

Consumer Health Informatics: Is There a Role for HIM Professionals?

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As recognition of the health information management field grows in the public sphere through wider understanding of the importance health information plays in everyday medical care, examining the roles HIM practitioners may play in relation to the general public served by our healthcare system is timely and important.

There has been a vast increase in information available to the public through advancing medical research and the growth of the World Wide Web. There has also been a growing sense of professionalism evident among practitioners within the HIM field. Is a convergence of these two trends likely to lead to the reconceptualization of the work roles of at least some HIM professionals, so that they become involved with health information issues in new ways? Will new job types emerge? Will schools offering degree programs in HIM need to modify or expand curricula in order to help the field develop in this direction? Fundamentally, is there a role for the HIM professional to play in the various processes through which the public receives and utilizes information?

This article expands on these questions and offers potentially fruitful areas of research and practice development for the HIM field. It explores a number of pertinent topics: the general history and focus of the consumer movement and the relationship of this movement to the health professions, the new consumer health informatics field, the concept of “health literacy,” the importance of the personal health record (PHR) in consumer behavior, and the range of Web-based tools now available that may be applied in various aspects of HIM practice. While not arguing for a *particular* role for HIM practitioners in the area of consumer health information, we suggest areas in which HIM professionals *might* find new opportunities in this area. We emphasize as well that, consistent with well-established theory in the sociology of professions, there are other occupational groups that may lay claim to expertise in the area of consumer health informatics, and conflicts between occupations are likely.

There are, of course, a number of useful research questions that this article does not explore. Researchers in other fields are already engaged in exploring these areas of inquiry, and though the HIM community can usefully become familiar with their findings, the methods and tools for such investigation have not figured in the training of HIM professionals. These questions include the following: How does the consumer use health information now? Is the information adequate, trusted, easily available to all, and provided in ways that are well understood by the ordinary member of the public? Learning about these research areas will likely be valuable for the HIM practitioner, but studies need not be replicated within the HIM field, given the developing nature of our research agenda.

Understanding consumer health informatics in relation to the HIM field requires recognition of the larger context within which both the consumer and other occupational groups relate to medical information. Many scholarly and popular ideas current over the last forty years or so have shaped our

thinking about the consumer and our ideas concerning how the consumer relates to *any* profession but also specifically (and importantly) to the health professions in particular. A brief overview of these ideas will help ground later discussion specific to HIM practice.

“Consumer” as a concept may be understood in a variety of contexts, and can have particular shades of meaning depending on who is using the concept and in what political, social, ethical, or action context it appears. By creating the label “consumer” to categorize individuals performing in some social role, we implicitly invoke its opposite, the “producer,” and may in the process make assumptions about values and desires of individuals that may or may not be valid. A consumer may or may not be interested in consuming a particular thing that a producer has to offer or deliver. One might more accurately then call this person a “potential consumer,” but from the producer’s perspective, if there is gain to be made through delivery of a product, “consumer” is in fact fully operative. In other words, the producer is naturally motivated to view others as “consumers,” whether they are customers that the producer must entice to purchase some good, or simply individuals to whom the producer’s “good” (such as instruction in the case of a teacher, a book to read in the case of a librarian, or a pat on the hand from a caregiver) is directed.

The general recognition of this aspect of the consumer/producer relationship in our society has had two important consequences: 1) the birth of a consumer “movement” in modern countries “characterized by the right to act based on informed choice, active participation, and full engagement in critical processes,” and 2) a closer and often more critical eye cast on doctors and other health professions in particular.¹

The advocacy of consumer rights, the gathering of comparative information, and the idea that empowerment provides protection against advertisers and retail establishments who may be trying to lure customers to try a product or buy a product or service are part of the complex that makes up consumerism.² An early example of consumer empowerment can be traced to the founding of the Consumer Union and its widely known and popular magazine, *Consumer Reports*. Started in the 1930s, the organization intended to protect consumers and “intended not only to report dangerous and largely unsuspected conditions affecting food, drugs, and cosmetics, but also, so far as possible, to give the consumer some measure of defense against such conditions.”³

Whether buying a car, choosing a diaper bag, or installing a water purifier, a consumer now has many information sources available to aid in decision making. Services such as Angie’s List, where a subscription fee gives consumers access to consumer reviews on many services, tradesmen, and other retail settings, are examples of consumer empowerment made possible through the Internet.

