Health Literacy Project, Phase 2:

More than Plain Language: Adapting Health Communication for Hard-to-Reach Patients

The Centre for Literacy of Quebec

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Background

The Health Literacy Project has been in place since 1999 at Montreal General Hospital, McGill University Health Centre as a partnership between the Nursing Department of the hospital and The Centre for Literacy of Quebec. The main goal is to improve the quality of the health information and education for hard-to-reach patients and their families, that will enable them to make informed decisions about their own health care. During Phase 1, which ended in the summer of 2001, we conducted a needs assessment of the health information and education for hard-to-reach patients and their families. Reports on this phase of the project are posted on the website of The Centre for Literacy. Phase 2 focused on finding ways to meet some of the identified needs based on recommendations from the needs assessment.

Key strategies identified in the Needs Assessment were to:

- Develop Health Education Centres in three units of the Montreal General Hospital to serve the information and educational needs of hard-to-reach patients.

- Establish Participatory Health Education Committees in each unit to create decision-making structures and guide the development of the Health Education Centres.

- Provide hard-to-reach patients with appropriate health information and education to help them make informed decisions about their own health care.

- Implement a training program for health care professionals to increase the capacity of staff to effectively inform and teach hard-to-reach patients.

- Promote an awareness of Health Literacy issues and the services of the Health Education Centres among patients, families, and health care professionals at the Montreal General Hospital to ensure sustainability of the project.

Project Model

The project was directed by a Steering Committee composed of nurses from the three units, two patient representatives, the hospital's Director of Volunteers, nursing librarian, a physiotherapist, the director and a researcher from The Centre for Literacy, and the project coordinator. An external evaluator sat in on some of the monthly meetings and provided continuous feedback that helped the committee make changes in the work plan as new information or knowledge became available. This model of evaluation, described in detail in this report, was a strength of the project.

Phase 2 Work Plan Objectives

A detailed work plan was developed to guide the project based on the findings of Phase 1. Three main objectives, with sub-objectives, and tasks connected to each, were developed as follows:

OBJECTIVE 1

Offer appropriate and effective health information and education to hard-to-reach patients and their families

Sub-objective 1.1

This involved setting up Health Education Committees consisting of health care professionals, patients, family members and/or volunteers in each unit to act in an advisory role.

Tasks

- to recruit members based on their sensitivity to the communication needs of patients and families
- to hold meetings and record their activities and decisions.

Sub-objective 1.2

This involved designing a teaching module in each unit on one health topic that met the different communication needs of hard-to-reach patients using input from the Education Committees. Due to time and funding limits, only parts of the teaching module could be implemented during this phase of the project.

Tasks in each unit

- to review existing documents, programs and other teaching resources, noting materials useful for hard-to-reach patients
- to adapt one or two print documents to Plain Language in English and French, with content and editorial input from the Education Committees
- to translate one print document that had been adapted to Plain Language into one of the following languages: Italian, Greek, Cantonese, and Cree
- if possible within the timeframe of the project, to identify and purchase one non-print document and the equipment needed to deliver the teaching modules in each unit. Also identify programs and interactive activities suitable for hard-to-reach patients to be implemented in the next phase of the project.

Sub-objective 1.3

Establish a Health Education Centre in each unit.

Tasks

- to identify locales for the Health Education Centre in each unit
- to identify potential partners internal and external to the hospital
- to identify sources for materials and ideas for programs
- to promote the Health Education Centres through presentations and information bulletins within the hospital.

Sub-objective 1.4

Ensure continuity of the project.

Tasks

- to hold and facilitate meetings of the Steering Committee
- to record activities and decisions, and to identify sources for funding and submit proposals.

OBJECTIVE 2

Increase the awareness and skills level of health care professionals with regard to issues surrounding health literacy and, more specifically, the health information and educational needs of hard-to-reach patients.

Sub-objective 2.1

Offer training to the health care professionals participating in the Health Literacy Project to provide them with certain skills, knowledge and tools needed to be actively involved with either the project's Steering Committee or the Health Education Centres or both.

