

Opportunities for Hospital Librarians in the Era of Genomic Medicine:

Helping Clinicians Implement New Approaches to Patient Care

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Abstract**PURPOSE:**

To evaluate ways in which hospital librarians can help clinicians keep up with the rapid growth of genetic information and incorporate it into patient care as we enter the era of genomic medicine.

SETTING:

Hospital medical libraries

DESCRIPTION:

The fast-growing new field of genomic medicine applies human genetic information to the understanding and treatment of disease. Historically, evidence-based healthcare has been informed by studies on large populations. Breakthroughs in genetic analysis technologies are presenting healthcare providers with new opportunities to diagnose and customize clinical treatment based on the genetic structure of individual patients. In the hospital setting, access to genomic medicine information resources, clinical guidelines, and continuing education will be critical in the near future. This research paper will explore resources and programs that hospital librarians can offer to clinicians, to serve their genomic medicine information needs and help them navigate through unfamiliar territory.

Introduction

The nature of biomedical research has been transformed over the past decade by the revolutionary contributions of genomics research (1). Genomics is the study of an organism's genome, which encompasses all the genetic material in its chromosomes (2). A simple definition of genomic medicine is "the use of information from genomes (from humans and other organisms) and their derivatives (RNA, proteins, and metabolites) to guide medical decision making" (3). Genomic medicine is the key to personalized medicine, which bases healthcare and drug therapy strategies on an individual's "unique clinical, genetic, genomic, and environmental information" (3). This new approach to medicine is rapidly reaching a tipping point: participants in a recent *Integrating Large-Scale Genomic Information into Clinical Practice* workshop commented that, during the year it took them to plan the meeting, "the future became the present" (4).

The information access and literacy expertise of hospital librarians and information professionals will be critical to clinicians in this time of rapid, information-intensive changes in medical practice. However, hospital librarians face immensely difficult challenges today. The current economic crisis has forced many hospitals to close their physical library spaces and convert to online-only collections (5). Hospital librarians must identify key needs and take on new roles to justify their continued existence. M. J. Tooley, Director of the National Network of Libraries of Medicine, Southeastern/Atlantic Region, declared in 2009 that "hospital librarians who survive and thrive will be defined by their value and indispensability to their individual organizations" and will demonstrate a "willingness to explore new directions and pathways" (6). This paper explores the status and promise of genomic medicine in the clinic, reviews the

changing roles of hospital librarians, and discusses ways in which they can address current needs and anticipate future needs of clinicians in the field of genomic medicine.

Genomic Medicine in Clinical Practice: Potential and Barriers

Medical uses of genomic data have recently entered hospital clinical practice, in applications such as the screening of at-risk populations, diagnosis of disease, and development of individual early-detection or prevention programs. Two well-known examples are the tests for *BRCA1* and *BRCA2* gene variants associated with breast and ovarian cancer, and for *MLH1* and *MSH2* gene variants associated with colon cancer (3). Whole-genome analyses identify specific subtypes of cancer tumors and enable clinicians to design individualized treatment programs (3). Pharmacogenomics, the “study of genetic variation as a factor in drug response, affecting both safety and effectiveness” (7), has also made inroads into clinical practice. Many clinicians order genetic tests for variants in the *CYP2C9* and *VKORC1* genes to determine an appropriate dosing regime for the anticoagulant warfarin, which varies in effectiveness based on a patient’s genetic background (3). Genetic tests are used to avoid adverse responses to drugs such as abacavir, which is counter-indicated for HIV patients carrying the *HLA-B*5701* hypersensitivity variant (7). Gene-expression profiling is used to target therapies to drug-responsive subgroups (e.g., the 10% of breast cancer patients whose *HER2/neu*-overexpressing tumors are responsive to Herceptin treatment) and to predict graft rejection in organ-transplant patients (3).