Specifically in the realm of healthcare issues, a very significant historical and scholarly shift began in the 1960s regarding how the health occupations, and medicine in particular, were viewed. Paul Starr, in the prize-winning book *The Social Transformation of American Medicine* (1982), noted that the shift in the organizational culture of physicians and other healthcare personnel from the ideals of professionalism and voluntarism to acquisitive activity changed the way citizens participated in healthcare.⁴ No longer was the “family doctor” the norm; rather, group practices became common, with decision making guided more in the nature of a business rather than a one-to-one judgment communicated between a doctor and a patient.

Besides the academic interest in challenging the motivations of doctors, our popular culture came to have an increasingly critical view of the medical professions. The rapid rise in the incidence of malpractice lawsuits, the increasing scrutiny from the press regarding the quality of healthcare and hospital performance, and the emergence of “alternative medicine” and other therapies that place the responsibility for care and expertise in the hands of a layperson (closer to a customer than a producer) all have led to public attitudes less trusting of the trained physician and to greater emphasis on self-reliance by the patient/client to become involved in his or her own care. Besides these changes, the commercialization of medicine, the advances made in drug development and medical care, the now common drug advertising on television, and the rise in government-funded medical research have contributed to the rise of a culture of advocacy and participation.

On the positive side, of course, are the many sources of medical information that have become ubiquitous in our contemporary media. Television news programs often have a “medical correspondent,” often a trained physician, to report on scientific advances in medical diagnoses, pharmaceutical breakthroughs, and the like, making judgments on the newsworthiness of issues that may well be best tackled through behavioral changes among large numbers of people. Recent attention to childhood obesity is an example of such reporting that can lead to changes in public policy. Similarly, the attention that news organizations gave to changing Medicaid benefits helped many seniors navigate the complexities of prescription plans.

Consumer Health Informatics

Out of all these social changes reflecting the new sense of health consumers’ responsibility, rather than perpetuating an older conception of medicine as an elite profession, it was natural that a new professional field, consumer health informatics, would emerge. Consumer health informatics has been defined by Gunther Eysenbach as follows:

Consumer health informatics is the branch of medical informatics that analyzes consumers’ needs for information; studies and implements methods for making information accessible to consumers; and models and integrates consumers’ preferences into medical information systems.⁵

Entrants to this new field of practice have come from various training backgrounds. Some of those defined as practitioners have MD degrees, some have PhDs, and others have a wide variety of nursing and allied health degrees, from occupational therapy to biostatistics. Consumer health informatics (CHI) professionals may provide electronic information tools, skills, and support to consumers. CHI practitioners may also provide assistance to other health professionals by engaging consumers and helping them manage certain aspects of their healthcare.⁶ AHIMA’s effort in the area of promoting the use of personal health records has been widely seen as a possible means of inclusion of at least some HIM professionals under the consumer health informatics rubric. There has also been speculation around other potential roles for those who hold RHIA certification and related degrees, though there have not yet been efforts to quantify any trend regarding how many HIM practitioners may have moved into job roles in which CHI issues predominate.

In a seminal article on how professions change, Bucher and Strauss argue that within professions are “segments,” or sub-professions, that are similar to social movements in that they undertake activities to define themselves, to argue for their particular missions, and articulate goals.⁷ The effort to define a CHI “movement” within the health information management profession is a clear case of an HIM “segment,” and its success will in some sense be determined by the degree to which it establishes a clear place in the HIM education curriculum, gains official status within the larger professional association, and differentiates itself from other occupational groups making similar claims for involvement in consumer health informatics activities.

There have been some efforts undertaken to designate activities in the CHI field as a responsibility for HIM practitioners. HIM practice has been largely confined to hospitals and large practice groups. Though some HIM professionals may have ventured into the community to speak to patient groups, this would be a new arena for many. Up to this point, health information managers have generally not concerned themselves with a range of consumer health informatics issues. At this point, PHRs are the only consumer informatics activity pursued by HIM professionals.

