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AUTHOR Shohet, Linda
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ABSTRACT

The concepts of literacy and health have been evolving and broadening, and interest in the connections between the two has been growing in Australia and elsewhere. However, the scope of practices related to health literacy in the health fields and in the adult literacy education field have remained fairly static. Research has identified the following levels of health literacy and related educational goals: (1) functional health literacy (communication of information); (2) interactive health literacy (development of personal skills); and (3) critical health literacy (personal and community empowerment). Driven by the focus of research, the medical system has responded in two main ways to the difficulties of low-literate patients accessing health information and health education. One has been to develop instruments permitting rapid measurement of patients' literacy levels, and the other has been to assess the readability of medical information and rewrite it in plain language. Health materials have long been part of literacy and English-for-speakers-of-other-languages curricula in Canada, Great Britain, and the United States. Research and policy initiatives in those countries can serve as models to Australian medical service and literacy education providers interested in developing and implementing health literacy collaborations. (A bibliography listing 35 references and an annotated listing of 7 World Wide Web links are included.) (MN)

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ED 473 575

Paper Title Health and Literacy: Perspectives in 2002

Author Linda Shohet: The Centre for Literacy of Quebec (Montreal, Canada)

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Abstract

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The concepts of literacy and of health literacy have been evolving and broadening, and interest in the connections between the two has been growing. However, the scope of practices related to health literacy in the health fields and in the adult literacy education field have remained fairly static. There are indicators that in the current decade, there may be more movement to consolidate our knowledge, to form partnerships and to integrate literacy and health initiatives. In this paper, I first want to develop a discussion about the links between literacy and health as they are currently represented in the discourse communities of the medical profession and of adult literacy. The definition of the terms "literacy" and "health literacy" underpins the research carried out in these communities and the policies and practices recommended in each. After comparing the positions taken by the medical field and the adult literacy field, and examining some selected government policies, I will outline some directions for the future and assume that respondents to the on line discussion will take this much further than I have.

Introduction

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For the sake of finding a point of entry to a complex topic, let me generalize by saying that most adult literacy practitioners who are concerned with health literacy have a primary goal of helping their students improve their literacy and take better control of their lives, including their health. Most health practitioners are focused primarily on better health outcomes for their patients, a much larger group than that of literacy learners; as poor literacy has been shown to be an impediment to that end, they seek ways to work around the problem. Between these poles are a variety of innovative practices, but they are scattered and often short term. A challenge to both the literacy and health fields is to create policies that recognize health literacy as part of the requirement for the well-being of a population; another is to find ways of merging and integrating practices to better meet the goals of both fields, and above all, to serve adult learners as well as the broader citizenry.

While the general concept of literacy has been broadening and demand increasing over the past thirty years, there is still considerable division over practice in adult literacy, depending on the academic orientation, implicit or explicit, that shapes practitioners' work. While the school of New Literacy Studies situates literacy in the realm of social and cultural practices and explores the concept of multiple literacies, reading specialists maintain a narrower focus on reading and writing skills. Another strand comes from the disabilities fields where literacy is

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linked to various cognitive and physical disabilities that create a category of citizen now being named "print-disabled" (Gayda, 2002). Yet another strand comes from the field of second language acquisition as the line between mother-tongue adult learners and second-language learners is blurred in many programs. A recent study found that many American adult literacy teachers did not distinguish clearly between these groups and could not make the further distinction between ESOL learners who were highly literate in their own mother-tongue and those who were not (Purcell-Gates et al). As a further backdrop to this discussion, large-scale government policy development in OECD countries has been built on the findings from the international adult literacy surveys of the past decade. The surveys have worked from a definition of literacy that applies to personal, work and community goals; they have, however, focused on print literacy despite widespread acknowledgment that electronic media are changing the nature of literacy and forcing a convergence of print, the visual and the oral. Many policy initiatives are caught between the political demand for quantifiable, measurable outcomes, and the recognition that literacy is a complex multifaceted issue that cuts across many domains.

Defining Terms



Selected definitions of health literacy

From The National Network of Libraries of Medicine, South Central Region:

Health Literacy is defined by the National Health Education Standards (Joint Committee on National Health Education Standards, 1995) as "the capacity of an individual to obtain, interpret, and understand basic health information and services and the competence to use such information and services in ways which are health-enhancing." This includes the ability to understand instructions on prescription drug bottles, appointment slips, medical education brochures, doctor's directions and consent forms, and the ability to negotiate complex health care systems. Health literacy is not simply the ability to read. Health literacy requires a complex group of reading, listening, analytical, and decision-making skills and the ability to apply these skills to health situations. Literacy varies by context and setting and is not necessarily related to years of education or general reading ability. A person who functions adequately at home or work may have marginal or inadequate literacy in a health care environment. (Sullivan, 2000, <http://nnlm.gov/scr/conhlth/hlthlit.htm#Definition>)

