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# Consumer-driven, patient-centered health care in the age of electronic information

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Americans are turning in increasing numbers to the Internet for information related to their health. Access to information that was previously difficult, if not impossible, for consumers to obtain has helped drive a shift in traditional roles for patients and physicians. Technology has made possible additional avenues for communication that can enhance new relationships. Ample opportunities exist for librarians to participate in a collaborative practice role, helping to serve the needs of both consumers and physicians as consumer-driven, patient-centered health care evolves to meet its full potential.

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## BACKGROUND

How many Americans turn to the Internet for health information? Facts and figures about the rapid integration of the Internet into American life vary from study to study, but this much is certain: the ubiquitous nature of the Internet is helping to drive the rise in health consumerism. Cyber Dialogue reported in 1999 that the "e-health consumer" revolution was partially driven by the very rapid integration of the Internet into American life. Although television took twenty-six years to reach mass penetration, the Internet has achieved the same level in just seven years [1]. In September 2000, PC Data Online reported that "net-connected Americans are turning to the Web for medical information in droves" [2]. That survey found that 60% of respondents had visited a health or medical Website in the past year, compared to 77.5% who had visited an entertainment site. Furthermore, more than 56% of health searchers were researching symptoms in attempts to self-diagnose. Nicholson, a Wharton School health care professor, reported in late 2000 on data from the Wharton Forum for Electronic Commerce's virtual test market [3]. Designed to study both use patterns of Internet health surfers and the implications of those patterns, the test market revealed that more than 75% of the subjects used the Internet to find information on diseases, women's health, nutrition, fitness, and pharmaceuticals. Internet health users were more likely to be married, college-educated Caucasian women, who described the Internet as convenient, current, available, and anonymous. Future data from the

Wharton study is expected to illuminate the effects of Internet health information retrieval on the patient, the physician, their relationship, and the health care system in general. In particular, Wharton researchers want to know if people who use the Internet to find health information are healthier than average Americans and whether their online activities tend to improve their health.

Cyber Dialogue's study "The Future of e-Health" estimates that 88.5 million adults will use the Internet for health information by 2005, noting that this growth will be driven by forces such as the increasing numbers of senior citizens on the Web, efforts by health insurance companies and providers to push their subscribers and patients to the Web much as airlines are currently luring their customers online, and new parents looking to the Web much as past generations looked to Dr. Spock for parenting advice [4]. More than 100 million Americans have gone online to search for health information at least once, according to Taylor, chair of The Harris Poll and inventor of the term "cyberchondriacs" to describe health Internet searchers. Taylor further notes that the Internet—which began by helping users to do tasks "better, faster, or cheaper"—is now being used to do new things that either could not be done at all previously or were too expensive to do [5]. Access to the wide range of health and medical information that is available online, still mostly free, any time of day or night, is certainly new. In an update on cyberchondriacs, Taylor reports that a majority of searchers use a search engine or portal to access health information rather than go directly to

a known health-related site and that they go online an average of three times per week [6].

Finally, the Pew Internet & American Life study group released *The Online Health Care Revolution: How the Web Helps Americans Take Better Care of Themselves* on November 26, 2000 [7]. The report, which dubbed its subjects "health seekers," noted that twenty-one million of the fifty-two million American adults who sought health information online reported that the resources they found on the Web directly affected both their health care decisions and interactions with their doctors. Like respondents in the Wharton test market, these health information seekers reported appreciating the convenience of Web searching and its round-the-clock availability. They also said they were able to get more information online than from other sources, and they liked being able to do so with seeming anonymity, especially regarding sensitive topics. Once again, women were much more likely than men to search online for health materials and were more likely to fear inaccuracies in what they retrieved.

## INFORMED CONSUMERS

Consumers thus have ample opportunities to become well informed regarding their conditions. What has been the effect of such dramatically expanded access to information? Physicians have realized that they need to know what their patients are reading, a fact evidenced by the existence of the "What Your Patients Are Reading" resources on MD Consult. This service not only alerts physicians to medical items in the popular press but provides informative, peer-reviewed material on each topic for physicians to read to be prepared for patient questions. Health sciences librarians use such resources in a similar fashion to maintain awareness of medical news and to gain clinical knowledge on newsworthy topics.

Because patients can afford to focus narrowly on their own concerns, learning only about their condition, they have the possibility of ultimately becoming "consumer specialists." In addition, all patients have the inherent knowledge of their own symptoms and the experience of living with a disease that physicians lack. Even with the sophisticated diagnostic tools available today, physicians operate at a severe disadvantage without the patients' input [8]. A growing population of extremely knowledgeable and involved consumer specialists have evolved, who go on to coordinate support groups, run chat sessions, or design and maintain outstanding Websites. As part of an online community of patients with similar conditions, individuals have the ability to compare treatment regimens and share practical advice gained through the experience of living with a disease as well as offer and receive emotional support [9].

