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# Lessons Learned from A Hospital-Based Health Literacy Collaboration

Presentation by

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# Overview

- Context –international literacy surveys, definitions of HL
- Evolving definition of the issues:  
Safety, risk, quality
- A participatory action research project partnership –  
McGill University Health Centre (MUHC) &  
The Centre for Literacy (CLQ)
- Findings
- Approaches to changing practice and policy
- Lessons learned

# International Adult Literacy Surveys

## (IALS) 1994 & IALSS 2003 (NALS)

- New survey in 2003, data released in May 2005
- OECD, StatsCan, and NCES (US)
- Compares literacy rates in participating industrialized countries
- 3 /4 scales of literacy – prose, document & quantitative (numeracy & problem-solving)
- 5 levels of literacy
- New survey includes health literacy component

# IALSS

- Measured 4 scales:
  - Prose
  - Document
  - Numeracy
  - Problem-solving

## Key Finding of IALS

- Up to half of North American adults have some difficulty with the printed word.
- Little change in IALSS

IALS: *International Adult Literacy Survey Database* <http://www.statscan.ca/english/freepub/89-588-XIE/about.htm#4>

Information on IALSS:

<http://www.statcan.ca/cgi-bin/imdb/p2SV.pl?Function=getSurvey&SDDS=4406&lang=en&db=IMDB&dbg=f&adm=8&dis=2>

# Health and Literacy - complex constructs

## Health:

- Disease management
- Prevention & wellness

## Literacy:

- Deficit of skills
- Meaning-making abilities

## Overview: Health and literacy research agenda

(Canada 2005)

Canadian Public Health Association (CPHA)

<http://www.nlhp.cpha.ca/clhrp/suminste/presentn/SI.Overview.pdf>

# Selected definitions of health literacy...

*Health literacy represents the cognitive and social skills that 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.*

World Health Organization (WHO), 1998

## *Definitions cont'd...*

- **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 identify

C. Zarcadoolas, A. Pleasant & D.S. Greer  
Center for Environmental Studies, Brown University

Information about environmental issues as focus for health literacy:  
<http://envstudies.brown.edu/env/people/faculty/czcdl/literacy.php>

## *Definitions cont'd...*

*Health literacy is the degree to which **individuals** can obtain, process, and understand the basic health information and services they need to make appropriate health decisions. **But health literacy goes beyond the individual.** It also depends upon the skills, preferences, and expectations of those health information providers: our doctors, nurses, administrators, home health workers, the media, and many others. Health literacy arises from a convergence of education, health services, and social and cultural factors, and brings together research and practice from diverse fields.*

*From **Health Literacy: A Prescription to End Confusion**  
Institutes of Medicine, 2004*

# Institute of Medicine

The Institute of Medicine linked *Health Literacy: A Prescription to End Confusion* (May 2004) - to three previous IOM reports:

- *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* (2003)
- *Speaking of Health: Assessing Health Communication Strategies for Diverse Populations* (2002)
- *Crossing the Quality Chasm: A New Health system for the 21<sup>st</sup> Century* (2001)

These connections to be continuously

highlighted, explained, reinforced

# Linked Issues

- Communication
- Disparities in health care
- Quality and risk
- Systemic and organizational change

Connections among these issues not often reflected in practice, as evidenced by recent reports on adverse events.

e.g., Agency for Healthcare Research and Quality. (2003). *Patient Safety Initiative: Interim report to the Senate Committee on Appropriations*. Retrieved January 3, 2005 from the AHRQ web site:  
<http://www.ahrq.gov/qual/pscongrpt/psini2.htm#RootCauses>.

## Typical responses to low health literacy:

- Increase professional and public awareness
- Education of medical students and physicians
- Improve patient-physician communication skills

### • **Future research needed:**

- optimal methods of screening patients to identify those with poor health literacy
- effectiveness of current health education techniques
- outcomes and costs associated with poor health literacy
- trace causal pathway of how poor health literacy influences health

# *In North America*

Most articles in the medical literature:

- start from NALS (U.S.) and/or IALS findings - ‘Up to half of North American adults have some difficulty with the printed word’
- reflect perspective of the health care provider
- seek better compliance and improved health outcomes

Scope of medical/public health literacy research narrow:

- reading level of materials
- patient comprehension
- match between patients’ abilities and reading materials
- utilization of services
- health outcomes related to literacy levels

# *In the United Kingdom*

Focus on:

- the ‘wider’ benefits of learning on health

But...a 2003 initiative to educate ALL health care providers at the National Health Services initiative (NHSU) –

<http://www.nhsu.nhs.uk> – scrapped in 2005

Recommended reading:

James, K. (2001). *Prescribing learning: A guide to good practice in learning and health*. Leicester, UK: National Institute of Adult and Continuing Education.