From The World Health Organization

Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health. Health literacy means more than being able to read pamphlets and successfully make appointments. By improving people's access to health information and their capacity to use it effectively, health literacy is critical to empowerment. (WHO, 1998)

From World Education

Health literacy is the ability to read, understand, and act on health care information. Studies estimate that almost half of American adults do not have the skills to meet their needs for health care information. The Health & Literacy Special Collection is a Web-based resource for adult educators and health educators who are trying to bring clear and easy-to-read health information to low literate populations. It contains health curricula for literacy or ESOL classes, links to health information in plain English and languages other than English, and information about health literacy. The Health & Literacy Special Collection is maintained by World Education, with support from the National Institute for Literacy (NIFL) and its LINC project. LINC is a national effort to provide Web-based resources for adult literacy practitioners. (www.worlded/projects_topic_7.html)

From the Massachusetts State Adult Basic Education System (SABES)

The Massachusetts Comprehensive Health Program is based on the belief that adult literacy programs are more effective when they tie learning to issues that are meaningful to adults. Health is an issue of critical

importance to adults, whether it relates to their personal health, to that of their children or parents, or to the availability and quality of health services in their communities. Through using a participatory model of health curriculum development, programs have strengthened learner/teacher partnerships, promoted student leadership, and enhanced learning through the creation of meaningful and relevant curriculum. This, in addition to facilitating collaborations with locally based organizations and health care providers, has enabled health education to reach far beyond the classroom to family, friends and community.
(www.sabes.org/health/index.htm)

Health literacy is a relatively new term that is also defined more or less broadly [See four definitions above; two from health organizations, and two from adult literacy organizations]. Articles on health literacy have used the terms "literacy", "functional literacy," "health literacy," and "functional health literacy." The earliest definitions focused narrowly on an individual's capacity to read and comprehend medical information and instructions. An expanded concept highlights that literacy, through facilitating access to information, enables individuals to make informed choices, to influence events and to exert greater control over their lives (Nutbeam, 1999). This concept is tied to a participatory empowerment philosophy that has been a continuing strand in the adult literacy field (Wallerstein & Bernstein, 1994; Hohn, 1998, 2002; Norton & Campbell, 1998; Perrin, 1998; Nutbeam 1999; Centre for Literacy, 2001).

Nutbeam has identified three levels of health literacy that reflect increasing degrees of autonomy and personal empowerment: functional health literacy, interactive health literacy and critical health literacy.

Health Literacy Level and Educational Goal	Content	Outcome: Individual Benefits	Outcome: Community and Social Benefits
Functional Health Literacy: Communication of information	Transmission of factual information on health risks and use of health services	Improved knowledge of health risks and health services, compliance with prescribed actions.	Increased participation in populations health programs (screening, immunization)
Interactive Health Literacy: Development of personal skills	As above, including opportunities to develop skills in a supportive environment.	Improved capacity to act independently, improving motivation and self-confidence to act on advice received.	Improved capacity to influence social norms, and interact with social groups.
Critical Health Literacy: Personal and community empowerment	As above provision of information on social and economic determinants of health, and opportunities to achieve policy and/or organizational	Improved individual resilience to social and economic adversity.	Improved capacity to act on social and economic determinants of health, improved community empowerment.



Condensed version of Nutbeam's classification created by researcher Odette Langlais(Centre for Literacy 2001)

While the chart lays out distinct divisions, health literacy practice is often based on a mixture of two or all three concepts. However, as Nutbeam noted, critical health literacy remains the exception. While he suggested that the interactive health literacy model is currently the dominant one, this too varies by field. The medical literature generally reflects a strong emphasis on the functional.

Health Literacy in the Medical Fields



Literature in the health communication field began in the 1950s and earlier to recognize the needs of poorly educated patients and of people who did not speak the dominant language of the country and who brought different cultural perspectives. These early articles did not use the term "literacy." Like most professionals, health care providers read mainly within their own area of specialization. Therefore, it is highly unlikely that many health care providers would have been aware until quite recently that colleagues in another specialty were discussing the same issue in different terms. In the past three decades, articles about the links between health and literacy have been increasing in both medical and adult education literatures. In medical fields, they have appeared in journals of nursing, public health, medical associations, nutrition, gerontology, as well as in journals devoted to specific diseases such as diabetes, cancer, heart and lung, arthritis, asthma, and many others.