Tasks

- to have health professionals visit the Hospital for Sick Children and the Princess Margaret Hospital Health Education Centres, Toronto, Ontario, and undergo skills development training in plain language writing at a Health Literacy Institute in Albuquerque, New Mexico.
- to visit The Harvard School of Public Health's Health Literacy Research Team to increase awareness of the research underpinning health literacy work.

Sub-objective 2.2

Offer training to the health care professionals working throughout the Montreal General Hospital who are not currently involved in the Health Literacy Project, to broaden their awareness of the issues surrounding health literacy and the communication needs of hard-to-reach patients.

OBJECTIVE 3

To gather and disseminate information and findings concerning health literacy in general

Sub-objective 3.1

Ensure liaison with key partners inside and outside the hospital system to build a pool of resources and data as well as to communicate the purpose, activities and results of the pilot project.

Tasks

- to create a list of pertinent resources and partnerships
- to disseminate the findings of the Project to key partners.

Phase 2 Evaluation

Evaluation was central to the project. The Steering Committee received continuous comments and feedback from the evaluator as well as from the coordinator, and made decisions and revisions to the plan based on them.

The final evaluation focused on Phase 2 as an initial development stage in an uncompleted longer term project and therefore concentrated on the establishment of participatory Health Education Committees in three units of the MGH and on the process of producing new materials by each committee under the supervision of the project coordinator and the Steering Committee.

This decision was debated at the Steering Committee since health care professionals, by the nature of their work, are task-oriented and focussed on concrete health outcomes. Most members wanted the evaluation to concentrate on the materials themselves and on patient reaction and ability to use them. After much discussion, the Committee agreed that the difficulty of identifying our target population and the short time frame of this phase would not allow for a valid evaluation of materials and their impact, and that we would take that up in the next phase. They reached a consensus that the processes and structures would become the foundation for sustaining the project, and that, therefore, the evaluation should examine these aspects in depth.

For the final evaluation, the evaluator used a qualitative methodology that included eight in-depth guided interviews with key informants, an examination of relevant documents and some participant-observation of the Steering Committee. His recommendations were based on the assumption that the Health Literacy Project would continue in some fashion, even if funding is not found to hire staff again.

The Process

Defining health centres

The project was carried out in the three units that had participated in Phase 1: Dialysis, the Pre-Operative Centre and the Haematology/Oncology Clinic. These units had been identified by the Health Literacy Steering Committee because significant nursing time is spent teaching patients complex and vital health information. Two of the units work with chronic care patients which could potentially allow for long-term follow-up in later phases of the project.

The initial vision of the Health Education Centres was of unit-based centres that would meet both the health education and consumer health information needs of hard-to-reach patients. The Centres would provide the expertise for selecting or developing new materials, using plain language and clear communication techniques. They would also provide the setting for planned group activities and support groups. It was anticipated that, eventually, the Centres would become part of a system of MUHC resource centres for health information that would be available in multiple formats to address a wide range of learning needs.

As Phase 2 was the first stage of what has been conceptualized as a long-term project, the Steering Committee began by asking which parts could be implemented immediately and within the time constraints of this phase. As a beginning, the project coordinator analyzed a cancer, dialysis and surgical patient's pathway through the medical system, and found that they encountered health information in a variety of places and times. These could be at a patient's bedside, in a doctor's office, or in a quiet room with a nurse, during direct teaching sessions. The location of the centres would depend on where patients encountered health information and who delivered it. After much consideration, The Steering Committee decided that during this stage there was a need for flexibility in defining a Health Education Centre. This led to changing the idea of centres from actual spaces to vehicles for providing services to the hard-to-reach. By taking a metaphorical approach and viewing the centres as a collection of *services* to hard-to-reach patients, the Committee could begin to implement smaller pieces of the vision without delay. This meant re-allocating some of the budget away from the purchase of equipment and physical resources and towards training to ensure local expertise.

Nevertheless, for future reference, in the event that the concept of physical sites was reconsidered, the project coordinator asked health care professionals in each of the three units the hypothetical question, "If a Health Education Centre were to be located in your unit, where would it be?" The main point to emerge was that a "one size fits all" approach would not work. Each unit had unique concerns and limitations, based on both the health care needs of patients and the physical lay-out of the unit.

