

Critical Analysis on Best Practices in Health Literacy

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ABSTRACT

From a holistic perspective, health literacy is a requirement for the well-being of entire populations. It moves beyond the focus on individuals to consider the role of organizations and systems. This perspective offers a context for discussing best practices in health literacy, and implications for research and policy development. This paper offers an overview of the best practices that were presented at the Second Canadian Conference on Literacy and Health. It discusses clear writing in some detail because it was emphasized at the conference. It also considers practices that were addressed less emphatically, such as oral communication between patients and health care professionals, training for health care professionals, non-written means of communication (such as video), and building capacity through action-research. The paper critiques some practices. It also notes the lack of research on the links between health literacy and oral understanding, on the impact of verbal and non-written interventions, and on the effectiveness of these practices on the health outcomes of the population. It briefly discusses policy issues and suggests some future directions.

MeSH terms: Health literacy; clear writing; patient education; research; policy

The term “health literacy,” although relatively new, has gained attention internationally in the past decade. The definition has not always been clear or consistent; however, in 2004, there were signs of a growing consensus about a broader definition. Earlier definitions focussed narrowly on an individual’s capacity to read and comprehend medical information and instructions. Recently the concept has expanded to highlight that literacy facilitates access to information, and enables individuals to make informed health decisions, to influence events, and to exert greater control over their lives.¹⁻³ This concept connects health literacy to a participatory empowerment philosophy that has long been a theme in both the adult literacy and health education fields.⁴⁻¹⁰

The US Institute of Medicine (IOM) in its 2004 report, *Health Literacy: A Prescription to End Confusion*, reinforces this broader concept of health literacy. The IOM acknowledges that health literacy is a complex interaction that goes beyond reading. They present it as a function of both social and individual factors. They say it is mediated by: education, culture, and language; by the communication skills of a lay public and health professionals; and by materials and messages. At the conference on literacy and health, speaker Rima Rudd referred to this expanded definition in glowing terms.¹¹

When individuals confront the health care system, regardless of literacy level, heightened anxiety can decrease their ability to effectively process all the information presented to them. On the other hand, there are large segments of the population who have barriers to communication that put them perpetually at risk. These segments include immigrants, seniors, individuals with limited literacy, those with mental or physical disabilities, and others. Health literacy has to take account of the needs of the entire population. Keynote speaker Ilona Kickbusch stressed that it must be seen as a human right.¹² Kickbusch pointed out that today’s health-conscious consumer is deluged with information from everywhere: news media; health institutions and organizations; peer-reviewed literature; self-help books; health associations; health care providers; government health organizations; popular media; television and radio; friends and family; and the Internet. She sees health literacy as

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a potential filter for this information that can help consumers make reasoned decisions. Rudd and Kickbusch both offered holistic perspectives that provide a thoughtful context for discussing best practices in health literacy, as well as future directions in research and policy development.

We use this broad understanding of health literacy to ground our discussion of best practices, many of which were highlighted at the conference. We have drawn others from recent reports and literature reviews on selected aspects of the subject.

What do we label a “best practice?”

While the conference presented a range of practices that might be called “best,” clear communication was mentioned most frequently. Presenters agreed that plain writing and clear verbal communication are necessary for accessible health information, whether talking about Aboriginal, Francophone, immigrant, hearing-impaired, or low-literate target groups. Guidelines for plain language are generally undisputed. They are based on a common set of principles, including that the provider should identify the audience, adapt to their needs and abilities, and choose a clear communication objective. The objective could be to change a specific behaviour or to communicate some information that the provider feels the audience needs to know. For written materials, writers are instructed to consider organization of information, language, sentence length and structure, tone, and layout/design. Presenters all recommended that writers test readability, although they cautioned that this is not sufficient to account for the motivation or experience of a particular reader. Almost all of the presenters had checklists of practical tips, many of them identical. For verbal communication, they emphasized a speaker’s awareness of her/his own attitude towards the listener, tone of voice, loudness, and pace. One presenter noted that gestures are responsible for more than half of all communication problems. These observations apply to both personal and video-based communication.¹³

