

# HEALTH LITERACY

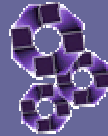
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Definitions, Quality and safety issues

presentation by

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# OVERVIEW

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- Selected definitions of health literacy
- Practices associated with these definitions
- A shift from an individual to system focus
- Accreditation standards & health literacy
- Using the standards for organizational improvement

# DEFINITIONS

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- Differences between “literacy and health”, “health and literacy” and “health literacy”
- Health literacy has different definitions. Health care providers tend to focus on the deficits of individuals.
- Literacy, health and health literacy are complex constructs.

# SELECTED DEFINITIONS

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## 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)

# National Network of Libraries of Medicine

The U.S. National Health Education Standards (Joint Committee on National Health Education Standards, 1995) defines health literacy 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>)

## **World Education (Boston-based NGO)**

Health literacy is the ability to read, understand, and act on health care information.

([www.worlded.org/projects\\_topic\\_8.html](http://www.worlded.org/projects_topic_8.html))

# Selected conceptual frameworks

## Australia: Dr. D. Nutbeam

<b>HEALTH LITERACY LEVEL AND EDUCATIONAL GOAL</b>	<b>CONTENT</b>	<b>OUTCOME: INDIVIDUAL BENEFITS</b>	<b>OUTCOME: COMMUNITY AND SOCIAL BENEFITS</b>
<b>Functional Health Literacy:</b> 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)
<b>Interactive Health Literacy:</b> 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.
<b>Critical Health Literacy:</b> Personal and community empowerment	As above provision of information on social and economic determinants of health, and opportunities to achieve policy and/or organizational change.	Improved individual resilience to social and economic adversity.	Improved capacity to act on social and economic determinants of health, improved community empowerment.

## Selected conceptual frameworks

### **Canada:** Canadian Public Health Association

#### Health Literacy Project:

- Attempt to create a more organic framework
- Account for direct and indirect impacts, personal and communal, of literacy on health & health on literacy
- Set a national agenda for research on the subject

## Selected conceptual frameworks

**United States:** Zarcadoolas et al., Brown University

Four domains of health literacy:

- Fundamental: language and numeracy
- Scientific/Technological: some competence with physical/natural sciences, technology, scientific uncertainty
- Civic/Community: media literacy, knowledge of civic and government processes
- Cultural: recognition of collective beliefs, customs, world view, social identity

# CURRENT PRACTICES

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A survey of articles published in the medical and public health fields from 1970 -1999 identified:

11 articles published in the 1970s

37 articles in the 1980s

200+ articles in the 1990s

(Rudd, Moeykens and Colton, 1999 b)

An AMA review concluded that:

Patients with inadequate health literacy have a complex array of communications difficulties, which may interact to influence health outcomes. 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>)

# The medical literature

## Most recent articles on health literacy:

- Start from international data on adult literacy– i.e., up to half of adults have some difficulty with the printed word...
- Reflect the perspective of the health care providers, to seek better patient compliance and improved health outcomes
- Take a narrow view of literacy
- Focus: reading level of materials; patient comprehension; match between patients' abilities and reading materials, etc.
- Generally examine only context of the medical encounter; rarely acknowledge vast array of tasks, besides accessing information
- (Rudd, 2000 b)
- Pay considerable attention to seniors - among the populations with the lowest levels of literacy, and the most frequent users of health services. (Roberts and Fawcett, 1998)
- In the U.K.: Focus is on the “wider” benefits of learning, and on educating health care providers (James 2001)

# RESPONSES IN PRACTICE

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Two main forms of response:

- Tests to measure the literacy levels of patients (more popular in the U.S. than elsewhere)
- Assess readability and rewrite medical information in plain language (common in English-speaking countries)

## Barriers to testing patient literacy:

- Staff not trained
- Insufficient time
- Direct assessment embarrassing and anxiety-producing for patients
- Not their job
- Patient's level of education not always an accurate indicator of literacy level; reading skill can diminish over time without practice

## **PLAIN LANGUAGE:** The most common response

- Proponents suggest that health education materials be written at three grade levels below the educational level of the target population.
- Recommend 5<sup>th</sup> or 6<sup>th</sup> grade reading level.