A Web manager was born when, after undergoing

a pneumonectomy and surviving "incurable" lung cancer, art librarian Parles realized that her access to information, specifically her ability to find precisely relevant material, had been key to her survival. Using her own experiences as a patient in conjunction with her professional expertise as a librarian, Parles created and maintains Lung Cancer Online,\* a high-quality, gateway site to lung cancer resources [10]. In a personal email to the author, she offered the following insights into her work as a patient/librarian Web manager:

Patients want a site that is easy to navigate . . . I often hear from Website designers that my site needs to be "jazzed" up, but I have never heard this from a patient and in fact, hear quite the opposite . . . I do not try to offer as many resources as possible on a given topic. My intention is to offer a handful of quality resources, evaluating the integrity, currency, reliability etc., of each source. My indexing is rudimentary, but guided by what I learned from being a patient. My initial thought was to use [Medical Subject Headings] MeSH or a consumer health indexing system, but I really arranged the site based on how I looked for information as a patient. [11]

In a similar vein, Dunn, cancer survivor and creator of Steve Dunn's CancerGuide,† states

I strongly believe, and indeed I know from personal experience, that information can save your life. This page is dedicated to helping cancer patients find the best treatment for their disease by finding, and understanding, the best and latest information on their disease. [12]

## PARADIGM SHIFTS

The paradigm in health care seems to be shifting toward a cultural belief in personal responsibility for one's health and away from the attitude that physicians can use pharmaceutical therapy, advanced surgical techniques, or modern technology to "fix" any health problems that arise. Consumers and physicians alike will need to espouse a partnership model rather than the passive, submissive patient model of the past, where patients depend upon physicians to repair their health much as they depend upon mechanics to repair their cars. Prevention, environmental causes, lifestyle issues, and compliance with advice or treatment are all very powerful forces affecting the outcome of health care. As consumers increase their involvement in health issues, Kassirer, former editor of the *New England Journal of Medicine*, believes that physicians will

\* Lung Cancer Online may be viewed at <http://www.lungcanceronline.org>.

† Steve Dunn's CancerGuide may be viewed at <http://cancerguide.org>.

be drawn into a new "partnership" with patients who are more responsible for their own care [13]. Roter notes that improved patient outcomes have been documented in studies where patients took the initiative for obtaining their own information [14]. Braddock proposes shifting to a more balanced, two-way dialogue between patients and their physicians to encourage the "informed participation" of patients in making important clinical decisions, providing an outline of seven elements needed for informed decision making at three levels—basic, intermediate, and complex [15]. Communication and patient-centered medicine was the subject of a special issue of *Patient Education and Counseling* in January 2000. Editor Bensing notes:

We are at the verge of a new paradigm-shift in health care. Norms and values that were long taken for granted seem to be changing. The authoritative doctor who is supposed to make all medical decisions takes gradually place for [sic] a model of shared decision making by physicians and patients together. There also is now a widespread belief that not diseases but patients must be the focus of health care [16].

She points out that rising rates of chronic disease have also affected physicians' roles. In chronic disease, "Much is dependent on the patient's own adaptation and coping capabilities, which prompts the physician for [sic] taking the role of 'teacher' or 'consultant' rather than the role of 'expert' or even 'guardian'" [17]. This is reminiscent of how the librarian's role has expanded to include the role of teacher or consultant as well as that of expert mediated searcher.

## PHYSICIAN-PATIENT COMMUNICATION

Part of this changing relationship between doctors and patients can be noted in the growing body of data suggesting that patients are very interested in exchanging emails with their physicians. Cyber Dialogue's figures indicate that 50% of surveyed patients would like to be able to email their doctors. A small but growing number of physicians and health care organizations also support this concept [18]. Kassirer predicts an enhanced level of care and greater efficiency for both patient and physician through the use of email. For example, physicians who receive electronic readings from their patients' home-monitoring devices could then communicate drug dosage adjustments via email. Routine tasks such as appointment scheduling, referrals, prescriptions, and patient reminders could be delivered effectively and efficiently through a secure email system [19]. Many issues must be considered regarding confidentiality, timeliness of response, archiving of queries, and responses for patient care and legal purposes. Guidelines on this subject are available from the American Medical Association (AMA) [20], the American Medical Informatics Association (AMIA)

[21], and the Beth Israel Deaconess Medical Center [22]. It is interesting to note that the AMA guidelines were issued at the request of the Young Physicians Section.