Although the translation of genomics research into clinical applications is rapidly accelerating (1) (8), many barriers stand in the way. Significant work is going into validation, guideline creation, cost reduction, and policy revision (3). However, obstacles also exist in the areas of physician attitudes, time constraints, and lack of genomic literacy (9) (10). In 2007, Guttmacher and colleagues, bemoaning how the medical genetics ignorance of many clinicians

makes them unable to give patients the best standard of care, wrote “If ever there were an area of medicine that is appropriate for lifelong learning, it is genomics” (11). In a systematic review on genomic medicine for chronic diseases, Scheuner and colleagues identified “a large gap between what knowledge is available and what health systems still need to know ... to ensure appropriate and effective clinical integration of genomic information and technologies for common chronic disease” (12).

Information overload is another major stumbling block. In a report on the information-seeking behavior of doctors, Davies wrote that “the hardest task now is to actually locate the information required from the flood of information received” and noted that this was a particularly onerous task in the field of medicine (13). Therapy questions relating to both drug therapy and interventions are of particular importance to hospital clinicians (46% of hospital clinicians in a 2004 study reported having questions in this area) (14). However, limited time, doubt that an answer exists, and inadequate search skills have been shown to be significant barriers to the ability of clinicians to find answers on their own (15). Clearly, hospital clinicians have unmet information needs that can be addressed by trained librarians.

How Do Hospital Librarians Currently Meet Genomic Medicine Needs of Clinicians?

Hospital librarians perform essential tasks to support clinical care in hospitals, including the development of “systems to acquire, organize, and disseminate essential resources,” expert searching, information literacy training, and other services that “assist clinicians in providing excellent clinical care” (16). Despite these critical contributions, skyrocketing healthcare costs, changes in how medical care is delivered and reimbursed, and hospital downsizing and closures have put tremendous stress on the operation and even existence of hospital libraries (17). The current challenging times call for the rigorous assessment of methods by which clinical

information needs are currently met, and for the identification of novel approaches and roles for hospital librarians.

To explore ways in which hospital librarians provide information to clinicians in the area of genomic medicine, I created and administered an informal online survey. The questionnaire asked self-reported hospital librarians to describe their current level of clinician requests and library services relating to genomic medicine (Appendix). The survey was designed as a simple information-gathering tool, not for statistical analysis. No identifying information was requested. A survey request was posted to three electronic discussion groups: MEDLIB-L, the Medical Libraries Association (MLA) Hospital Libraries Section, and the MLA Public Services Section. A total of 39 librarians took the survey during the week of November 2-7, 2011.

In response to the first three questions, 20% (8/39) of survey-takers reported that they had received requests from clinicians for genomic medicine information. Descriptions of the types of information requested included “topical questions relating to diagnosis or treatment of syndromes or diseases related to an individual’s genome,” “what markers predict sensitivity (or lack thereof) to particular drugs,” “cancer genetics,” and “information to share with a patient family on a rare condition.” The librarians used a variety of resources to fill these requests, including medical and scientific literature databases (PubMed; Scirus; Ovid), medical content databases for clinicians (MD Consult; AccessMedicine; UpToDate), a systematic review database (Cochrane Reviews), clinical practice guidelines (ASCO, NCCN, and AHRQ Guidelines), genetic information databases (NIH/NCBI databases; Online Mendelian Inheritance in Man; Genetics Home Reference), rare disease databases (National Organization for Rare Disorders; Orphanet), a consumer health information site (MedlinePlus), and a search engine (Google Scholar). One librarian noted that PubMed’s Clinical Queries allows one to easily set up

an automated search filtered for medical genetics and have the information delivered to the requesting clinician on a regular basis.

In the final two survey questions, 13% (5/39) of respondents reported that they were currently developing genomic medicine resources for clinicians. They described the resources as LibGuides, genomics webpages, or links to relevant databases on their hospital library website. One mentioned reference and article look-up services on genomic/genetic topics. The results indicate that some clinicians are requesting genomic medicine support from hospital librarians, and some librarians are providing website-based resources on genetics/genomics topics. However, the fact that 80% of respondents indicated they had received no requests and 87% were providing no special genomic medicine resources suggests that interactions between hospital librarians and clinicians in this area are still at an early stage.

Librarians Can Help Overcome Barriers to the Entry of Genomic Medicine into the Clinic

Although translation of research into clinical practice must be evidence-based, delayed entry into the clinic may keep large numbers of patients from receiving the best available healthcare (8). Hospital librarians can use their information management skills to aid the implementation of genomic medicine applications in several ways. These include dissemination of the latest information on upcoming and approved clinical applications, providing authoritative and patient-friendly genetic information handouts to doctors and nurses, improving electronic medical record (EMR) systems to accommodate genomic data, and providing continuing education resources to improve the genomic literacy of clinicians (8).