Information: [kathryn.james@niace.org.uk](mailto:kathryn.james@niace.org.uk)

## *Most frequent responses in practice:*

- Develop tests to measure the literacy levels of patients  
(more popular in U.S. than elsewhere)
- Assess readability of patient information
- Rewrite medical information in plain language  
(in English-speaking countries)

# Barriers to patient testing:

- Staff not trained
- Insufficient time
- Direct assessment can be embarrassing and increase anxiety for the patient
- Not part of the job
- A patient's level of education is not always an accurate indicator of literacy level – reading skills can diminish over time without practice

# Assessing readability– beyond formulas

- SAM - or Suitability Assessment of Materials (Doak et al., 1996) rates factors such as content, literacy demand, graphic, layout and typography, learning stimulation and motivation, and cultural appropriateness.
- PMOSE/IKIRSCH - measures complexity of documents that contain tables, forms, graphs, charts and lists; translates five levels of proficiency to grade-level equivalencies.

Concept of document design holds promise for materials design.

# Plain Language - the most common response

Principles suggest materials be written three grade levels below education level of target population – 5<sup>th</sup> or 6<sup>th</sup> grade

Skepticism about assumptions underlying common claims of benefit:

- Claims that plain language writing saves money come primarily from legal, business, insurance and government environments.
- Benefits that have followed from plain language revisions more often attributable to changing behaviour of end-users than to simplifying the document.
- Evidence rarely gathered through rigorous reader testing
- Tests often ask about preference - an unreliable indicator

# Plain Language - a literature review

Review of studies conducted on plain language in the health sector revealed that:

- Many focused on user preference or satisfaction
- Very few evaluated outcomes related to usability
- Majority excluded anyone with less than Grade 9 education and non-speakers of English as a first language
- Unreliable to generalize findings to populations with limited literacy

Atkinson, T. (2003). *Plain language and patient education: A summary of current research*. Montreal, QC: The Centre for Literacy of Quebec.  
<http://www.centreforliteracy.qc.ca/health/briefs/no1/1.htm>

# Health Literacy Project at the McGill University Health Centre (MUHC)

MUHC -- 5 hospitals in downtown Montreal serve a multi-cultural, multi-lingual population

Began as professional development initiative in 1995

Evolved into series of action-research projects 1999...

Building on conceptual framework developed by  
Dr. D. Nutbeam (Australia)

## Beginnings 1995

- Launch of national project on Literacy and Health - Canadian Public Health Association 1994
- 1995 Centre for Literacy workshop for local hospitals –initial incomprehension
- Uptake by Director of Nursing Staff Development at Montreal General Hospital -- champion
- Series of in-house PD workshops and public displays 1995-1997 – building ground support

# Beginnings

- 1997 Creation of MUHC –merger of 5 hospitals
- 1997 Formation of Health Literacy Committee-  
MGH (MUHC) – cross-specialization

1995-1997—300 health care providers trained

- 1998 Committee raises local research question  
seeks funding to explore it

## First study 1999

Needs assessment of health information and education needs of low-literate patients identified by nurses as “hard-to-reach”

### Rationale

- 1994 International Adult Literacy Survey (IALS): Nearly half the population of adult Canadians has some degree of difficulty with everyday reading materials.
- Serious consequences : Everyone needs to understand and use information on health and health care in their lives.
- Low-literate patients face health information, materials and procedures that are difficult or impossible for them to understand and apply.

## Rationale cont'd

- Other groups of patients also have difficulties  
“Hard-to-reach” patients include those who face language and cultural barriers, and those who have difficulties processing health information because of physical or cognitive disabilities.

Study started by asking, "What can be done to improve health education and information for ‘hard-to-reach’ patients at the Montreal General Hospital (MUHC)?"