Forming Health Committees

Health education committees, formed in each of the three units, consisted of three to five members, including the project coordinator, a health care professional from the Steering Committee, and a patient or family caregiver. The three committees met a total of 25 times over several months and each decided on one key health message that would be used in their unit to develop patient information in a variety of formats and media in an effect to inform the hard-to-reach.

Creating patient materials

Between March and May, three health messages were developed into teaching materials for hard-to-reach patients. In Oncology/Haematology, a poster storyboard outlined the 10 steps in a patient's first day in chemotherapy. A member of the health education committee (who was also a hospital volunteer) portrayed a patient on her first day in the Chemotherapy clinic. In Dialysis, a health message about MRSA infection was delivered via posters and pamphlets adapted to easy-to-read formats. In the Pre-Operative centre, the health message was about managing pain using a device called the IV-PCA pump. The print materials, written in plain language in English and French, were designed in different formats and colours. The Pain Management pamphlet was translated into Spanish and Simple and Traditional Chinese. Audio versions for patients were recorded in five languages – English, French, Spanish, Mandarin and Cantonese. In all, 24 versions of the three items were created.

Patient feedback on simplified materials

Although there was no provision for formal evaluation of these materials at this stage, the coordinator worked with the unit nurses to gather informal feed back from twenty-seven patients and eight family members about how useful they found the materials. She concluded that the concept of "hard-to-reach" is too broad, touching on many barriers to understanding health information, ranging from low reading skills to complicated cognitive problems. Linguistic, physical, and cultural barriers may also play a part in preventing access to information. What may work for one group of patients, may not work for another. Working with such an undefined concept made identifying a hard-to-reach patient problematic. The nurses' decisions about informants were based on their observations of linguistic barriers (i.e. English or French as a second language) or an instinctive feeling that a patient did not grasp health information, even in their first language. Of the informants, nine were loosely identified as hard-to-reach -- seven by the nurses and two by the project coordinator.

Lacking a framework for identifying the hard-to-reach made it difficult to correlate patient reactions to specific communication barriers. Still, the coordinator found that feedback from patients and their families offered "a tantalizing glimpse" of some of the communication problems they face.

Feedback from patients and family members was gathered in an informal manner. Patients and family members were approached in the waiting areas of the three units and asked for their general impressions of the print materials. Input was voluntary and anonymous. They were asked to comment only on the print material created for the unit they were in, not on the materials for other units. Only the English and French versions were shown. Feedback on the Spanish and Chinese translations, as well as the multi-lingual audio-recordings, should be carried through in the next phase of the project. The coordinator left notes on all interviews, but provided more detailed observation and feedback from the patients identified as "hard-to-reach."

She found that patients who did not speak either English or French paid little or no attention to visual materials on the walls, and suggests that this underlines the need for multi-lingual translations of key information. It also calls into question the role of visual cues and their ability to attract attention and convey information if there is a language barrier. She also found that some patients whose mother tongue is neither English nor French may have a functional knowledge in either of these two languages; this can deceive nurses who may over-estimate what the patient understands. For example, a dialysis patient, who spoke English as his second language, read the MRSA pamphlet, but did not know the word "pneumonia," one of the potential effects of an MRSA infection. He had never used this word in English. Once explained, he understood.

Sometimes the line between a linguistic barrier and another type of communication barrier was not clear. The husband of a chemotherapy patient identified as hard-to-reach for linguistic reasons looked at the storyboard, *A Day in Chemotherapy*. Like his wife, he spoke little English or French. He looked at each board carefully, but not in sequence. His only reaction was a nod of the head. It was not possible for the coordinator to know within the framework of the informal feedback process why he did not follow the sequence. She wondered: Was it because the words were not in his native language? Was it a sign of a sequencing problem - a learning problem? Did he lack basic reading skills - following text from left to right being an essential basis for reading the Roman alphabet? In further discussion, the Steering Committee wondered whether there might have been something in particular posters that attracted his attention. Whatever the reason, he was not receiving the message that was intended.

The feedback uncovered cognitive barriers in a patient who had had a stroke and visual impairment among some older patients who chose the simpler messages in larger typeface. The coordinator noted that new patients in Chemotherapy were so anxious that they never looked at the wall display until it was pointed out to them; returning patients, however, commented positively on the materials.