The provision of genomic medicine information resources and reference services is a natural outgrowth of traditional hospital librarian duties. A recent personalized medicine internet resource list in the *MLA News* includes six genomic medicine resources that would be excellent

additions to a genomic medicine page on a hospital library website (18). These resources, written for clinical practitioners, include the Coriell Personalized Medicine Cooperative (Coriell Institute), the Genomic and Personalized Medicine Forum (Duke Institute for Genome Science and Policy), Medicine and the New Genetics (Human Genome Project Information), GeneTests and GeneReviews (National Center for Biotechnology Information), and the Pharmacogenomics Knowledge Base (U.S. Department of Health and Human Services). Easy access to a selection of genomic medicine resources such as these would be a valuable and time-saving service for clinicians.

In addition to having difficulty meeting their own information needs, many clinicians do not feel competent to provide appropriate resources to patients and their families (19), although this is an activity considered to be “critical for the successful introduction of genomics into healthcare (8). Hospital librarians can provide clinicians with accurate and informative consumer-oriented print and online genomic medicine information resources at appropriate reading levels. This service would increase the ability of clinicians to give accurate and user-friendly information to patients and their families at the point of care.

The lack of adequate genomic literacy among clinicians provides opportunities for librarian support in the area of continuing education. Simply put, genomics literacy is the “ability to perceive a need to locate genetic information and to comprehend how to apply it to a health and medical context” (19). In a discussion of the integration of information literacy into the education of public health professionals, Cobus writes that librarians are “uniquely experienced in knowing how to instruct in, communicate about, and manage” the complex array of genomic resources (20). Honing these skills in the area of genomic medicine will enable hospital

librarians to design sessions to train clinicians in the use of relevant databases, tools, and reference resources.

Large hospitals may employ a variety of types of medical librarians and information specialists. One of these specializations, the informationist, offers skills that would be particularly valuable during the transition to genomic medicine. Storage, accessibility, retrieval, and privacy protection of a patient's genetic data require advanced data-handling skills that are the hallmark of a trained informationist (21). Informaticists can also help redesign and maintain electronic health record systems to incorporate genomic data. The integration of genomic data with protected health information such as family history and lifestyle factors is necessary for clinicians to make the best use of a patient's genomic information (22). As Perry and colleagues pointed out, "librarians and informaticians are increasingly seen as 'boundary spanners' who can bridge the technical and the human information needs inherent in providing healthcare" (23).

Conclusion

In 2010, Michelle Klein-Fedyshin wrote that "there is a certain irony to libraries in hospitals being closed at a time when the value and impact of evidence-based information for patient care is increasingly being recognized" (24). As the growth of genomic medicine changes the nature of clinical practice and patient care, hospital libraries will need to employ librarians and information specialists who understand genomic concepts and vocabulary, can identify appropriate resources and assist clinicians with genomic literacy, and can manage associated information storage, retrieval, and privacy issues. Hospital librarians will do well to anticipate and train for these new roles and responsibilities in the fast-approaching era of genomic medicine, and to begin implementing services to meet the changing needs of their clientele.

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Appendix

Genomic Medicine Survey for Hospital Librarians

I'm working on a Medical Librarianship course project to evaluate ways in which hospital librarians can help clinicians keep up with the rapid growth of genetic information and incorporate it into patient care. The focus of this survey is clinical needs in the new field of genomic medicine. If you are a hospital librarian, I would very much appreciate your feedback. Please complete the online form at <http://tinyurl.com/genomicsurvey> or insert your responses below and return the completed form to kelliottsd@earthlink.net by November 21, 2011.

Thanks for your help!

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1. Have you received requests from clinicians for genomic medicine information? *

Yes

No

2. If yes, what information was requested?

3. What sources did you consult to find this information?

4. Are you developing any genomic medicine resources or services for clinicians? *

Yes

No

5. If yes, please describe the resources or services

* answer required