A recent article in the *Journal of AHIMA* proposed some new roles:

- PHR liaison: “PHR liaisons may be hired in HIM departments and ROI companies to help patients assemble their medical records. They might be called PHR guest relations liaisons. They would locate, copy and disseminate health records to patients, as well as offer advice on what type of records should be included in a PHR.”⁸

- Independent PHR consultant: These consultants could “do the leg work in PHR assembly. The services would be most valuable to elderly and chronically ill patients who may find it difficult to assemble the record themselves.”⁹

AHIMA has also identified the following role:

- Patient information coordinator: “This person would be responsible for fostering high levels of customer service in coordinating all information provided to patients and their families and caregivers and ensuring that they receive appropriate, timely and accurate health information about the services provided by caregivers, financial services, social service and other medical and legal entities.”¹⁰

AHIMA first identified the patient information coordinator role in 1999.¹¹ Two of the job functions were showing patients how to manage their personal health histories and showing patients how to access computer-based information resources. Additional information can be found in the *Journal of AHIMA* article “Defining the Personal Health Information Management Role.”¹² There may be potential roles for health information managers to undertake activities defined under the CHI rubric if PHRs or other patient tools are adopted by a wider group in the healthcare community than at present, and there may be other areas of change within HIM practice that may bolster the claim for CHI involvement. The adoption of PHRs, though, is contingent on consumer demand, and the HIM practitioner is not currently the primary provider of associated health information that consumers seem to want.¹³ One area of “movement” activity, as Bucher and Strauss highlighted, would be the educational process for training new HIM professionals so that CHI becomes a distinctive part of the curriculum.

Current programs for HIM students do not include consumer health information management, information on health literacy, or information on dealing with communities regarding healthcare or health information. In a 2004 study of health information managers, over 120 different types of positions were identified.¹⁴ Interestingly very few of the positions involve health education roles similar to those envisioned for personal health record advocates.

A variety of recent rhetorical efforts have attempted to bind CHI issues to the larger scope of HIM practice. One of those efforts has been the creation of new language to describe CHI: “information therapy.” Adopting this new term may (or may not) provide a means for differentiating HIM activity from other professions and thus furthering the CHI “cause.” It may become important for any HIM professional interested in patient advocacy and the promotion of the PHR to understand what information therapy is and how it should be used in the education and cooperation of the individual in his or her healthcare and health maintenance.

Information therapy (or “Ix” in the language of its promoters) is defined as “the timely prescription and availability of evidence-based health information to meet individuals’ specific needs and support sound decision making. Ix prescriptions are specifically targeted to an individual’s needs at a particular moment in care and are delivered as part of the process of care.”¹⁵ It is interesting to note, consistent with the Bucher and Strauss formulation of segments, the rhetorical use of language from a higher-status occupation in the above definition (“prescription,” “evidence-based,” “delivery of care”) to promote the status of the CHI practitioner.

Also as Bucher and Strauss suggest, the path to establishing a clear professional segment of a larger occupational group is often fraught with conflict. Other professions may lay claim to the same activity area as HIM professionals, and there are at least two such occupational groups that appear currently to hold particular strength in CHI: health educators and medical librarians.

Health educators are defined as “professionals who design, conduct and evaluate activities that help improve the health of all people.”¹⁶ They work in a variety of settings, including schools, communities, healthcare facilities, businesses, universities and government agencies. They work under a range of job titles such as patient educators, health education teachers, health coaches, community organizers, public

health educators, and health program managers, and have established certification programs set by the National Commission for Health Education Credentialing, Inc.¹⁷

Medical librarians have long-established associations, professional publications, standards, and other institutional trappings common to many professions. They have a tradition of supplying information to consumers in certain settings, though their locus of activity is much more carefully defined than has been the case with HIM professionals aspiring to become involved with consumer health informatics.

Health educators and medical librarians have long been concerned with health literacy. Health literacy, like consumer health informatics, has a range of adoption problems. In essence, this, too, is a new segment, a closely related attempt to define another social movement.