A 1999 survey of professional journal articles published in the medical and public health fields between 1970 and 1999 turned up 11 in the 1970s, 37 in the 1980s, and more than 200 in the 1990s. (Rudd, Moeykens & Colton, 1999 b). Also, in 1999, The Council on Scientific Affairs of the American Medical Association mandated an Ad Hoc Committee on Health Literacy to produce a report on the scope and consequences of poor health literacy in the US, to characterize the implications for patients and physicians, and to identify policy and research issues. The Committee reviewed 216 published articles written between 1966 and 1998 as well as unpublished manuscripts, and telephone and internet conferencing. They concluded:

Patients with inadequate health literacy have a complex array of communications difficulties, which may interact to influence health outcome. These patients report worse health status and have less understanding about their medical conditions and treatment. Preliminary studies indicate inadequate health literacy may increase the risk of hospitalization. Professional and public awareness of the health literacy issue must be increased, beginning with education of medical students and physicians and improved patient-physician communication skills. Future research should focus on optimal methods of screening patients to identify those with poor health literacy, effective health education techniques, outcomes and costs associated with poor health literacy, and the causal pathway of how poor health literacy influences health.

(<http://jama.ama-assn.org/issues/v281n6/abs/jcn80003.html>)

Most of the more recent medical articles start from the national surveys finding (NALS and IALS) that close to half of North American adults have some difficulty with the printed word. Most are written from the perspective of the health care provider seeking better compliance and improved health outcomes on the part of patients.

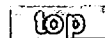
The scope of the medical/public health research has remained narrow, primarily on the reading level of materials; patient comprehension; the match between patients' abilities and reading materials; the utilization of services; and, in the past three to four years, health outcomes related to literacy levels. The focus has been on comprehension; effective functioning; adherence/compliance; use of available services; and health outcomes. These have generally been examined only in the context of medical encounters, usually without acknowledging the vast array of tasks, besides accessing information, involved in a medical encounter (Rudd, 2000 b).

The literature has focused considerable attention on the needs of seniors who were shown in surveys to be among populations with the lowest levels of literacy. Some studies, such as one by the Canadian Council on Social Development, have considered this from the perspective of a social justice issue (Roberts and Fawcett,

1998). IALS corroborated other research demonstrating that literacy skills are lower among seniors who are also the most frequent users of health services (Walmsley, 1982; Williams, 1995). Low-literate seniors are less likely to obtain health information from a wider selection of sources than their more literate counterparts, and a large number of senior citizens overestimate their literacy abilities.

Driven by the focus of the research, the medical system has responded in two main ways to the difficulties of low-literate patients accessing health information and health education. One way has been to develop instruments to rapidly measure the literacy levels of patients; the other has been to focus on assessing readability and rewriting medical information in plain language.

Testing Patients



There are several tests in use. One commonly used reading test, the Rapid Estimate of Adult Literacy in Medicine or REALM, consists of three lists of increasingly difficult words to read. Each list contains 22 words taken from medical terms. The REALM can be administered in five minutes. Its results give a grade range estimate that generally indicates to health care professionals the appropriate level of health material. A longer version of the REALM test uses 125 common medical terms (Davis, et al., 1993). An older test instrument is the Wide Range Achievement Test or WRAT. Its reading portion is similar to the REALM but it also includes portions that assess writing and numeracy skills. A third instrument is the Test of Functional Health Literacy in Adults or TOFHLA which measures ability to complete basic reading and numeracy tasks required to function in the health care setting. This test is limited as a rapid screening tool because it takes 22 minutes to complete. Health literacy pioneers have recommended that patients who score at 6th grade or higher on the WRAT or REALM be given a Cloze test filling in the blanks in a short passage dealing with medical information (Doak, et al., 1996, p.35).

There are however significant barriers to assessing patient literacy. Most health provider are not trained to do this type of assessment, and even if they were, they rarely have sufficient time to administer tests. A recent study in a Montreal hospital showed that many health care providers were reluctant to give literacy tests (Centre for Literacy, 2001). Direct assessment can be embarrassing and increase anxiety for the patient (Brez & Taylor, 1997). Research has also demonstrated that there can be a gap between level of instruction and functional literacy level. A patient's level of education is not always an accurate indicator of literacy level. Over time, reading skills can diminish without practice. In the US, many adults have been found to read 3 to 5 grade levels below the last level of education completed, and some low-literate patients have claimed on hospital intake forms to have a higher level of education than they actually had. The Montreal study, searching across Canada, did not find hospital forms that even asked patients for information about their education.

Where hospitals have decided to use tests, there are still limitations. A patient's ability to understand a word does not necessarily mean that she understands the significance of the instruction that includes that word. A patient may be able to read all the words in a sentence without fully comprehending its meaning. Tests, such as REALM, assess only the capacity to decode but not comprehension skills. In all the definitions of health literacy, patients are expected to understand and apply health information.

Plain Language



A more common response of the medical establishment has been to evaluate the readability of health materials such as pamphlets, booklets, basic medical instructions and self-care information and to recommend the use of plain language. Many articles in medical journals repeatedly confirm that health education material is written at a level far above average patient reading ability. A typical suggestion is that health education materials be written at three grade levels below the educational level of the target population. Researchers generally recommend that health materials be written at a 5th or 6th grade level.

