
Health Information Literacy: A Library Case Study

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ABSTRACT

CONCERN ABOUT HEALTH LITERACY IS ONE FACTOR driving an international movement to develop and disseminate health information that is easy to understand and appropriate for people who have difficulty reading or whose first language is not English. Libraries can work with organizations in their communities to improve the accessibility of materials. Strategies for effective collaboration will be outlined in the context of health literacy promotion efforts. Finally, the role that librarians can play to help deliver appropriate health information, using the example of one patient resource center, will be discussed.

INTRODUCTION

This article will discuss how libraries can participate in the dissemination of plain language and easy-to-read health information to the general public. People should have access to information that is appropriate for their needs and play an active role in their health and well-being. Understanding the information available with respect to health issues increasingly is the responsibility of the patient. Recent surveys evaluating the basic literacy skills of Americans, Canadians, and Europeans have turned up alarming results. Libraries and librarians can contribute to the health of their communities through their involvement with health literacy initiatives and by keeping literacy issues at the forefront.

This article will present a general framework of how illness, stress, fear,

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and cultural differences can impact the way in which people understand their health problems—not to mention the health care system itself. The example of one patient resource center will illustrate how libraries can collaborate with the communities they serve to increase understanding of health.

Using criteria familiar to many librarians for evaluating the appropriateness of printed materials, librarians can make management decisions that will benefit users and libraries alike. The concepts of purpose, scope, authority, currency, and audience help us understand who libraries are serving, which organizations are key targets for collaboration, and the purpose of library programs. Hopefully, this practical structure will help others get involved with issues of health literacy.

WHAT IS HEALTH LITERACY?

Literacy is used in many different contexts today. Libraries have long played a role in basic literacy education and are beginning to carve out their place in the new arena of information literacy. Finding definitions for the terminology of literacy is controversial. It is useful to understand the scope of the issue in order to develop programs and communicate with the community. A few definitions inform our work as librarians.

Literacy is “using printed and written information to function in society, to achieve one’s goals, and to develop one’s knowledge and potential” (National Center for Education Studies, n.d.). Health literacy is “the ability to read, understand, and act on health information” (Pfizer Clear Health Communication, n. d.), and “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (U.S. Department of Health and Human Services, 2000, p. 20). Information literacy is a set of abilities enabling individuals to “recognize when information is needed and have the ability to locate, evaluate, and use effectively the needed information” (American Library Association, 1989).

A working definition of health information literacy is “the set of abilities needed to: recognize a health information need; identify likely information sources and use them to retrieve relevant information; assess the quality of the information and its applicability to a specific situation; and analyze, understand, and use the information to make good health decisions” (MLA Net, 2003).

WHAT IS KNOWN ABOUT BASIC ADULT LITERACY?

The National Adult Literacy Survey, conducted in 1992 and again in 2003, and the International Adult Literacy Survey, completed in 1994, gave North Americans and Europeans some startling news about the reading and writing abilities of those sixteen and over. Both surveys evaluated three types of literacy:

Prose literacy—the most common form of prose literacy used is the newspaper or magazine article

Document literacy—the questionnaire required participants to read information in table form or in lists, such as a bus schedule or a table of contents

Quantitative literacy—using a graph, chart, or performing an arithmetic operation, such as calculating a tip

Within each type of literacy, five levels were defined, with level one being the lowest and five the highest. In both surveys, so few respondents scored at level five (about 3 percent for both Canada and the United States) (Clark, 1996) that the results were deemed statistically insignificant and the scores were combined with those at level four.

Those adults at the lowest levels of literacy (levels one and two) are of greatest concern for literacy advocates. Between 20 and 23 percent of Americans scored at the lowest level of prose, document, and quantitative literacy, while closer to 15 percent of Canadians fell into this category (Clark, 1996). The numbers increased for level two, with over 25 percent of both Americans and Canadians scoring at this level (*Reading the Future*, 1996). These two levels combined represent close to half the adult population.

WHERE DOES IT END? BEGIN?

