

### Challenges for libraries creating one world: information ethics and policy issues for medical librarians\*

#### Introduction

Even though I have worked in the information sciences field since early 1962, I am not a medical librarian; however, I think that many of the policy and ethical issues facing medical librarians are similar to, if not the same as, those across our profession. Because of some rather unusual medical situations in my own large family over the years, I have experienced many facets of the use of medical information by patients and caregivers, and I have gained a special appreciation for what medical librarians do every day. I also want to make clear that I do not pretend to be an ethics expert; my interest is in the application of ethical reflection to our field.

As I worked with librarians and others in the information profession over the years and with individuals at the international, national, state, and local levels in developing and implementing information policy, it became increasingly clear to me that ethical issues related to information demanded our attention. I also recognized how important it was for us in the library and information field to take an active role in developing policy.

My objective in writing this editorial is to highlight some of the trends and challenges I think are facing us today.

#### Context (emerging trends)

I have selected six trends I see shaping the context in which we live and work.

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**1. Greater focus on the individual.** Over the years, we have moved from "just in case" library service to "just in time," to "just for you," and, most recently, to "just for me," with each type of service continuing as a new type is added. The shift to "just for me" is more than just semantic; it indicates the change from producer or provider pushing information *out to* the user to pulling *in from* the user, or potential user, needed information sources wherever and in whatever format they are located.

**2. Increasingly global society.** A second trend is the increasingly global nature of our society. In part because of the Internet (and certainly as a result of the events of September 11, 2001), we all recognize the seeming dichotomy that, while we live in a "global village," we observe greater conflict and tension among groups and less understanding and appreciation of different cultures.

**3. Connecting across wider and more varied communities.** We are making connections across wider and more varied communities than we have in the past. Medical librarians have been doing this for years, of course, and have demonstrated a growing interest in areas such as complementary medicine, sharing information across units in a complex organization like a hospital or a university, an even greater emphasis on patient and caregiver information, curricular changes in educational programs moving toward a more patient-focused and integrated curriculum, and a growth in teams across specializations.

From a family caregiver perspective, when my younger sister came to Pittsburgh for a kidney, pancreas, and bone marrow transplant three years ago, I experienced firsthand the importance of this connection through the great array of

information services provided to the outstanding team of doctors, nurses, pharmacists, dieticians, therapists, and others, as well as to her and our family. The human and information connections made by the outstanding medical personnel, and of course the medical librarians, across the wide community in the University of Pittsburgh Medical Center were key to the success of her surgery and recovery.

**4. Need to balance the "old" and the "new."** It may seem strange for someone who has focused so much on the application of technology to problem solving and decision making to raise a note of caution about too much emphasis on technology, but, remember, I do come from a liberal arts background. In their excellent book, *The Social Life of Information*, John Seely Brown and Paul Duguid [1] make a strong case for understanding *how* individuals function within society and *why* they hold to certain traditions and practices, rather than attacking people for being reluctant to adopt new technologies or make other changes in their lives. They urge us to pay attention to how the "new can learn from the old. . . . [R]ather than condemning humanity as foolish, primitive, or stubborn for sticking with the old and rejecting the new, it seems better to stop and ask why" [2].

New does not just refer to technology, but to many other aspects of change in our lives, such as the vast quantities of information in all forms bombarding us each day, theories and practices of management, increased accountability, and so on. The authors are not against technology, but they urge design that takes into account what people care about. They contend that "while information and its technologies cannot solve all society's problems, society and social resources can solve many of the

problems of both information and technology" [3].

Brown and Duguid's focus is on human sociability. Going back to the example of my sister's transplant surgery, over the many weeks she was in the hospital and recovering at home, I observed the excellent care she received, and, of course, I could not help but focus on how individuals got, used, managed, and shared information. Two practices startled and intrigued me. While she was in intensive care, I watched as nurses went to her bedside and looked at readouts from numerous machines, taking notes with pencil and paper. They would then go to a workstation in an adjacent area and enter data into a different system. I wondered why the data were not fed directly into the workstation and thought about the potential for human error.