A US-developed evaluation model for health materials entitled SAM or Suitability Assessment of Materials (Doak, et al., 1996, p.49) rates factors such as content, literacy demand, graphics, layout and typography, learning stimulation and motivation, and cultural appropriateness. For each factor, SAM assigns a numerical score, the weighting of which leads to a rating of superior, adequate or not suitable.

The consensus is that to be effective, patient education materials should include short and simple information, be written in simple language, contain culturally sensitive graphics and focus on the desired behavior of the patient (Mayeaux, 1996). Many organizations train professionals to use readability formulas such as the FOG or the SMOG.

Studies in the United States and Britain have suggested that plain language writing saves money. The next step after assessing materials is to rewrite them.

The use of plain language in written health materials has also been promoted as a tool for creating more open lines of communication between patients and the health care system. In Canada, the Canadian Public Health Association (CPHA) via its National Literacy and Health Program has been a champion of plain language through its publications, conferences, training programs, directories, and advocacy to more than 20 medical partner associations. They have produced guidelines on assessing materials and on producing plain language materials. They do acknowledge, however, that while more Canadian health education material is written in plain language, its use is uneven across Canada, within regions, and even within large health-care centres.

Many writers offer concrete and useful tips on how to present information, how to design visuals and how to choose appropriate language (for example, Doak, et al., 1996; Mayeaux, 1996). In the US in particular, there is a small industry growing up around assessing and re-writing health materials.

Many researchers, however, question an over-reliance on plain language in health education to address the issue of low-literate patients (Perrin, 1998; Hohn, 1998, 2002; Rudd 2000b, 2002). A recent Health Canada profile paper suggests:

Plain language is a useful step but not the answer. Presenting written health information in easy-to-read, rather than complex, technical language, is undoubtedly a useful step... Plain language is not the primary solution to addressing the health difficulties associated with literacy. As the CPHA has indicated, written information should be secondary to verbal communication and should only supplement the exchange between physician and patient. Personal contact between patient and physician is the best way to ensure the transmission of a message. (Perrin, 1998)

American researcher adult literacy practitioner Marcia Hohn also criticizes the over-reliance on plain language but looks beyond the individual patient-physician relationship. She sets health literacy in the context of community dynamics and group participation.

Some researchers focus on an array of strategies for effective patient education, such as better oral communication between patients and health care professionals, better training for health care professionals and developing more non-written means of communication, although this is less common in the literature than information on plain language. Perrin argues for the need to make health information available in other formats and media than via the written word. Health information alone, he suggests, is not sufficient for individuals with low literacy skills who often feel powerless to make changes in their lives. Combining easy-to-read written patient education materials with oral instructions in simpler language has been shown to greatly enhance patient understanding (Mayeaux, et al, 1996). Yet, there has been almost no research on the links between low literacy and oral understanding, or on the impact of verbal and non-written interventions (Rudd, 2002).

The training of health care providers is also discussed and case studies are cited. In the state of Maine, a model for teaching oral communication skills to health care providers who deal with low-literate adults was developed in partnership with their largest rural health centre delivery system (Plimpton, 1994). The CPHA emphasizes clear verbal communication. More web sites are appearing with references and guides for health care providers [See web sites at the end of this article.]. The literature does touch on the need to develop non-written means of communication, including audiovisual materials, storytelling, and drama. Guides exist on how to assess and produce effective health education videos.

The literature, looking to good adult education practice, stresses that adults learn best when information is

relevant to their lives, when they know the purpose of the information in their lives, when they have a specific educational plan or program and when evaluative feedback is given. Motivation to learn may be enhanced by involving family members in the patient education process and giving feedback. The need for sensitivity to cultural differences in health care is frequently cited.

Despite these interests, there are more queries posted about plain language and readability to a National Institute for Literacy (NIFL) health literacy listserv than about any other topic. The moderator recently asked subscribers why they thought there was so much attention focused on this topic, and received very few responses. I would suggest that it is at least partly because assessing materials and re-writing them is easier to do than engaging in some of the other suggested changes, and there is a tangible product at the end.

Adult Literacy Practice and Health



Health materials have long been part of literacy and ESOL curricula, and there are many models of effective collaboration between health educators and adult educators both in terms of developing materials and integrating them into adult education programs. These practices have been actively supported by a number of national health organizations in the US, and many individual teachers have seen a natural connection between helping their students improve their language skills while learning about health issues that could improve the quality of their lives. Still, despite the many initiatives, a survey by the National Center for the Study of Adult Learning and Literacy (NCSALL), found that teachers and programs directors were cautious about teaching health content when they lacked expertise. (Rudd, 2002).