Quite apart from the alarmingly low basic literacy rates in North America and Europe, health issues are notoriously complex and bewildering. The most educated person when confronting a major health crisis can have problems understanding the information presented. Emotional exhaustion, medication side effects, and general fatigue can all play a role in obscuring messages. In Quebec as elsewhere, issues of language confound comprehension every day. Problems navigating the health system exacerbate many problems. Cultural issues or lack of sensitivity to cultural issues can create problems of cooperation in health care and foster distrust and secrets between doctor and patient.

Much research is now being done on the impact of low literacy, language barriers, and cultural issues on health. Some studies focus on the cost of treatment, while others focus on the health outcomes associated with poor health communication. Cost analysis generally concludes that, while health outcomes may not be significantly different, those with low literacy require two to three times as many visits to understand the same information as those with excellent literacy skills. Other studies show that low literacy contributes to more hospitalizations, thus costing the health care system billions of dollars (Gordon, Hampson, Capell, & Madhok, 2002; Weiss & Palmer, 2004; Baker, Parker, Williams, Clark, & Nurss, 1997; Ad Hoc Committee, 1999).

Healthy People 2010 recognizes health communication as an important focus area and leading health indicator toward more effective preventative health initiatives:

Closing the gap in health literacy is an issue of fundamental fairness and equity and is essential to reduce health disparities. Public and private efforts need to occur in two areas: the development of appropriate written materials and improvement in skills of those persons with limited literacy. The knowledge exists to create effective, culturally and linguistically appropriate, plain language health communications. (U.S. Department of Health and Human Services, 2000, p. 15)

CASE STUDY: A NEUROLOGICAL DISORDER PATIENT RESOURCE CENTER

The Neuro-Patient Resource Centre began as an initiative of members of the Patient's Committee of the Montreal Neurological Hospital, who saw a need for quality health information to be made available to all patients of the hospital. The mission and goals of the Resource Centre are as follows:

The mission of the Neuro-Patient Resource Centre is to provide health information in English and French to patients, their families and caregivers, and the general public. Our services are designed to help individuals become informed and active partners in their health care. Our goals are

To provide patients, their families, and caregivers with easy access to a source of reliable consumer health information

To create awareness among hospital staff regarding the health information needs of patients and their families

To advocate and promote the individual's right to confidentiality and unrestricted access to medical and health information

To work in partnership with hospital staff to create patient education materials

To initiate and participate in research dealing with the impact of health information on human behaviour (Montreal Neurological Hospital, n.d. a).

This mission and goals are based on ideas put forward in the hospital's Patient Services Steering Committee Report: "Individuals who are active in making decisions about their care generally do better than those who are not. For patients to take control of their health and well-being and make informed health care choices, they need both information and knowledge" (McGill University Health Centre, 1997).

Structure and History

The Resource Centre is an independent patient and family information library. It was conceived as an initiative of members of the Patients' Committee, which is a government mandated patient advocacy group in

the hospital. Instead of positioning the Resource Centre under the auspices of either the Nursing Department or the Medical Library, where patient libraries are often positioned, it was decided that it should collaborate with, but be independent of, these groups. This decision was made because of concerns that, if it was organized under the Nursing Department, the focus would likely be more on patient education than information. Within the Medical Library, it was felt that doctors, nurses, students, and patients in the same library would not be the best way to serve the needs of these groups. The environment of the Resource Centre needed to be more family friendly than scholar friendly. Ultimately, due to space limitations, the Patients' Committee moved in with the Resource Centre. This has been found to be an excellent partnership.

Use of the Resource Centre—Purpose

It did not take long, working within the context of a hospital, to begin to realize where the barriers preventing patient and family members' "access to health information" lay and in how many ways the Resource Centre could ameliorate the situation.

It is common for patients to arrive at the door of the Resource Centre looking for information on a condition of which the library staff has never heard. As the Resource Centre is in a specialized hospital the staff know that very rare diseases are diagnosed and treated here, and it is entirely possible that the patient has a condition that is, in fact, new to everyone. More often than not, however, the patient has misheard the diagnosis or heard only incomplete information. This can be attributed partially to the stressfulness of the medical appointment itself. The appointment is often hurried and patients are reluctant to take up too much of the doctor's time.