This raises the question of the role of mediation in conveying health messages. Simply relying on print or visual cues without showing or giving explanations may not be effective. Several feedback sessions seemed to indicate the importance of direct intervention.

Overall, the majority preferred the new materials, but it was not clear that plain language or visuals necessarily made information more accessible for the hard-to-reach. This will have to be investigated more thoroughly in the next phase.

Evaluation

Health committees

The evaluator found that interviewed members of the participatory health committees had a strong sensitivity to the communication needs of patients in their respective units. He could not tell if this was a reason for their recruitment or if it had developed during their participation in the committee. He noted that some members were former health care professionals or professionals in other fields, and that while they cared deeply about this issue, they were not necessarily representative of the average patient, let alone the hard-to-reach. One non-health care professional committee member told him that, as time went on, she became more and more aware of the importance of reading messages, signs and posters that abound in the MGH and in other hospitals, and more critical of the small typeface or the complex language used in published documents and posters.

The evaluator found that decision-making processes appear to have been very inclusive, with non-health care professional committee members actively participating at each stage. Every person interviewed stated that he or she participated freely in all decisions taken when he or she was present and felt that the tools produced by each committee proved that the advice that they had given was taken into consideration. None felt that their participation was merely token.

The frequency of meetings varied. All members attended meetings at least once, but absenteeism was high, generally related to health problems or jobs.

Review, purchase, creation of materials

Review of existing information and training tools showed very few materials appropriate for hard-to-reach patients or adapted to special needs.

In each unit, documents were adapted to Plain Language in English and French based on decisions and input from the Education Committees. The criteria used to choose the topic to be adapted or developed included being common to all patients in the unit, having an impact on the greatest number of patients, and being a fundamental prevention issue. Patients were surveyed during the draft stage of production.

The languages chosen for translation were different from those named in the objectives. This change was based on profiles of patients in the three units.

While some materials were purchased prior to the arrival of the project co-ordinator, this objective was informally suspended afterwards for several reasons. These included a growing ambiguity concerning the notion of “hard-to-reach” and the related difficulties in

establishing selection criteria, as well as concern over impact on budget. The identification of programs and interactive activities suitable for hard-to-reach patients was also informally suspended primarily because of the ambiguity concerning the notion of "hard-to-reach." The co-ordinator did, however, identify many possible places to look for appropriate programs and models. She also suggested taking a deeper look at the existing infrastructures in the different units and considering better utilisation of underused assets.

Ensuring continuity

Other funding sources were identified and proposals were written by The Centre for Literacy and submitted to various potential funding sources. The MGH Foundation gave the Health Literacy Project a small grant for 2002-2003. The Centre for Literacy of Quebec has committed matching funds for specific purposes such as training for nurses and the cost of a "one day a month" plain language editor for the Nursing Department to review the language, organization and layout of new written documents.

Training

Awareness training included visits by five health care professionals and The Centre for Literacy's director to the Hospital for Sick Children and the Princess Margaret Hospital Health Education Centres, Toronto, Ontario. This gave them a basis for comparison. One participant described it as "an eye-opener." Skills development training involved two health care professionals and The Centre for Literacy's executive director in a Health Literacy Institute in Albuquerque, New Mexico; this resulted in a greater sensitivity to the communication needs of hard-to-reach patients and their families. One nurse commented, "I realise now, by watching some patients and by being exposed to the idea of low literacy or hard-to-reach patients, you know, we overwhelm them so, we give out information but we are realising that it's maybe not tailored to the hard-to-reach." The three participants made a commitment to facilitate training sessions for colleagues at the hospital.

The evaluator noted the excellent results of these training activities. Each health care professional who participated (with one exception) was actively engaged in both the Steering Committee and the Health Education Committee of her unit. They also demonstrated a remarkable sensitivity to the communication needs of patients and their families in general and to those of hard-to-reach patients in particular. According to one health care professional interviewed, this training had sparked a paradigm shift of sorts among some personnel in her unit, moving from a paternalistic attitude when communicating with patients to a more empowering one. The evaluator suggested, "The appropriateness of the training offered is such that it should be offered to anyone playing a leadership role on either the Steering Committee or the Health Education Committees as well as to any future management staff."