There are many positive attributes to email communication in the health care setting. Mandl describes the new health care environment in which the need to transmit information is on the increase, just as the opportunities for face-to-face communications are on the decrease. Communication when it does occur is often too brief, with little opportunity for discussion or follow-up questions [23]. Once patients have left the office or the hospital, reinitiating contact can become an onerous task. Because email communication is asynchronous, it can reduce or eliminate the annoying and inefficient interruption of other activities to answer telephone calls or the frustrating "phone tag" problem. Of course, there is no "context" to an email exchange—no body language, no tone of voice, no visual cues, and no warm handshakes or pats on the back. Mandl notes that a well-designed interface could guide both physicians and patients in optimal use of email interactions [24].

The ideal system would involve patient-physician communication in a wide variety of modes with sensitivity to personal preferences and comfort levels taken into consideration on both sides. Email would be an adjunct to personal communication, while information garnered from a Website or support group would enhance instructions obtained directly from the physician. Terry and Healey compared satisfaction of patients who received self-care information during an office visit with those who received the information through direct mail or who experienced usual care [25]. Receiving the material during an office visit resulted in patients who were "significantly more satisfied with their care and the physician-patient communication experience . . . . Our findings lend support to the growing evidence that patients informed by their physicians are more satisfied with their care" [26].

If patients prefer receiving information directly from their physicians, would they not also prefer to access the physicians' Websites? Cyber Dialogue's surveys indicate that they would. More than a quarter of the Internet users who express an interest in doctor Websites indicate that they would be likely to switch doctors to do so [27]. O'Connor and Johanson find that 25% of surveyed clinic patients have searched the Web for health information in the past twelve months and that 60% intend to use the Web in the future [28]. Based on these findings, O'Connor and Johanson urge fellow physicians to create their own Websites, use the Web for patient-education information, and help patients to evaluate the information on the Web. This is a common thread in articles and surveys regarding the opportunities that still exist for physicians to establish an elec-

tronic presence in their patients' lives. These opportunities for physicians also represent opportunities for librarians to lend their expertise to the process. In this way, as the model for physician-patient relations shifts toward collaborating and shared decision making, librarians can assume similar collaborative roles with both physicians and patients.

## EVALUATION OF CONSUMER INFORMATION

Many articles have been written describing electronic consumer materials available in various specialty areas, pointing out that information was difficult to pinpoint, misleading, out-of-date, or pure quackery. A recent study, commissioned by the California Healthcare Foundation and conducted in part by the RAND Corporation, surveyed the accessibility, quality, and readability of Internet consumer health information in both English and Spanish [29]. Four common conditions were investigated: breast cancer, childhood asthma, depression, and obesity. Coverage of topics was evaluated related to clinical elements considered critical to the topic, in other words, the key elements that might have been left out of the provided information. This could be a problem in all sorts of health information—the “Oh, didn't I tell you that you should eat low fiber diet while undergoing pelvic radiation?” type of information that, while not life threatening, could have a significant impact on the patient's comfort and quality of life. Examples of the type of missing elements included “alternatives to standard . . . treatments for breast cancer (28%), symptoms suggestive of poorly controlled asthma (48%), evaluation of depression (33%), and safety and effectiveness of dietary supplements used for obesity (61%)” [30].

Librarians who routinely provide patient education information will find the following aspect of Berland's report an affirmation of personal experience:

Although we found thousands of pages of material related to key questions, there were substantial gaps in the availability of key information. Only half of the topics that the expert panels thought were important for consumers were covered more than minimally. This deficiency was particularly striking across Spanish-language sites. [31]

This finding reaffirmed earlier studies, such as Impicciatore's 1997 survey of Web advice on the home management of children's fevers [32]. Of the forty-one relevant sites reviewed, only four provided information that closely followed the standard guidelines regarding temperature measurement, drug treatment, sponging procedures, other physical remedies, and symptoms requiring a call to a doctor. In many cases, correct but incomplete information was provided. This issue raised some concern for librarians, because standard evaluation techniques did not actually take clinical content into consideration but instead used sec-

ondary indicators of quality, such as authority of authors or producing organizations, currency of information, documentation of sources, and so on. An ideal situation would seem to be one in which librarians would locate candidate materials, perform initial evaluations, and then pass the materials to clinicians for final review. Unfortunately, this model requires a time commitment that is often difficult for clinicians to make. Another option may be for librarians to follow a set of guidelines regarding what elements should be addressed, much as the evaluators did in the Berland study.

Reading level is another issue of great concern. As Berland and her associates find, the average sampled health information in English is on a Grade 13 reading level, while the reading level for Spanish materials is at Grade 10 [33]. A similar survey of neurology brochures and Websites reveals that most are written at Grade 9 level or above, even though Grade 9 level or below has been identified as the desired standard [34]. Once again, librarians will recognize this problem immediately. Along with requests for various foreign language materials, queries regarding sources of low-literacy, patient-education information are standard features on both MEDLIB-L and the Consumer and Patient Health Information Section (CAPHIS) discussion lists.