Another way of working toward the goal of integrating health and literacy learning is through focusing on health action in classes. Community development approaches and participatory health education offer alternatives to a focus on content (Perrin, 1998).

Working on the premise that low-literate individuals often their health information from people around them rather than from health experts, it makes sense to look at community groups and how established community networks can become involved in health literacy efforts. In this model, health care professionals change their role and become facilitators, working in partnership with others in the community to provide health information by tapping into existing community networks, peer groups, social support networks, etc. A 1994 US study showed that using a peer-helper approach and community volunteers was a more effective way to reach out to older, low-literate women regarding health than using traditional and educational approaches.

There are also examples of programs where participatory pedagogy has been used to engage literacy students in a reflective process, discussion and action concerning health issues. This process involves the active participation of literacy students or patients within a group process through which they identify health issues that concern them, explore them, develop the content and the methodologies for sharing information, and take action in the community. Health specialists play the role, not of experts but of human resources who share knowledge with the group. This participatory process enables students/patients to gain confidence and to take more control over their health and their lives.

Empowerment education allows people in group efforts to identify their own problems, critically analyze the cultural and socio-economic roots of the problems and develop strategies to effect positive changes in their lives and in their communities (Wallerstein, 1994). Empowerment becomes the strategy to address the lack of control that characterized individuals in positions of perceived and actual powerlessness. This is achieved through greater participation in community actions, a stronger sense of community, vibrant social networks, promoting a belief in people that they can control their environment and through actual socio-economic changes.

One of the most sustained examples of this type of health literacy education has happened in Massachusetts in a program called Operation Bootstrap that has been documented by Marcia Hohn, a pioneer in this area. Hohn insists that an empowerment process must include direct teaching by peers; a safe and respectful atmosphere to ask questions and talk culture; and creative and inclusive methods. It starts from the reality of learners' lives, their issues, problems, challenges, cultures and aspirations. Involving participants in the development of learning

materials is often used as a strategy. The final product reflects both the reality and the language of people in the community (Hohn, 1998).

A thoughtful example of a participatory health education process comes from the Learning Centre Literacy Association based in Edmonton, Alberta. Following a series of participatory health literacy education workshops for women, the Centre produced *Learning for Our Health: A resource for participatory literacy and health education* (1998). This resource was written by and for women with the objective of empowering women. It puts participatory education in a larger context and analyses the links between health and literacy. The resource includes a series of ten workshop plans on stress, saying no, exercise, healthy weight, eating for our health, menopause, anger, STDs, living healthy on a low budget and living with welfare.

The kind of change linked to individual and community empowerment requires time. The student action health team of Operation Bootstrap began in 1994 with the full involvement of Ms. Hohn for approximately two years.

The model of Health Teams continues in Massachusetts until today. The experience of the women in the Edmonton literacy class showed that it took almost five months before some women began to speak with comfort and confidence (Norton and Campbell, 1998). That project, like most of the ones documented in the literature, was based on short-term project funding. While the resource manual is in print as a model for others, there has been no sustained funding to maintain these health learning groups. One of the great challenges for the adult literacy field in all its endeavours, including health, is to work within a framework of clear policy that provides stable (non-project based) funding for models that have been found effective.

One Model of Hospital-based Health Literacy Collaboration



The Montreal General Hospital, McGill University Health Centre, is a large urban bilingual teaching hospital affiliated with a major medical school. A large proportion of its patient population is multicultural. Many do not speak English or French as a first language, and many of them are low-literate.

The hospital has been involved in a health literacy staff development project since 1995. It began with a series of professional development workshops on health literacy for health care professionals, the product of a partnership between The Centre for Literacy of Quebec and the hospital. The Department of Nursing Staff Development, with a continuing interest in health literacy, set up a Health Literacy Steering Committee in 2000 in collaboration with The Centre for Literacy and developed the concept for a proposed Patient Health Literacy Centre to address the communication needs of low-literate patients. They undertook a two-phase study was designed. Phase 1 included a literature review/background paper on literacy and health with descriptions of all related projects in Canada, and a needs assessment of the situation at the MGH. After the literature review was completed, the concept of "low-literate" was changed to "hard-to-reach" to reflect recognition that communication barriers could have diverse causes, of which low literacy was one, and that low literacy itself could be attributed to different causes.

The Needs Assessment was to determine the health information and health education needs of hard-to-reach patients at the hospital, and to formulate recommendations for the creation of a Health Literacy Centre to improve the communication of health information and education for this group of patients. The focus was not on teaching literacy but on accommodating health communication to a segmented group of patients who likely account for half or more of the entire patient population.

The study was conducted through interviews and focus groups with 114 informants from four groups -hard-to-reach patients, members of their families, support staff and health care workers-from three units -- Dialysis, Oncology Hematology and the Pre-operative Centre. The interviews included health care workers from two affiliated community health clinics. Physicians from the three hospital units were asked to comment on a synopsis of the results.