There was little challenge to the assumptions that underlie these practices, despite a body of research that suggests we should be examining the claims more critically. For

example, the Communication Research Institute of Australia suggests that the benefits that have followed from plain language revisions have been drawn mainly from the insurance and legal fields. The institute says they may often be attributable to factors other than simplifying documents. They also suggest that evidence is rarely gathered through rigorous testing with readers. When they are done, tests often ask about preference. This is an unreliable indicator.¹⁴ These concerns are corroborated by a recent review of studies on the use of plain language in the health sector. Many studies focussed on user preference or satisfaction. Very few evaluated outcomes related to usability. Most studies also excluded anyone with less than a grade nine education and people who did not speak English as a first language. Therefore, it would be unreliable to generalize findings for populations with limited literacy.¹⁵

Rudd has argued for many years about the narrow scope of health literacy research. It has focussed primarily on the reading level of materials, patient comprehension, the match between patients’ abilities and reading materials, utilization of services, and, in the late 1990s, health outcomes related to literacy levels. She noted that these have generally been examined only in the context of medical encounters. This is usually done without acknowledging the vast array of tasks, besides accessing information, involved in a medical encounter.¹⁶ Other 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. Combining easy-to-read written patient education materials with oral instructions in simpler language has been shown to greatly enhance patient understanding.¹⁷ 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.¹⁸ Little has changed since these observations were made, although recent reports on health literacy offer hope that the scope of research will broaden.

Beyond plain language

While the largest number of sessions in the Best Practices theme focussed on practical advice about plain writing and changing the communication practices of providers, some looked at potential changes in professional training through curriculum and train-the-trainer programs.^{19,20} These initiatives, such as the video and materials created by the American Medical Association, also tend to build on a set of simple principles: create a shame-free environment and provide easy-to-understand information for *all* patients.^{21,22} The focus in these sessions was on the importance of human interaction between health care providers and users.

Other sessions focussed on sharing information and resources and building capacity. For example, the British Columbia Health Literacy Network offers an online network. Service providers, academics, librarians, and anyone else with an interest in accessible health services can use the network to share information, advice, and practices. From the literacy side, projects such as one at Bow Valley College seek to reduce literacy barriers and increase awareness about adult literacy among community service providers and volunteer groups. They offer workshops and literacy audits and initiate partnership projects to address the issue.²³ In the US, the health and literacy fields are connected through the appropriately named LINC (Literacy Information and Communication System) Health and Literacy Special Collection. This professionally vetted website provides information on health curricula and easy-to-read resources for adult basic education programs and for health educators. It includes an index of materials in languages other than English.²⁴ The use of technology to create such networks and nodes of learning is a promising practice.

Many examples of best practices were embedded throughout the keynote addresses and the other themes, especially “Focusing on Language and Culture” and “Building Knowledge.” Examples included working in grassroots organizations to help seniors navigate health care systems and create health messages, or teaching adult basic education students to be peer facilitators on health issues in their own communities.

Researcher and adult literacy practitioner Marcia Hohn criticizes the over-reliance

on plain language. She sets health literacy in the context of community dynamics and group participation. Operation Bootstraps, a long-running program in Massachusetts, has demonstrated the power of this model. It rests on the often-professed credo that adult education should build on the strengths of students. Several participants in a workshop given by Hohn and two student facilitators commented on the confidence and insight of the two students. They contrasted the students' presentations to several keynote sessions that featured heart-break stories from students. This observation raises a question about the ways in which we portray and present adult literacy students. Program models that train students to become part of the community resource base for health literacy education are an alternative to a model where learners start out and remain disadvantaged.

Another longstanding project at a major Montreal hospital network highlights the potential for knowledge transfer and capacity building. The project designs action-research projects on aspects of health literacy. It uses the local learning as the framework for professional development and training.^{25,26} This approach holds promise for constructive changes to the health system. Some compelling insights into best practices came from keynote speakers who offered alternative frameworks for thinking about health literacy. In addition to Kickbusch's concept of health literacy as a filter, Dyanne Affonso focussed attention on the importance of and respect for cultural knowledge. She described health and healing practices that accept and honour diverse ways of thinking and knowing. Affonso distinguished among "cultural metaphors" that offer insight into frameworks of thinking, such as the Hispanic concept of "familia" or obligation to family, "cultural scripts" that say what is important to a group, "cultural stories," and "cultural rituals" that can build capacity. Janice Longboat, a Six Nations Elder, shared some cultural metaphors from her community through telling grandmothers' stories that have been used to pass on knowledge from generation to generation through story and symbol. Longboat spoke of the power of literacy, whether oral or symbolic, to teach us a worldview. When she was growing up, she never heard the

word "health." Elders spoke about "well-doing." Practices that flow from these frameworks would take account of whole persons, history, and culture. They would challenge the homogenized frameworks that dominate North American health care systems. The theme of culture crossed all the conference themes. It serves as the starting point for many best practices.