## ROLES FOR LIBRARIANS

What are the implications of the electronic information age for health sciences librarians, for other health care professionals, and for the consumers librarians count as clients? What are the opportunities for our daily practice and our future roles as information experts? Where do we fit in among the health seekers, the cyberchondriacs, and the physicians?

Having provided a variety of training programs to public librarians, this author strongly believes that public librarians are being queried on a very regular basis for health information. The Consumer Health Credential Program—officially launched at MLA 2001 in Orlando, Florida, in May—seems a worthy endeavor [35]. Although the program has provoked some impassioned discussion on MEDLIB-L, the fact remains that consumers will seek health information from a variety of sources. If they are already users of the public library, they will likely seek information there. It is logical that medical librarians partner with public librarians, sharing our expertise for the mutual benefit of colleagues and consumers. Furthermore, whether the Digital Divide is shrinking or increasing remains unclear [36]. Public access to computers and the Internet has become a standard feature on the menu of public library services and can help to narrow the effects of the Digital Divide.

In this regard, hospitalized patients are fortunate.

The Joint Commission on Accreditation of Healthcare Organization (JCAHO) requirements mandate that patient education be delivered as part of inpatient care. The standards also require that the patient-education encounter be documented on the patients' charts. Librarians at The Cooper Health System have been providing patient-education information since December 2000 as part of a pilot project to improve compliance with JCAHO guidelines. Requests may be initiated by any staff member who has patient care responsibility and authority to access the Clinical Information System for placing orders. Librarians receive requests at a shared printer in the reference office. Two copies of all materials are sent to the floor via staff "runners," employed by the Department of Nursing. One copy is delivered directly to the patient, while the other is placed with the patient's chart.

Groundwork for this level of collaborative practice has been underway at Cooper for at least ten years. The library director is a member of the Health Education Committee. Earlier in her career, she participated in critical care rounds as a clinical librarian with the senior physician who cochairs the committee. The cochair is a nurse administrator who is also an active, enthusiastic library user and supporter. In addition, the library previously provided a Literature Attached to Chart (LATCH) service, which helped to set a precedent for direct provision of information to the patient chart by librarians. An added benefit of this project has been that the librarians have become more attuned to the institutional character of the health system, because the received requests reflect the patient population—the types of cases seen most often, the geographic areas, racial and ethnic groups, socioeconomic classes, and so on. A six-month evaluation of the project is still in the planning stages, but the initial response from hospital staff has been quite positive. A survey of patient reactions will be undertaken in the future with full consideration of their rights to privacy and confidentiality.

A multifaceted program for providing patient information is offered by librarians at the Patient Informatics Consult Service (PICS), Eskin Biomedical Library, Vanderbilt University Medical Center [37]. PICS represents a highly developed collaboration among physicians, librarians, and consumers. Patients are referred to the librarians via an information prescription form, filled out by either a physician or a nurse. PICS librarians provide a level of value-added service beyond the usual compilation of evaluated resources. They highlight salient features of retrieved materials as well as write summaries of information. Because copies of the packet are sent to both the patient and the referring clinician, there is opportunity for feedback and continued dialogue concerning the information provided. Finally, the librarians maximize their time and efforts by saving information for reuse in

their Pathfinder database.‡ Especially valuable for librarian colleagues are the editorial guidelines and instructions for authors that were written for contributors to the database [38].

What other scenarios can be envisioned in the collaborative model for patient-centered information? Opportunities can be found easily once an awareness has been created. For example, a case came up while this article was being written: A radiation oncologist requested information about food and cancer from one of the librarians. This broad question was negotiated into "What I really want is material on cancer and appetite. Not just the effects of various treatments on appetite but also the effects of the disease process itself. I am thinking of putting together a booklet for our patients." In addition to compiling information on this topic, it was decided that it would also be useful to find any existing pamphlets on the subject and schedule an interview with the physician to discuss how the materials were different from the booklet he envisioned. The librarian would then have a clearer understanding of what information was needed and what the finished brochure should include. Once provided, the information could be evaluated and synthesized by both the physician and the clinical dietitians. Also, when the brochure was completed, it could be provided and distributed in a variety of formats, both print and electronic, again with assistance from the librarian.

Medical librarians have unique skills, the ability to learn new tasks, and the desire to work as part of the health care team. Both the slogan from the Friends of the National Library of Medicine—"The more you know, the better you heal"—and C. Everett Koop's statement—"The best prescription is knowledge"—should inspire medical librarians to fully explore the available opportunities in the age of consumer-driven, patient-centered health care.

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