. These laws also change due to new concepts, technologies and the complexities created and impact on several social issues by them.

Conclusively, it appears that a collection on MH is a necessity, as is observed by most of the library professionals. However, this study was limited to a small group whose ideas have been the basis of outlining some guidelines which could help in evolving a MH collection development policy. A major challenge in this regard is the need for a change in the mind sets of the medical profession and health administrators. They must first accept the field of MH into the fold their discipline; it is only then that hospital libraries will develop MH collections in hospital libraries.

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