Patients identified their primary needs as medical information about the illness; information about daily living: diet, exercise, activity level; and teaching about tests and taking medication. They wanted less information and more one-on-one communication, respect and sensitivity for themselves. Family members/caregivers wanted to know about affective impacts on the patient, about coping with the illness, about impact on family life, and about

health resources in the community. Health care professionals believe these patients need more disease-specific information, better-adapted teaching material, and an improved teaching process. They also believe that there is a core group who probably do not understand the health information currently given to them, and some who will be difficult to reach under any circumstances.

A majority of patients found that the written documents given in each unit are not directly useful to them, because they have a language barrier, or because they do not read and their caregiver does the reading for them. However, a significant number (40%) did find them useful. A majority of patients were dissatisfied with the oral communication with medical staff. Few patients receive health information from sources other than written documents and oral communication. The only other source cited by a significant number was videos. Learning with computers was not a popular option among patient interviewees.

Health care professionals need more time to assess the literacy and comprehension level of patients, and to teach hard-to-reach patients; written material available in languages other than English or French; and more posters and health videos to show and to lend. They need more funds allocated for translation, plain language writing, training health care workers and buying videos and visual materials. They did not have a clear sense of what "health literacy" means although they had heard the term.

Patients wanted an Education Centre attached to each unit in a clearly marked, easily accessible space, with all the pertinent information/services. Health care professionals wanted the Centres to offer training on aspects of health literacy.

The patients interviewed had been identified as hard-to-reach by nursing staff. However, they did agree to the interview or to participation in a focus group, which indicates that they were reachable when approached individually and accorded time and attention. Most of the health care workers felt that there is a core group of patients that is harder to reach than those with whom we met. Caregivers often play a major role as listeners and readers for these patients, and health care providers rely on that. Patients and providers differed in their assessment of patient needs. Patients expressed a need for information and good teaching, but also wanted respect and sensitivity to their concerns. While health care workers spoke about empowering patients, most of them tended to focus on giving information and validating teaching. All groups saw the possibility of health education centres filling some of these diverse needs. Like any cross-section of the population, hard-to-reach patients are hard-to-reach for different reasons; they may be low-literate, speak another language, be traumatized by lives in war-torn countries, have a physical or cognitive disability, or belong to a cultural community other than the two mainstream ones. These sub-groups have different ways of learning. One of the most provocative findings was that most of these patients do not, and do not want to, use computers. As many Canadian hospitals and health care centres are increasingly relying on computer-mediated information systems for patients, this finding is important. We will have to find ways of bridging the gap of new technologies and health information for low-literate patients (Centre for Literacy, 2001; Shoheit).

As an outcome of the Assessment, three pilot health education centres are being set up in three units, with participatory committees of health providers, patients, family/caregivers, and project coordinator guiding the development of each, based on the suggestions gathered from the first phase. Training is being designed for providers, and an evaluation process is being developed to track the impact of various interventions. Participatory pedagogy has been adapted to the hospital setting that traditionally has been hierarchical.

Despite the strong investment of time and commitment by the health providers and initial two-year funding from Health Canada, it is not yet clear that the project will continue for the three to five years required to document outcomes. A funding search is underway, but like many such initiatives, it is competing for dollars in a stressed environment, and participants still do not know if there will be a Phase 3. However, there is strategic support internally and externally, and hope that this will translate into multi-year funding. There is agreement among all the parties that the collaboration has been very effective to date and that the potential for long-term impact inside the hospital is strong.

Where Are We Now?



There are many signs that health literacy is becoming recognized as an issue that touches a significant proportion of every population. There seem to be converging trends in the adult education field and the health field. It may be that health will become the way in to justify greater investment in adult basic education.

Annotated bibliographies from these fields are being created and regularly updated (e.g. Irvine, Greenberg, Rudd, and others). Information from medical organizations is also now being picked up and disseminated by adult literacy organizations. For example, the Michigan Adult Learning and Technology Center has a health literacy section on its web site with information shared from the Maine AHEC Health Center, one of the pioneer organizations in addressing health literacy. The number and quality of health literacy sites and links are growing and gaining in visibility. Conferences are being held, research is expanding, and collaborations are increasing.