Training was also offered for health care professionals not working on the project. These included three 45-minute presentations to the nurses who were interviewed or who

participated in focus groups during Phase 1, summarizing the results of the Needs Assessment. A one-day Communication Skills workshop in collaboration with the Nursing Practice and Quality Improvement Council (PQIC) was held in March. Awareness Training in Clear Communication was offered through three 45-minute presentations for nurses in each unit who could not attend the one-day workshop. In addition, the project co-ordinator made two presentations to the PQIC. These short strategically focussed presentations allowed for greater interaction between the health care professionals who actively participate in the Health Literacy Project and other staff and volunteers throughout the MGH, since they now have a common understanding of some of the rudiments of health literacy. They also seem to have been an excellent promotional tool for the Health Literacy Project.

Dissemination of information within the hospital

The original plan to write bulletins was replaced by the development of a Health Literacy page on the Nursing Web Site on the MUHC Intranet. A text on health literacy was produced and posted. Nevertheless, the evaluator felt that there was not a true dissemination strategy.

Dissemination of findings to key partners

Two articles were written by the director of The Centre for Literacy during Phase 2. One on health literacy was posted on the Web site of the ALNARC (Adult Literacy and Numeracy Australian Research Consortium).[1] Another on health literacy and hard-to-reach patients was published in an issue of *Literacy Across the CurriculuMedia Focus* (Vol.16, N° 1, pp. 15-16), a bulletin published twice a year by The Centre for Literacy. In addition, this project has been cited in other research articles in Harvard's *Focus on Basics* and in the Canadian Health and Literacy Research Project currently being conducted by the Canadian Public Health Association. A report on the project is being printed and posted on the web sites of both The Centre for Literacy and the MGH Intranet.

Potential partnerships

The coordinator produced a list of potential partners and noted the many initiatives that could be pursued, such as forming partnerships with the Canadian National Institute for the Blind, with other hospitals that have specific programs meeting one or more of the needs identified, or with the many cultural communities whose members use the MGH. The Steering Committee has many contacts and suggestions to carry into the next phase.

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1 See: http://www.staff.vu.edu.au/alnarc/onlineforum/AL_pap_shohet.htm#Abstract.

Issues

The evaluation noted the difficulty of scheduling meetings of the health education committees at convenient times and within the workday of health professionals. Gender balance was a further concern. Membership on the Steering Committee is entirely female, and the Health Education Committees were predominantly female.

The structure of the committees was thought to be too informal, and advice was to formalize mandate, structure and function. There was some concern about the danger of losing the main focus on the hard-to-reach. The relationship between The Centre for Literacy and the MGH was also not considered to be formal enough at this stage.

Conceptually, the need to define the boundaries of "hard-to-reach" was identified as central to ongoing work. The evaluator summarized his recommendations as follows:

Selected Recommendations from the Evaluation Report

Clarification of concepts

- Attempt to clarify the notions of "hard-to-reach" and "health literacy" as soon as possible, using the knowledge gathered in the first two phases of the project to produce the foundation for a conceptual framework. If funding is obtained, undertake research to complete whatever is missing.

- Define the meaning of a health education centre and decide whether or not those set up by the Health Literacy Project will occupy a specific space in each unit.

Organization

- Clarify the status of the Health Literacy Project: A decision should be made about whether it will be autonomous from The Centre for Literacy; if it is, then legal status, mission, membership and governance mechanisms will need to be determined in such a way as to ensure the predominance of its literacy objectives.
- Find a mentor, either volunteer or paid, within the Montreal General Hospital's management, to act as a key informant about what is going on in the hospital.
- Integrate into the project's strategic planning some flexibility to accommodate the hospital's ever-changing organizational structure.

Steering Committee and Health Education Committees (These have been combined where identical)

- Determine the roles and responsibilities of the Steering Committee and Health Education Committees, including their relationship with one another, and communicate these to its members.

- Establish more formal meeting procedures while keeping them as simple as possible.
- Foresee appropriate training and support when sensitivity to the communication needs of patients and families is not a selection criterion of committee members.
- Provide all non-health care professional committee members with particular support to assist them in voicing their opinions during meetings.
- Consider recruiting "external" members whose principal concern is literacy, especially for hard-to-reach patients and their families.
- Make an effort to recruit at least one man to the Steering Committee.