Sometimes the doctor has bad news to impart. Once a person has been told that they have a serious health problem like a brain tumor, cancer, or multiple sclerosis or a disorder with a name that is new to them, like chronic inflammatory demyelinating polyneuropathy or syringomyelia, it is very difficult to hear anything else. The patient can easily forget to ask necessary questions like, What kind of brain tumor? What is this disease and what is the treatment for it? In addition, a diagnosis can be just as shocking and difficult to understand to a family member as the patients themselves.

There is also the problem that the language or jargon of medicine is unfamiliar to most people regardless of their level of education. One would like to believe that doctors and nurses have become more sensitive to this and have adjusted their language accordingly when dealing with patients. Unfortunately, based on our experience, this is often not the case. A related difficulty that people have in understanding what the doctor is saying is that many people do not know very much about anatomy and physiology. When the doctor says "you have a lesion in your occipital lobe" or "we are

going to place this tube down to your duodenum," the patient may not know where on the body these parts are located.

Even before a diagnosis is given there are major communication problems between the health care professional and the patient. People are told they are scheduled for diagnostic tests and will undergo examinations that they do not really understand. What exactly is an MRI or a lumbar puncture? Why does the doctor want to see me walk as part of a neurological exam? Often a doctor will not stop and explain. Sometimes a patient is too shy to ask or does not think of asking these questions until after the appointment is over.

After a diagnosis is made or after the medical team has determined an inability to make a comprehensive diagnosis, there may be a discussion of treatment options. Usually the patient comes to this appointment armed with nothing. Sometimes the doctor may have made a decision on the best treatment and may present this to the patient without discussing the rationale. The pros and cons of other treatment options may not be presented at all. Side effects may or may not be discussed. The level of pain involved, for example, may not be brought up.

The result of these stresses and omissions is that crucial information is never given or, if it is given, it often gets lost. The health professional may believe that the information has been given and frequently is not sensitive to the fact that the communication is not complete. Although the information may have been presented, it has not been received. These common scenarios provide many opportunities for the Patient Resource Centre to participate in patient care by providing information that educates and empowers patients and their families.

From first contact, the Resource Centre may be involved with the patient. Many telephone calls and e-mails are received requesting information on how to get an appointment at the hospital. The Resource Centre provides the names and contact information of specialists and clinics that focus on specific disorders. The Resource Centre can provide information on whether or not a specific treatment or surgical operation is performed at the hospital.

Another point of first contact with patients is online. The Resource Centre maintains a Web site that includes information about the Resource Centre, about diagnostic tests, about some disorders and procedures, and about clinics at the hospital (Montreal Neurological Hospital, n.d. b). The Resource Centre provides links to quality Web sites both on neurological subjects and to more general health search engines, as well as links to information on evaluating health information. Judging by the calls and e-mails received by the Resource Centre, this is the first contact many patients have with the hospital.

The Collection—Scope

The goals of improving health literacy and health information literacy inform almost all the activities of and services provided by the Neuro-Patient Resource Centre. The Resource Centre maintains an up-to-date bilingual (French and English) collection of monographs written in plain language on neurological and psychiatric disorders, as well as books on coping with chronic illness, pain, and death for adults and children. The Resource Centre also has reference books on general anatomy, neuro-anatomy, and physiology; medical dictionaries and encyclopedias; and guides to medical tests, as well as neurology textbooks.

The Resource Centre buys, or is given for distribution, pamphlets, information sheets, and booklets for patients on neurological disorders and related health promotion topics. The staff of the Resource Centre considers these “give-aways” extremely valuable. They usually come from very authoritative, unbiased sources like national organizations for a particular disorder. They are almost invariably written in plain language (although with varying degrees of difficulty in the vocabulary), and sometimes are available in more than one language. The fact that the patient or family member can take the information home with them means they can read it over and over again and they can show it to other members of the family; if they have trouble with the language the patient can get help with it. They can bring it with them to their medical appointments to discuss with the doctor and nurse, and they do not need to know how to use a computer to get it.

As discussed in the MLA satellite conference *Reading Between the Lines* (2003), it is difficult to tell, just by a request, the level of material a patron will need. While some tips were offered, excellent comments were made by Michele Spatz, who emphasized that the needs of the largest number of patrons can be met by offering materials with a wide range of difficulty. The collection philosophy at the Resource Centre is that the collection seeks to achieve equal amounts of information in French and English. The bulk of the collection needs to be written in plain language, that is, words in common usage, with some references in technical language and some simplified materials that are easy to read. Dictionaries and encyclopedias are other crucial tools in deciphering medical information.

