

## Health literacy and hard-to-reach patients by Linda Shohet

Who are the hard-to-reach, and how do you identify them? A research team at the Montreal General Hospital has grappled with these questions for more than a year as we have tried to determine how a major medical facility might help low-literate patients take better control of their own health care.

The Montreal General Hospital is a large bilingual teaching hospital inner hospital located in downtown Montreal. An important proportion of its patient population is multicultural. Many patients do not speak English or French as their first language, and many of them are low-literate. The hospital first became involved in health literacy in 1995 when the Director of Nursing Staff Development attended a conference on health literacy and realized that this issue touched many patients at the hospital. Professional development workshops on health literacy for health care professionals were held in 1997-1999, the product of a partnership between The Centre for Literacy and the Hospital. Since then, the Nursing Staff Development Unit has expressed ongoing interest in health literacy. Hospital staff recognize that the changing nature of health care is leading to a growing number of patients having to care for themselves at home. Many are potentially unable to because of difficulties reading, understanding and applying health information received at the hospital.

In 2000, a Steering Committee set up at the Hospital in collaboration with The Centre for Literacy started out to do a Needs Assessment of the health education and information needs of low-literate patients. In conducting preliminary interviews and discussions, the Committee became aware that it was going to be difficult to identify patients with low literacy. There was strong feeling against testing and little confidence in patient selfreporting. There was considerable uneasiness about the word “literacy” itself which was corroborated as the study went on. Finally, the Committee recognized that people could be low-literate for different reasons requiring different interventions, and that some people might appear to be low-literate because of language barriers. So, we enlarged the concept of the target groups to “hard-to-reach” and created an operational definition for this study. For our purposes, “hard-to-reach” patients included low-literate patients, patients who face language or cultural barriers, and patients with learning difficulties due to cognitive or physical disabilities.

The question of how to identify these patients remained. While the term low-literate is an attribute of the patient, the term “hard-to-reach” is not a straight descriptor. It forces one to add “by whom?” And once the question is added, the responsibility is shifted to the person trying to do the reaching, in this case, the health care provider. The next step in our process followed from this. We would ask health care providers to identify patients with whom they found it difficult to communicate both through writing and orally. For these patients, health information and education is often communicated in ways that they cannot understand and is not useful to them. It is difficult for them to get answers to their health-

related questions. Health literacy has been defined as: “The ability to use written materials to function in health care settings and to maintain one’s health and the skills needed to advocate for and request needed clarification.” As a prior step to this Needs Assessment, a Background Paper on Health Literacy was developed. During the course of this research, it became apparent that the Steering Committee wanted to investigate more than the “ability to use written materials.” The Committee also wanted to look at the capacity of hard-to-reach patients to understand and use health information transmitted orally information included in videos, as well as information from other sources (visual materials, workshops, patient discussion groups, etc.). Could these other sources of information and education processes complement and/or replace written information as useful sources for hard-to-reach patients?

### **The Needs Assessment: Methodology and limitations**

The Committee chose a qualitative methodology as most appropriate to this type of exploratory research. We decided to use a small sample of informants and to focus on issues rather than numbers, knowing that the data collection would encompass many uncontrollable variables and that results would require significant interpretation.

The Committee wanted to work with hospital units that care for large numbers of patients and where patients (and/or their families) need to be involved in self care at home. Three hospital units—dialysis, oncology hematology and the pre-operative centre—expressed a desire to participate in the Needs Assessment. Patients from these units require a lot of health information and education. Health care professionals take significant time to teach patients and their families. Patients and families are generally “hungry” for relevant health information. In two of the three participating units (dialysis, oncology hematology), patients face a chronic health problem and are likely to receive medical care for many years. This would facilitate the potential tracking of patients in terms of evaluating over time the impact of more appropriate patient education methodologies.

Committee members decided to contact four groups: hard-to-reach patients themselves, their families, support staff and health care professionals. These informants were involved in the process of patient education either directly or indirectly. The decision to talk to patients and health care professionals is an obvious one: they are the groups directly involved in the education process. We knew that for many patients at the hospital, the role of the family in caring for the patient and processing health information was very important. We also decided to collect the perspective of support staff knowing from the literature that their role was frequently overlooked and unexplored.

Data were collected through individual interviews and focus groups with the four groups informants from the three units: hard-to-reach patients, members of their families, support staff and health care workers. Individual interviews were conducted with health care workers from two near-by CLSCs (community clinics). Physicians from the three units were asked to comment on a synthesis of the results. The research process was approved by the hospital’s ethics committee after the Informed Consent form was revised in plain language to meet institutional standards of research practice. Patients and families were

invited by a member of the nursing staff to participate. In total, 114 informants contributed to the findings.

## **Findings**

The findings showed that hard-to-reach patients often do not speak either official language. Some have physical or cognitive disabilities caused by or increased by their illness. A majority do not use the written information they receive, but rely on care givers to read or interpret it for them. They would like clear pertinent information, not necessarily in print only, related to their illness and to daily living. Family wanted more information about coping, and about community resources. They all wanted more empathy and responsiveness to their individual needs. Most also welcomed the idea of a centre, but did not want a large centralized facility. They recommended small diseasespecific centres located in or near the area where they come for treatment. A large majority of the patients interviewees did not, and did not want to, use a computer.

Health providers recognized that much of their material needed updating. They focused heavily on written resources and tended to feel that making materials clearer through Plain Writing would answer many of their concerns. They also generally felt that patients needed more rather than less information. They agreed that centres should be small and inviting, and wanted professional development activities integrated.

The Steering Committee has used the findings and recommendations from the three units as the basis for a follow-up project to establish pilot education centres where selected interventions will be implemented and tracked. The Centres will be guided by participatory education committees made up of providers, patients, caregivers, possibly a volunteer, and the project coordinator.

The Committee is aware that any new ways of informing and educating the “hard-to-reach” will have to be sensitive and pro-active. We will be involving some community participation for multi-cultural training and translation, and offering staff development on material design and clear communication. There is also recognition that the patients who gave input are probably among the easier “hard-to-reach,” and that there are harder “hard-to-reach,” and some who may never be reached. However, these groups of patients are not the minority they have been made out to be. People who have communication barriers likely comprise at least half the population, and as with special needs and learning disabilities in schools, when the health care sector finds ways of meeting the communication needs of the “hard-to-reach,” they will be improving health communication for the mainstream as well.

The *Background Document on Health Literacy* and the full *Needs Assessment* report with findings, analyses and appendices, including questionnaires and *Informed Consent* form, can be downloaded from The Centre’s web site [www.nald.ca/litcent.htm](http://www.nald.ca/litcent.htm) or ordered in print.