Specific to Health Education Committees

- Consider increasing the number of non health care professional committee members to ensure attendance and continuity.
- Attempt to include at least one member who is or has been a patient in the relevant unit and who is not and who has not been a health care professional.
- When meetings are held during lunch hours, if attendance becomes a problem, consider defraying the cost of meals to encourage participation.
- If and when medical issues are involved in the execution of tasks by volunteers who are not active health care professionals, have their work reviewed by a health care professional member of the Health Education Committee.
- Include, in future budgets, a line item for professional clinical approval of materials developed in the project.
- Until the organizing of the Health Education Committees is completed, avoid attempts to measure the effectiveness of the strategies used to improve patient education.

Activities

- If creating teaching modules remains an objective in the next phase of this project, build as much as possible upon the conceptual framework produced in the first two phases of the project and with whatever research is available.
- In the next phase of this project, consider the production of a print document or more in each unit, adapted to Plain Language in English and French and translated into other languages, without waiting for a complete conceptual framework.
- Do research in medical journals and on the Internet before committing resources to the production of completely new materials.
- Consider translating some of the existing print and audio-visual materials that are available at no cost from certain foundations, associations and corporations, but often only in English.

Training

- Offer awareness and skills development training to anyone playing a leadership role on either the Steering Committee or the Health Education Committees as well as to any future management staff.
- Continue to offer short awareness and skills development training sessions to health care professionals and volunteers working throughout the MGH and who are not actively involved in the Health Literacy Project.

Challenges

This project was complex and challenging. A gap between the funder's fiscal year and the project structure, and delay in release of funds can create challenges for many organizations in the not-for-profit sector and for funding consultants overseeing projects. Trying to carry out the project for best outcomes was often difficult within the strictures of the time line. The evaluator talked about the need for greater flexibility in the next phases of this project. This can be hard to achieve when working within a rigid funding mechanism.

Additional challenges were created by the project being based in a hospital which was undergoing structural change and reeling under the stresses in the healthcare system, including a severe shortage of skilled professionals, especially nurses. This meant that committee members could sometimes not get to meetings, or in one case, could not travel to a training session. It has also meant that people are changing jobs and moving between institutions more than normally, so knowledgeable people are regularly being lost. The shifting structures plus the extreme lack of physical space made it difficult for an outside coordinator to find working space inside the hospital. Although the level of commitment from the Nursing Department was very strong, the coordinator was often frustrated and overwhelmed by bureaucracy when she needed a telephone or a desk.

Despite these challenges, this project was engaging and achieved more than anticipated, opening new questions about patient interventions that should resonate across the Canadian health care system.

The Next Steps

The Health Literacy Project is continuing at a slower pace while the Steering Committee awaits response to funding proposals for the next phase. In the fall of 2002, the Steering Committee has already acted on some recommendations:

- They have begun to formalize the meeting procedures of the committee and are discussing its mandate and membership.
- They have put the development and maintenance of the Health Education Committees on hold because there is no paid coordinator. The Committees have been included in

the new proposals, and the recommendations regarding the composition and function will be taken into account when they are revived. The model of participatory health committees is one of the achievements of this project, even if the model is not yet perfected.

- They have voted to allocate the MGH Foundation grant to hire a researcher to do in-depth evaluation of the materials that were created in Phase 2.
- The Director of Nursing Research has agreed to help with the design of the research.
- The Director of Communication for the MUHC has indicated interest in training around health literacy and clear communication for the entire organization.

Conclusion

This innovative project is being cited in Canada and internationally as a groundbreaking example of a professional-community partnership that is crucial to our understanding of the complexities in patient communication and the relationship between literacy and health. The integration of participatory health committees and the process of continuous evaluation are fundamental to the outcomes that were achieved and are being shared.

The Steering Committee began by presuming that the "hard-to-reach" were only a minority, and now think that these individuals may represent a significant proportion of the Canadian population. They believe that projects such as this one will eventually help change the nature of communication in the health care system and heighten awareness of the links between literacy and health.