For more in-depth medical research the Resource Centre uses its affiliation with McGill University for electronic journal access, and the Resource Centre maintains a very close relationship with the hospital’s medical library staff downstairs. The librarian at the Resource Centre will conduct a literature search for the patient and provide copies of journal articles for personal use only. The Medical Library provides an interlibrary loan service for a small fee that is paid by the Resource Centre. If a patient wants to do his/her own research in the library, he/she is welcome to use the collection of the Medical Library on a consultation basis only.

Reference service is by phone, in person, and by e-mail. Consultations are made by patients and the general public in French and English from all over the world. Nurses from other hospitals call the Resource Centre to get patient information and community referrals.

Other McGill University Health Centre librarians call the Resource Centre for information and vice versa. Since not all information requests are neurology or neurosurgery related, the patient can easily be referred to another McGill University Health Centre library better equipped to handle his/her particular information need.

As a library, the Neuro-Patient Resource Centre aims to provide resources to all types of patients and families. This is a continual challenge. The issue of language is a particularly acute one for the Resource Centre. The information available, in all formats, is overwhelmingly English. About one half of the user population is French speaking, and many of these patients and family members do not read English well enough to understand most health information—even if it is written in plain language. Some Canadian organizations and Web sites have information in both languages, but these are very few. European resources can be helpful, but there can be differences in the way medicine is practiced in Europe; anyone using information from other countries needs to understand the potential for these differences. The biggest obstacle is finding authoritative plain language material in French that is for a Quebec audience, not a European one.

When information in English or Spanish is needed, there is a great deal of patient information being made available, by very reliable sources, in the United States. However, there are some differences in the practice of medicine between Canada and the United States. A striking example is in medications: Canada and the United States often have different commercial names for the same drug; a medication may be approved for use in one country but not in the other, or it may have different indications for use.

LITERACY AND HEALTH INFORMATION LITERACY

The issues of literacy and health information literacy cut across a broad spectrum of patrons. At the Resource Centre there have been patrons who are very highly educated but simply lack the skills in the medical arena to find the information they need. In that case the Resource Centre helps them by providing more technical information and by providing training on the use of medical databases.

The Resource Centre participates in events that are organized by different groups in the hospital to promote awareness of health issues or to provide information about specific disorders such as stroke awareness days, epilepsy information days, and public lectures given by our doctors and researchers. The Resource Centre maintains patient information bulletin boards all over the hospital. These outreach efforts are particularly

important. People do not expect to find a patient resource center in the hospital. That is why at the front door there is a large bulletin board full of information for patients and their families with a big welcome from the Neuro-Patient Resource Centre.

AUTHORITY

Authority of health information is critical in the environment of the Resource Centre. Numerous times the staff has experienced desperate people coming for information on unproven medications and treatments as well as doctors and clinics who practice a form of medicine that is not based on scientific evidence. The staff researches these practitioners and treatments and explains why the legitimate medical community would not endorse them.

There is also much "patient information" being produced by pharmaceutical companies that is really nothing more than thinly veiled advertising for one medication or another. The staff of the Resource Centre is vigilant in weeding out these marketing tools from its collection and making every effort to reduce its presence in the hospital.

The staff of the Resource Centre strives to keep an open dialogue with hospital staff; when the Resource Centre receives new materials on a topic, say, metastatic brain tumors, the members of the brain tumor team are informed that this material has arrived. Recently a publication on amyotrophic lateral sclerosis in Chinese was put into the collection, and the members of the ALS team were immediately informed. The result of these efforts is that many of the health professionals at the hospital refer their patients to the Resource Centre. In turn the Resource Centre welcomes suggestions from the health care staff for additions to the collection.