## Barriers to plain language:

### Skepticism about assumptions underlying claims

- Studies that suggest plain language saves money come primarily from legal, business, insurance and government sources.
- Some research suggests that benefits from plain language revisions may more often be attributable to changing the behaviour of end-users, than to simplifying the document.
- Evidence is rarely gathered through rigorous reader testing
- Tests often ask about preference, an unreliable indicator

(Sless, 2003) The Communication Research Institute of Australia

A recent review of medical articles on the use of plain language in the health sector found:

- Many focused on user preference or satisfaction
- Very few evaluated outcomes related to usability
- Majority excluded from their sample anyone with less than Grade 9 education and non-speakers of English as a first language
- Cannot generalize findings to populations with limited literacy

(The Centre for Literacy, 2003)

# A DIFFERENT PERSPECTIVE

## Health Literacy Project

at the

McGill University Health Centre (MUHC)



Montreal, Québec

# PHASE 1: 1999 – 2000

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Conducted needs assessment of the health information and education needs of low-literate patients identified by providers as “hard-to-reach”

An interview and focus group-based survey of 114 invited patients, professionals, support staff and family members or caregivers, revealed:

- A majority of patients did not find written documents directly useful because of language barriers; this format is one of most common forms of health information.
- Patients and professionals have different perceptions of the health education needs of this group.
- Family members want different information than patients.
- Family members and caregivers are interpreters, readers and mediators when there are barriers to communication.
- Professionals recognize the need to validate their teaching but they require time, skills and tools to do that.

# PHASE 2: 2001-2002

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Set out to implement and evaluate recommendations from Phase 1.

## Steps:

- Participatory health education committees on three hospital units chose key health messages that could have impact on patients' ability to care for themselves.
- Writers and designers created multiple versions of each with the intention of identifying the most effective ones.

## Conclusions:

- Need a clearer understanding of who comprise the “hard-to-reach”, before we can begin to develop differentiated means of communicating with them
- The term “hard-to-reach” says more about the providers than about the patients
- Health information currently is largely a one-size-fits-all enterprise

*Phases 1 & 2 funded by Health Canada, Population Health Fund, and Friends of The Centre for Literacy, with support from the National Literacy Secretariat, Human Resources Development Canada.*

# PHASE 3: 2003 - ongoing

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## Part 1: Literature Review

Review of the medical and education literatures on alternative methods of health communication such as plain language, audiotapes, videotapes, interactive media and visuals

### Findings:

- Most evaluative studies on plain language and audiotapes excluded patients who did not speak English, who were unable to read or who had other physical or cognitive deficits, in other words, the marginalized groups we set out to help.

Other searches not yet analysed

*Phase 3 funded by Pfizer Canada, Community Investment Program, The Montreal General Hospital Foundation, and Friends of The Centre for Literacy, with support from the National Literacy Secretariat, HRDC.*

## Part 2: Rethinking the Conceptual Framework:

### Successful Health Communication with Marginalized Populations

Framework incorporates elements from Canada, United States, Australia, and the U.K.

#### Premises:

- At its core, health literacy has to do with communication
- The desired outcome for communication around a health issue: That the client understands the information necessary to manage his/her health.
- The client could be the patient with the health problem or a family member or designated caregiver.

## Necessary conditions for successful health communication:

- Both parties must have the ability to understand and to be understood.
- The client has to be receptive before meaningful communication can happen.
- The professional has to recognize that information must be understood to be useful, and that to be understood it must be in a form that is accessible to the client.
- The client must have the confidence and ability to question the professional when the information is unclear.

## When these conditions are not met:

- Gaps in communication
- These gaps have negative health consequences.

Gaps in communication occur more frequently in the populations that have been referred to as “hard to reach”:

- These are populations who are marginalized due to lack of literacy skills, language and cultural barriers, and cognitive or physical impairments.
- These disabilities may be temporary or permanent and some clients may have more than one of these barriers.
- These populations frequently have significant health problems.

A gap in communication often seen as a problem of either the client or the professional

In reality -- a problem **shared** by the client and the professional and situated in the health care system

Linked to issues of patient safety and quality

## To close the gap:

- The professional must know their clients, including who they are, what they believe in, their history – medical, cultural, educational, etc.
- The professional must respect the client as an individual
- The professional must communicate a clear message
- Client learning that contributes to a change in health behaviours requires time, readiness and a willingness to learn
- Gaps in communication can generally be closed if these conditions are met
- These conditions can only be met through changes in medical education and changes in practice and assessment in the health care system

# What is needed?

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## Staff Development:

- Health care professionals need training to recognize the barriers faced by marginalized populations
- Health care professionals need training to assess and respond to these communication needs

## Strategies for decreasing gaps in communication:

- Involve more one-on-one communication
- Include plain language documents in a known language
- Include the use of alternative approaches

### **Examples:**

- audio or visual material in the language of the patient/client
- tele-lines to maintain contact
- culturally sensitive material in any medium
- an acceptable mediator who is familiar to the patient/client.

The emphasis shifts from the individual patient/client to a shared responsibility involving the professional and the health care system

## Practices that arise:

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- Medical education curriculum that includes health literacy in compulsory communications training
- Training for staff in conducting literacy audits and matching client profiles to appropriate medium and materials
- Inventories of current means of communication in institutions
- Specific staff positions and budget lines for patient education and communication
- Institutional policies and monitoring that explicitly link these issues to system quality and patient safety
- Accreditation standards that make clear statements about health literacy in relation to communication practices ( JHACO model rather than AIM)
- Action research that tracks impact and outcomes of specific measures

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