The second practice was to observe the many test results and numerous data sets generated each day by different individuals and groups in the Thomas Starzl Transplant Center. All of these were entered into her chart in electronic and often in print form. On the wall near her bed was a single sheet with numbers entered throughout each day in pencil, showing her "history" over time. Robert Corey, the head of the Pancreas Transplant Center and of her team, came twice a day, first talked with her, and then looked at the paper sheet. This single sheet provided for him the "big picture," the most current map he wanted to start with each visit. We could fault Dr. Corey for not looking first at the workstation with all the detailed information in digital form, but rather than "condemning him" for "sticking to the primitive," we should ask why.

**5. Balancing the many roles of information professionals.** Among our many roles, I think the roles of educator and expert/advisor, including that of "translating," are especially important. So often, we are called upon to translate from technical jargon to language understandable by nonexperts (for med-

ical librarians, especially, from Greek and Latin to language that patients and family members can understand) and to synthesize multiple resources into understandable language.

**6. Emphasis on trust.** For all librarians, earning trust has always been essential to our profession, and, for medical librarians, it is crucial. I include this in the list of trends because of the growing emphasis on trust resulting from the many recent incidents of betrayal of trust by some individuals in industry, government, and not-for-profit organizations. This trend encompasses trust of individuals, of the quality and accuracy of information, and of the organizations themselves.

## Challenges

Several challenges face us in the years ahead. Among these are the following eight.

**1. Educating our "publics."** The first set of challenges relates to the ongoing need to educate the many "publics"—the diverse groups with which we work—about who we are, what we do, the *value* of what we do, and why we do it. Part of our job of education is to help people understand, and participate more fully in, the life cycle of information from its creation (whether through the thought and/or creative process or from a body scan, blood test result, or whatever source), through its evaluation, organization, management, and preservation to its dissemination and use. With ready access to the Internet, many people focus on quick retrieval and do not always understand the importance of evaluation or preservation of information.

**2. Balancing the "old" and the "new."** We have done very well in meeting this challenge as we have focused on our values of service and on the vast knowledge of our discipline and profession, while incorporating the "new," whether it is new technologies, innovations in

management, techniques and practices, or other developments. We must continue to be vigilant and work to overcome some of the limits of content (such as inequities in resources around the world, English-language limits, bias toward Western traditions, etc.) keeping us from meeting all the needs of specific users, especially as we work toward true customized, individualized services.

**3. Teaching and learning "mediacy."** Part of our challenge to educate our publics is the need to understand more fully and to teach what I call "mediacy." Many people use information literacy (or worse, computer literacy), but I prefer mediacy to encompass the competencies—the knowledge, skills, and attitudes—needed to explore information space, find, evaluate, manage, organize, preserve, disseminate, use, and create information. These competencies, needed throughout the stages of the life cycle of information, are different for information resources in different formats and media. Mediacy has three dimensions: (1) the knowledge and skills for each of these abilities, (2) the format or medium, and (3) the traits and preferences of the individual (including how people learn and use information according to their individual learning styles). A challenge for us is to work to understand these competencies more fully, to learn how best to teach and learn them, and then to do so.

**4. Developing "just for me" services.** Many of you have been deeply involved with developing "just for me" services for some time. We have already made great progress, particularly in the health-related areas, and we have a wealth of opportunities ahead. As part of this work, we will need to continue to address the many learning styles, preferences for different formats, and cultural differences as we gain greater understanding and appreciation of how best to customize services for users.

**5. Understanding and appreciating cultural differences.** Even before the terrible events of September 11, we recognized the need for deeper and broader understanding of cultural differences in our own country and across nations. In our role as information providers, we are frequently confronted with the need to understand and appreciate significant differences across cultures and will need to pay even greater attention to these differences in all of our services. Meeting this challenge will require additional resources to meet the language and cultural needs of our many users and potential users.

**6. Collaborating across boundaries.** Similarly, librarians' work to develop resources and services across boundaries—whether departments in a university or hospital or across institutional, state, or national boundaries—has already resulted in significant progress. Questions of state licensing, authentication of users, decisions about whose rules or laws prevail, organizational politics, and others will continue to demand attention and resolution. The question of authentication of users, especially those in faculty positions who also have access to medical records, along with computer and network security (particularly in the increasingly wireless age), is one requiring much more attention.