Other forces are also driving this agenda. Accreditation and liability issues are powerful motivators. In the health care sector, health organization accreditation processes in every country are including standards on patient communication that link to literacy. In the US, the Joint Commission on Accreditation of Health Organizations (JCAHO), a private accrediting agency that inspects all licensed health care facilities and establishes minimum standards for hospitals and other health care institutions, now requires that instructions be given at a level understandable to the patient. JCAHO emphasizes affording each individual the care and attention that is necessary to his/her particular situation. This includes the recognition of the psycho/social, spiritual and cultural values that affect a patient's response to care given (Brandes). Hospitals and other health organizations are required to assess how well their patients understand their health care instructions and to provide education specific to the patient's assessed needs, ability and readiness (quoted in Mayeaux). (Centre for Literacy, Part 1)

In Canada, the AIM (Achieving Improved Measurement) accreditation program of the Canadian Council on Health Services Accreditation, involves hospitals and health care facilities. The basic principles of AIM are: client focus, quality improvement, teams, leadership, process and outcomes, recognizing the continuum of care and service provision (each health service organization must ensure that the client can easily access all the components of health care services), a population health approach and better measurement.

The AIM program calls on health teams to evaluate how AIM standards are being met through a process of self-assessment. Many of the AIM standards touch, directly or indirectly, on the issue of patient literacy. They focus on the need for patients and their families to be well informed and involved as active participants, and to demonstrate that they understand the information provided. Although the term "patient literacy" is not used, AIM refers to "client's abilities," "clients with special needs," and "client's level of education." The standards state that health information must be based on the client's and families' information needs, and that it must be easy to read and use. Another section of the standards asks that clients and families receive appropriate education and support regarding medication and other therapeutic technologies.

From a world perspective, the determinants of health are being seen more broadly to include socio-economic factors such as income and education. There is consensus that every increase in social position increases the likelihood of good health. Issues such as age, neighbourhood, welfare policies, race/ethnicity, discrimination, gender bias, and income distribution have all been subjects of research in relation to health. Countries have addressed these issues in various ways. In the 1980s, there was recognition that literacy was linked to health in developing countries, for example in the relation of a mother's literacy to child health. In the late 1980s and early 1990s, both Canada and the US published studies making the link in their own countries.

The US and Canada have currently incorporated references to literacy levels as determinants of health. Health Canada has listed the Impact of Literacy on Health as a link on the front page of their web site on determinants of health (www.canadian-health-network.ca/1determinants_of_health.html). The US has gone further, including health literacy as an objective among 467 in *Healthy People 2010*, the blueprint document used for both state and national planning. Objective 11.2 under area Health Communication is "to improve the health literacy of persons with inadequate or marginal literacy skills" (US DHHS, 2001). The National Assessment of Adult Literacy (NAALS) will include activities involving health tasks.

Responding to Australia's *Health 2000* report on the determinants of health, the Public Health Association of Australia said "that widening inequalities are a barrier to Australia's future social, economic and cultural

development," and called for reduction of socio-economic related health inequalities in Australia (www.pha.org.au/policy/HealthInequalities.htm).

Finally, there are policies being developed at local, provincial, state and national levels. A recent survey of several state basic education directors in the US turned up diverse policy initiatives that hold some promise (Hohn 2002). They ranged from interagency cooperation to leveraging of existing funds where no additional funds were available. [See summaries of several state initiatives below].

Hohn has just published a fine overview of issues related to policy on health literacy. She is sanguine about what needs to happen, but cautiously optimistic that changes are happening. She recognizes that efforts are still in the very beginning stages, and that good policy needs "to be in place to provide a firm foundation on which to rest literacy and health work." These include a need for secure funding, for teacher training on integrating health content and on handling potentially sensitive situations, for support structures on information-sharing and interagency referrals, and for creating a climate that supports literacy and health programming.

Hohn also raises a series of critical questions to be addressed:

When literacy and health are joined, what comes first, literacy or health?

Which approaches work best under what circumstances, for example, an empowerment approach that emphasizes student leadership? A disease-specific approach that concentrates health learning in one health topic separated from regular instructions or an integrated curriculum approach?

In what ways do the practice of literacy teachers and programs change by being involved in health work?

What evidence can be produced that documents changes in health knowledge, beliefs, and attitudes — and, ultimately, behavior — through linking literacy and health education?

What influence does an interagency approach have on the partners involved?

Selected US Policy Initiatives: Summaries Condensed from Hohn 2002



Pennsylvania has created an Interagency Coordinating Council (ICC), an advisory body charged with improving the delivery and outcomes of basic skill services across several state agencies, including economic and workforce development, welfare reform, school improvement, the Department of Aging and the Department of Public Health. Embedding health literacy in the work of the a well-established and visible organization, helped bring greater attention to the issue.

California took a different route lead by California Literacy, a private, non-profit organization that develops organizational capacity and leadership among community-based organizations delivering ABE services. When members of the agency did research and wrote about low literacy and poor health, they were startled by their findings. Recognizing that the state had many exemplary small programs and individual efforts but no coordinated effort to address literacy and health issues, California Literacy organized a two-day event in November, 2001 that brought together people from Health and Human Services, medical providers, insurance groups, the state Department of Education, nursing associations, and other stakeholders. The purpose was to build awareness, develop ideas and broaden involvement, and build an action agenda for working together across agencies.