CURRENCY

A critical concept in health information is that of currency. The field of medicine is a rapidly advancing one. A good example is treatment for multiple sclerosis. It used to be that there was nothing that could be done. When a patient was diagnosed with multiple sclerosis there was no proven treatment. Over the past few years studies have shown that, if certain disease modifying medications are initiated early, they can slow the progression of the disease over time. If a newly diagnosed patient is having a number of attacks per year, it will now be recommended that they follow a course of medications even though they may not be experiencing disability. This is an area of active research. For patients who have a condition called benign multiple sclerosis, there is an 80 percent chance that it will develop into a more progressive type of multiple sclerosis in the long term (about fifteen years). Under investigation is whether it is useful to give medication to these patients. There is also recent proof that certain types of chemotherapy,

which had been used only for cancer patients, can reduce the number of attacks experienced by patients with certain types of multiple sclerosis. These therapies can have serious side effects, and patients who are deciding whether or not to take them need the best, most current information.

In addition, the hospital staff needs to know that when a patient has questions about his/her treatment they can send the patient to the Resource Centre for current, authoritative information. This has been one of the most important steps in establishing the Resource Centre as part of the health care team. It has also motivated a number of doctors and nurses to make donations of quality materials to the Resource Centre.

PRODUCTION OF MATERIALS—AUDIENCE DRIVEN

One of the most important ways that the Resource Centre collaborates with the health professionals in the hospital is through our program of producing patient education and information materials. For example, information on diagnostic tests, clinic handbooks, caregiver guides, and fact sheets on specific disorders and procedures have all been produced collaboratively with the Resource Centre. All of these projects require the involvement of doctors and advanced practice nurses. Sometimes the Resource Centre collaborates with physical, occupational, and speech therapists; social workers; and technicians. Part of the Resource Centre contribution to these publications is to edit the information and, when needed, change the language to something that can be understood by people who do not have a medical vocabulary. All publications are produced in both English and French. After editing is completed, two patients (without a university education) are recruited and asked to review the text. Resource Centre staff work with a graphic designer to make the information visually interesting and inviting. All the patient information produced follows plain language guidelines, which include using the active voice, writing directly to the reader, using common words rather than technical jargon, and using short words and sentences. The materials are monitored for reading level, usually no more than grade eight. The Resource Centre has recently begun producing easy-to-read versions of some of these materials to reach people who may have difficulty reading in English or French. The challenge is that it can be difficult to translate complex concepts into very simple words. Using pictures can often help explain a procedure more clearly than words. Clear graphic design can also help people penetrate a “wall of words.”

The response of the hospital staff to Resource Centre productions has been overwhelmingly positive. This, perhaps more than anything else, has influenced the Resource Centre’s acceptance as part of the patient care team and has highlighted the need for better communication with patients by all members of the team as well as providing some strategies for achieving this.

WHAT ROLE DO LIBRARIES HAVE?

Libraries are recognized for their firm belief in the right to access information, and this naturally extends to the right to access and understand treatment and disease information. Libraries are often perceived as neutral territory and a welcoming environment for community members. Public libraries play important roles in basic literacy training and provide space for local organizations to meet and exchange ideas.

However, people with low literacy skills are not necessarily the same people who come into the library. Despite our belief that libraries are nonjudgmental places, open to everyone, many people may find libraries intimidating and never come to us for the information they need. Public libraries are alive and well in Sweden. In the report *Catching up with the Swedes*, Kapsalis (2001) shows a correlation between library usage and literacy rates. Unemployed Canadians rarely use public libraries, with only 23 percent stating they used libraries at least monthly, compared to 33 percent of Swedes. About half of Canadian youth use libraries, compared to 81 percent of youth in Sweden (Kapsalis, 2001).

As illustrated above, the library can provide multiple functions within a broad context: welcome desk, information provider, information producer, referral agent, and authority controller. These efforts can only be successful through partnerships with nonlibrarians and librarians alike. As discussed elsewhere in this volume, librarians increasingly need to leave the confines of their library buildings in order to reach the wider community. If not everyone considers the library a place for learning and information, then we need to expand our reach through a variety of partnerships.

We encourage every librarian, regardless of setting, to develop a good working relationship with a medical librarian. Health issues affect almost everyone over the course of a lifetime. Knowing someone you can turn to for document delivery, a good referral, and a specialized list of resources can be invaluable. With the right partnerships, our role as literacy brokers can span the wide range of basic adult literacy to health literacy, and using the principles of information literacy we can develop the concept of health information literacy.

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