**7. Addressing issues and developing policy.** So many critical policy issues exist that selecting among them is difficult. In my view, the key issues relate to access. Who should have access to what information? As it always does in discussions of policy, the word "balance" comes to mind. How can we provide the best and fairest balance between access and protection? How do we protect the privacy of each individual while also providing the best health care? Who needs to know what information about an individual, and how do we ensure that they and only they get the needed information quickly and accurately? Over-

all, the sound policy seems to be to protect private information to the fullest extent possible, unless there are very compelling reasons not to do so, and then to share it only with those who absolutely must know it for the greater good either of the individual or of society. In contrast, policy toward public information is to share information as widely as possible, unless there are very, very compelling reasons for protecting it.

The challenge for us is to be ever vigilant to ensure that policies throughout the entire life cycle of information provide access to—as well as the active dissemination of—public information and services to empower individuals. Where appropriate, information technologies, coupled with these policies, can be used to provide government of the people, by the people, and for the people. This is often referred to as "e-the people."

Another key area of policy relates to the balance between the protection of intellectual property and fair use. This is a complex topic that warrants careful examination, and it is important to include this among the policy challenges facing us in the years ahead. Much of the discussion on intellectual property protection focuses on commercial value, with questions of how long Disney should be able to protect the Mickey Mouse image or a company should be able to restrict generic versions of a drug. Lost in some of the heat is the importance of protecting the integrity of content, and we need to pay more attention to the protection of integrity. It is so easy to select bits and pieces from various Websites and integrate them into a new information resource or to change and distort still or moving images, not to mention editing text, that it is difficult to ensure a document's integrity. Digital signatures, encryption, electronic "watermarks," and other technologies are helping with this protection, but more will need to be done to protect the integrity of a source so we can be certain that the information is accurate,

timely, and credited to the correct source.

Among the many other critical policy issues are those related to the authentication of users, defining the roles and responsibilities of various government bodies (local, state, federal, national, and international) vis a vis those of the private sector (both for-profit and not-for-profit) and determining who will decide on the provision of health care and who will pay for it. I believe that the challenge for us is not only to stay informed about these policies but also to take a role in developing and implementing them. Too often, information professionals have not been directly involved in the creation of policies from the beginning but have had to react to—and sometimes work to change—them after the fact. So much is happening so quickly that this will be a difficult challenge, but, through our networks, including conferences, we can share what we know and strive to meet this challenge.

**8. Earning trust.** The final challenge is that of earning and keeping trust—something that librarians have done effectively for years. To earn and deserve trust, we have striven for integrity: of ourselves, of the information we provide, and of the organization for which we work. Of all the areas of librarianship and the information professions, I can think of none in which integrity is more critical. It is no exaggeration to say that life or death decisions are made based on the information you provide. This brings me back to ethics.

In 1988 at our School of Information Sciences at the University of Pittsburgh, we introduced a lecture series on the ethics of information in society to encourage thinking and discussion about ethical issues in our field and, more widely, in society. This series helped form the basis of our course on information ethics, which brought together students from the many specializations in our school, from the medical school and others in the health sciences, and from many other pro-

grams on campus and at Carnegie Mellon and other colleges and universities in the greater Pittsburgh area. This course was developed and initially team-taught by Stephen Almagno and me; he then taught the course for several years before retiring in December 2001. In our course, we defined ethics as:

The art and science that seeks to bring sensitivity and method to the discernment of moral values.

We devote the first half of the course to understanding ourselves: our attitudes, biases, belief systems, and values through a series of readings, short papers, and discussions. We also work through the process of solving problems and making decisions. The second half of the course addresses ethical issues in our profession as we continue to work on individual topics. Our ob-

jective is to help all students develop their sense of ethics and then to translate this reflection into action—living our moral values. The course is a process of reflection and of discovery.

Understanding what it means to be an ethical person is a huge challenge. Translating the results of our reflection into action each day is an even greater one. It is only by doing this that we will continue to earn and keep the trust given to us.

### **Conclusion**

While these challenges may seem daunting, medical librarians have been meeting them every day. We are fortunate to be in the most exciting profession and to look forward to tomorrow's changes and challenges. My family and I are very grateful to the many medical

librarians who have helped us so much over the years, and I extend my sincere thanks.

*Toni Carbo  
tcarbo@mail.sis.pitt.edu  
Professor, School of Information  
Sciences and Graduate School of  
Public and International Affairs  
University of Pittsburgh  
and  
Madison Council Fellow in Library  
and Information Science  
John W. Kluge Center/Library of  
Congress*

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