The state of Virginia, lacking a dedicated stream of funding, integrated the concept of health into English language services with an emphasis on technology. They offered bonus points in a funding process to projects that included a health literacy component. The state is initiating two levels of activity: enhancing current services and curriculum development. Results from the first year were encouraging. For example, one team created web-based virtual tours of local hospitals, supported by the state technology component that provided equipment,

technical assistance, staff development, and software support. Their state director recommends leveraging existing funds to make initiatives interactive when there are not enough funds.

The state of Georgia is experimenting with a new approach to literacy and health through the development of two activities that will emphasize referrals and collaborations between ABE programs and health care facilities. One is training for ABE teachers on how to modify and incorporate health content into existing ABE programs. The other is to create "health literacy" classes to be taught jointly by literacy and health education teachers in a variety of sites such as hospitals, churches, and public health agencies. They recognize that many individuals in need of services will not go to a regular ABE program but might attend "health literacy" classes that have a dual agenda — learning about health topics important to you while simultaneously developing literacy skills — and perhaps transition to regular ABE in the future. In this case, health education can thereby become a vehicle for literacy.

Massachusetts has a long record of exemplary adult education policy that contextualizes health work in the lives of students. They have concentrated on building student leadership through the development of Student Health Teams that have been both the foundation and the outcome of the literacy and health work. These teams of groups of students work with facilitators, teachers, community health organizations, and health practitioners and use teamwork and creative methodologies such as drama, art, and music, to engage in a variety of activities such as researching health information, teaching other students about health, making and distributing brochures, developing and conducting surveys, participating in or running health fairs, arranging for medical screening services at a program site, and documenting and taking action around community health issues.

Conclusion



My intention in the article has been to provide a skeleton for respondents to flesh out. I have concentrated on initiatives in Canada and the US because I am most familiar with them. I look to colleagues from the UK, Australia and elsewhere to enlarge the canvas.

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Web Links



www.nlhp.cpha.ca

The Canadian Public Health Association, National Literacy and Health Program

This site describes the National Literacy and Health program of the CPHA and also links to their projects, publications and services such as Plain Writing. The more than 20 partner associations working in collaboration with CPHA are also listed.

www.hc-sc.gc.ca/hppb/healthpromotiondevelopment/pube/literacy-health

Health Canada

This site makes an overt link on the front page between literacy and health. It has a PDF version of a Profile Paper entitled *How does Literacy Affect the Health of Canadians?* as well as a Factsheet on Literacy and a short analysis of the literacy profile of senior Canadians.

www.worlded.org/projects_topic_7.html

Health & Literacy Special Collection

The Health & Literacy Special Collection is a Web-based resource for adult educators and health educators who are trying to bring clear and easy-to-read health information to low literate populations. It contains health curricula for literacy or ESOL classes, links to health information in plain English and languages other than English, and information about health literacy. The Collection is maintained by World Education, with support from the National Institute for Literacy (NIFL) and its LINC project, a national effort to provide Web-based resources for adult literacy practitioners.

www.sabes.org/health/index.htm

System for Adult Basic Education Support

This site contains health literacy materials developed in the state of Massachusetts where projects and research have been supported for many years. It contains curriculum materials, guides for collaboration, as well as models of participatory practice in developing student leadership.

www.hon.ch

The Health On the Net Foundation

The Health On the Net Foundation is a not-for-profit Swiss organization whose mission is to guide both medical practitioners and non-medical users to reliable online medical and health information. Created in 1995, HON claims to provide leadership in setting ethical standards for web site developers through its Code of Conduct for Medical and Health Websites. The website has a number of search engines by key word and medical term, and links to other databases such as MEDLINE.

www.navigator.tufts.edu

Tufts Nutrition Navigator

This site provides a rating guide and links to nutrition web sites that have been rated using criteria developed by nutritionists at Tufts University. The evaluation criteria include accuracy, depth, site updates, and usability. Evaluations are updated quarterly. It does not address literacy levels. However, their criteria for usability are of interest when considering literacy levels of users.

www.scipich.org

Science Panel on Interactive Communication and Health (SciPICH)

The Office of Disease Prevention and Health Promotion of the U.S. Department of Health and Human Services (DHHS) convened the **SciPICH** to examine interactive health communication technology and its potential impact on the health of the public. It includes fourteen national experts from a variety of disciplines related to interactive technologies and health, including medicine, human-computer interaction, public health, communication sciences, educational technology, and health promotion. The general goal of the panel is to accelerate the appropriate development, adoption, use, and evaluation of IHC applications. The Web site reports on the panel's work and includes articles, guidelines and links to related information. While they do not specifically address literacy, the work they are doing is closely tied to questions of literacy and of access.



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