Healthy People 2010 defines health literacy as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.”¹⁸ The Agency for Healthcare Research and Quality (AHRQ) showed that just 12 percent of American adults are health literate at a level that allows them to manage their care.¹⁹

The American Medical Association Council of Scientific Affairs definition is even more explicit in that it provides a definition of functional health literacy, “the ability to read and comprehend prescription bottles, appointment slips, and the other essential health-related materials required to successfully function as a patient.”²⁰ This includes reading and understanding medical education brochures, completing consent and health history forms, locating healthcare providers and services, taking medicines appropriately, managing chronic illnesses, and even negotiating healthcare systems.²¹ A National Adult Literacy Survey (NALS) suggests that nearly 50 percent of adults are possibly functionally illiterate.²² A recent government study estimates that over 89 million Americans adults have limited health literacy skills. Many of these consumers hide their limited skills from their providers because they are confused or too ashamed to ask for help.²³

There has been careful policy research related to the health literacy movement and its impact on quality. Poor or limited health literacy can have a significant financial impact on our healthcare delivery system. In 2001, low functional literacy resulted in an estimated \$32 to \$58 billion in additional care costs because of less ability to care for chronic conditions, the use of more healthcare services, such as ER visits, the increased use of expensive procedures, and a need for more diagnostic tests.²⁴ In 2007, the University of Connecticut released a report stating that the lack of health literacy cost the U.S. economy between \$106 billion and \$236 billion annually. The 47 million Americans without healthcare coverage could be insured for this amount.

Besides a financial impact, lower health literacy is associated with higher mortality and poorer health status. Low health literacy may also have a legal impact on the healthcare professional. Organizations such as the Food and Drug Administration, the Joint Commission, and the National Committee for Quality Assurance all say there must be evidence that the patient understands the medical information provided and can follow instructions. In addition to the legal ramifications of misunderstanding instructions, patient safety is at stake. Because some patients are confused, are not proficient with the English language, or are too ashamed to admit that they do not understand what they are told, mistakes are made and patient care suffers as a result.²⁵

Changing health literacy rates can result in healthcare savings and improve health. Experts believe that effective communication is the key that will, over time, improve health literacy.

Though the health literacy movement has included substantial research and policy development, unfortunately the HIM profession does not have the same background and supporting evidence for the adoption of personal health records. Additionally, there does not exist the organizational and institutional infrastructure for PHRs that there is for health literacy, such as the National Council on Health Literacy, the support of the Joint Commission, and the evidence of consumer health libraries in hospitals.

All of these represent a substantial investment of both resources and commitment to this movement. Until the issue of physician adoption, reimbursement for time, or another avenue to facilitate the use of PHRs in the practice setting is resolved, it will be difficult to implement a robust policy and support infrastructure. There remains skepticism and limited empirical evidence that patients will actually use

PHRs and that the tool will ultimately add value to an individual's healthcare experience. Several studies have been done, but the focus has been on health literacy more than on personal health records. The various tools studied indicated an increase in knowledge about healthcare. "Among the more substantive findings, some studies suggest that the use of information tools can increase patient knowledge of treatment alternatives and patients report that they like the tools."²⁶

HIM professionals have been promoting the use of a personal health record, yet without additional research, it is not clear that physicians will support patients' use of a PHR by actually consulting with patients and either reviewing data within the PHR or transferring data to the legal health record. With issues regarding liability, the legal health record will need to be redefined, perhaps to exclude from litigation the data presented by the patient. Another option that might serve as a PHR is a module such as the one offered in the Epic system. This module allows patients to see what drugs they are taking and read current test results. The AHRQ notes the need for further study regarding the effects of PHR use:

Although patients may tend to ask their physicians more questions as a result of using the tools, their effects on time burdens or on broader patient/clinician communication patterns imposed on clinical staff have not been studied. Some studies have shown that information tools can increase patient adherence to prescribed medical regimens and influence patient preferences for nonsurgical interventions. The body of literature would improve if future studies assess a wider range of treatment choices, describe the context of implementation, and document the effects of information tools on patient attitudes, treatment selection, health behaviors and outcomes, and costs.²⁷

Ultimately, until a system can be identified and adopted for patient consultation that would compensate the physician to review the PHR, the widespread adoption of PHRs may not occur in the physician practice community.

An additional problem is that until a standard PHR format is defined, most physician practices will not take the time to learn the format of each presenting patient's PHR. This, in itself, could take a lot of staff time as each interface or paper-based booklet has the potential to have a different format.