Policy to underpin practice

Issues related to policy on health literacy were touched on briefly. Hohn remarked elsewhere that good policy needs "to be in place to provide a firm foundation on which to rest literacy and health work." These include secure funding, teacher training on integrating health content and on handling potentially sensitive situations, support structures on sharing information and inter-agency referrals, and creating a climate that supports literacy and health programming. Havi Echenberg's two linked sessions offered participants a primer in understanding and shaping public policy in relation to health literacy. She drew on wide Canadian experience to create a generic overview that oriented practitioners and researchers to the complexities of policy development. Ellen Balka suggested that the Internet is changing the landscape of health information. She said that future understanding of literacy and of health literacy will have to take account of the array of new possibilities and challenges.

The Canadian Public Health Association, through its National Literacy and Health Program in partnership with different associations, has embarked on a project to engage researchers and practitioners to develop priority policy issues and research questions on literacy and health pertinent to Canada. This initiative may provide the leadership to build more coherent policy and enlarge the range of best practice in this country. Sessions facilitated by Rudd, Scott Murray, and Irving Rootman presented current US, Canadian, and international perspectives. They engaged participants in discussing the future agenda. The article on building healthy public policy further explores the development of literacy and health policy.

Concluding thoughts

If we consider the keynote presentations in relation to what is currently meant by

health literacy, we are challenged to consider what best practice might be if we defined "best" and "practice" more rigorously.

Two recent literature reviews on the use of plain language and audiotapes with patients who have various barriers to communication turned up disturbing, but not surprising, results.^{15,27} Very few credible evaluative studies have been carried out on the health outcomes of using these interventions with patients who have limited literacy, are immigrants, or have a cognitive or learning disability. Most studies have eliminated subjects with less than grade nine and who did not speak English as a first language. These findings suggest that some practices assumed to be "best" have not been tested with target populations who are not well served by the health care sector.

From the conference, we can conclude that there are many good practices in many different settings – working with people with specific disabilities, with various language and cultural groups, or with specific demographic groups such as seniors. Nevertheless, we did not generally hear examples of broad holistic approaches. In addition to being fragmented, most efforts were project-based and had not been absorbed into standard practice. Many had only lasted the duration of a project. Only a few of them had been well evaluated. Most did not examine health outcomes. Very few addressed literacy outcomes or examined the link between literacy and health. Most examples of "best practice" were for health communication and materials. It is important and necessary, though not sufficient, to simplify and adapt communications. This is because communication has been identified as a frequent root cause of adverse events. However, addressing health communication involves more than using plain language and testing readability.

There is a need for more systematic research to ascertain a range of "best practices" that can be adapted for different groups. In addition, this research will identify goals for health literacy efforts and suggest ways to reach these goals. Many hypotheses can be drawn from practices that have been pilot-tested or are already in use in Canada and elsewhere. Mapping all the practices we heard about at this confer-

ence alone would give us a good starting place for further research as part of the national agenda being developed by the Canadian Public Health Association. Working with Kickbusch's diagram of the factors that have to be filtered through health literacy and with the cultural framework proposed by Affonso might offer an interesting point of departure for such an investigation.

At the moment, policies are being developed at some local organizational levels, as well as at provincial, state, and national government departments, but they tend to be fairly narrow and based on untested assumptions. There is clearly a need for the federal and provincial and territorial governments to invest substantially in research and in national and international information-sharing around health literacy practices that hold promise to enhance health outcomes. There is also a need to examine the link between literacy and health more closely. Its exact nature is not yet understood. The Canadian Public Health Association started its work by focussing on literacy and health. It should not abandon that perspective, even while it addresses the more specific issue of health literacy.

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