Barriers to Adoption

Personal health record

Healthcare providers that render care may or may not be aware of other ongoing health-related activities of the patient. It is up to the patient to ensure that the provider has all the information needed for treatment. The PHR could be the most valuable tool a physician could use for treatment, but providers are very skeptical about the accuracy of the information contained in the PHR, especially if it is entered by the patient. They are worried that the patient may have misunderstood other providers and that the information is not accurate. If the patient receives copies of reports and incorporates them into the PHR, the provider's skepticism is decreased. It is still important for the patient to document other items, such as medications, allergies, emergency contacts, family/social history, and current conditions.

Less time with providers

Currently, the amount of time we spend with our providers is decreasing. What should be a 15-minute appointment is now less. There are many issues that surround this phenomenon. Patients need to be prepared when they see their doctor. They need to have a list of questions written down, they need to have a full description of their symptoms, they need to bring with them basic health information about themselves (list of medications, health history, current conditions), they need to write down what they are told, and they need to get right to business when the doctor enters the room. Everyone is pressed for time, but with a little preparation the visit will be very productive.

Lack of consumer understanding of healthcare terminology

Healthcare is a language unto itself. Providers talk that language every day, but patients do not. It is imperative that providers talk at the level of the patient for understanding. It is also important that patients learn some basic medical terms.²⁸

Education and Roles for HIM in the Consumer Health Informatics Movement

The curriculum for HIM professionals will need to be expanded with additional training in health education, sociology of consumers, and consumer information management. A new Health Data Analyst certification was recently announced. The effort and synthesis to bring about this type of change, the creation of an additional area of professional expertise, takes a lot of time, a concerted effort of the various bodies that review the curriculum, and the buy-in of many HIM professionals. A similar effort will have to be undertaken to both legitimize the PHR movement and train HIM professionals for it. The Health Data Analyst certification is described as follows:

This prestigious certification will provide practitioners with the knowledge to acquire, manage, analyze, interpret, and transform data into accurate, consistent, and timely information, while balancing the “big picture” strategic vision with day-to-day details. CHDA-certified professionals will exhibit broad organizational knowledge and the ability to communicate with individuals and groups at multiple levels, both internal and external.²⁹

It may be possible that a new certification in consumer health informatics will be created to address the movement of healthcare from a doctor-centered model to a patient-centered model.

There is a role for HIM in this area of healthcare. If healthcare is moving from a doctor-centered model to a patient-centered model, then patients must have access to the information they need to make good decisions and changes to help them improve their health. Physicians in practice do not have the time for patient education of this nature. In one study, family physicians were surveyed about the impact of patients bringing Internet information to their appointments. If the patients were perceived as confused or distressed by the information, they needed reassurance and further education, which consumed time not scheduled for the appointment. If the patient used the information for self-education regarding a previously diagnosed condition, the physician felt more favorable, as though the patient was confirming what he or she had learned. Another group of patients, those who used information to self-diagnose or test the physician, were more difficult. They used their information to challenge the physician’s treatment plan and were perceived as almost adversarial. Some of the strategies used were recommending reliable Web sites, suggesting a follow-up visit, charging the patient for extra time, and firing the patient.³⁰ Eysenbach suggests that consumer health informatics can help address the information needs of patients:

The greatest contribution of consumer health informatics research to the healthcare sector may eventually be found in its attempts to systematize and codify consumers’ needs, values, and preferences; in its research into how information is digested and is best presented to consumers; and in its research into how these variables influence outcome measures. Thus, current health informatics research may have greater implications for the practice of medicine than medical informatics ever did before.³¹

Conclusion

It is clear that health information professionals have a role to play in the consumer health movement, but it will require systematic pursuit to resolve many issues that are barriers to widespread use of PHRs—additional education and certification, connections with health literacy professionals and medical

librarians, resolution of the physician adoption issue, and role of consumer-collected information in the legal aspects of health.

All these issues offer a potentially exciting and important entrée for the HIM profession into the consumer health movement, but present efforts that have focused on consumer adoption are ultimately limiting the prospect of a broader introduction of the PHR into the U.S. healthcare system.

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