Conceptual framework  
of Dr. D. Nutbeam, Australia

**Functional Health Literacy:**

Communication of information

**Interactive Health Literacy:**

Development of personal skills

**Critical Health Literacy:**

Personal and community empowerment

## Purpose of the study

- To determine the health information and health education needs of hard-to-reach patients at the Montreal General hospital (MUHC).
- 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.

# Methodology

Qualitative methodology because of nature of research.

Data collection through :

- 66 individual interviews (included health care workers from two affiliated community health clinics (CLSCs))
- 7 focus groups (45 participants in total)
- Four groups of informants:
  - hard-to-reach patients,
  - members of their families,
  - support staff
  - health care workers-from three units of the Montreal General Hospital (MUHC)-Dialysis, Oncology/Hematology and the Pre-operative Centre
- 3 physicians (1 from each of the three units) commented on a synopsis of the results

- Developed
  - Consent simplified form
  - Questionnaires
  - Interview protocols
  - Presentation for ethics committee

# MUHC Health Literacy Project

## Phase 1 1999 -2000

- Selected key findings
  - A majority of the patients found written documents not directly useful because of language barriers although this is one of the most common formats for 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 require time, skills and tools to do that.

## Phase 2 2001-2002

# Implement and evaluate selected Phase 1 recommendations

- Participatory health education committees chose key health messages that could impact on patients' ability to care for themselves.
- Writers and designers created multiple versions; intended to identify the most effective ones for specific populations.
- Solicited feedback from patients on selected versions
- Findings:
  - Need a clearer understanding of who comprises the “hard-to-reach” before we can develop differentiated means of communication
  - The term “hard-to-reach” says more about providers than patients.
  - Need a conceptual framework to guide initiative and identify goals
  - Patients' responses to health materials are influenced by many factors beside language and image

## Phase 3 – Review medical and education literatures on alternative methods of health communication

- Reviewed alternative methods of health communication, e.g. plain language, audiotapes, videotapes, interactive media and visuals.
- Findings to date:
  - Most evaluative studies on plain language and audiotapes excluded those who did not speak English, were unable to read or had other physical or cognitive deficits, i.e. the marginalized groups
- Developed a conceptual framework to guide the project
  - · health communication as a shared responsibility of patients and professionals
  - · role of systemic factors, language, culture, education
  - · need to customize communication according to identified barriers/needs
  - · need to start with the most disadvantaged populations
- Full reports on all phases including findings and tools are available at [www.centreforliteracy.qc.ca](http://www.centreforliteracy.qc.ca) under the button Health Literacy Project.

# Phase 4 Proposal -- June 2004

## An Approach to changing practice and policy

2005 - 2009 Successful Health Communication with Marginalized Populations

A proposed four-year project of unit-based action research projects, professional development, and creation and assessment of a system wide common communication strategy for the hospital's most disadvantaged populations

Framework incorporates elements from Canada, US, Australia, and UK

Gaps in communication exist with most clients but especially with those who have barriers such as:

Literacy

Language

Education

Culture

Disabilities: physical, cognitive, LD

## Phase 4 cont'd

Proposed to:

- Develop participatory action research projects to provide new information and understanding about communicating with selected groups of marginalized patients
- Influence local medical education curricula
- Develop tools, i.e. Inventories of current means of communication in institutions, literacy audits, ways to measure costs of various practices/interventions, etc
- Conduct continuous staff development incorporating local project findings with macro-level research in the field
- Seek funding for staff positions and budget lines to account for development and assessment of communication practices
- Help develop and monitor institutional policies on communication [collaboration with UHN, Toronto, Patient Education Network (PEN)]

# Where are we now?

- Stalled -- No funding since 2004

# Why?

- Competing priorities
  - \$billion building of Super-hospital
  - Funding sources exhausted
- Political environment
  - Threat to “consolidate” some MUHC hospital services
  - Language issues in Quebec

# Why?

- Systemic issues
  - Early retirement/buy-outs of health care providers--Loss of knowledge
  - Personnel shortage
  - “A focus per year” approach – 2005 Year of Patient Safety –narrow lens

# Why?

- Institutional issues
  - Five hospitals= five cultures
  - Clash between traditional hierarchies and new team approaches
  - Overload
  - Misunderstanding of issue:
    - “We’ve done that, now let’s move on.
    - “We already do this well; why are we talking about it?”

## Accomplishments

- Several hundred health care providers trained
- 6-8 ranking administrators onsite
- Strong relationship with Nursing Research Dept
- Funding record
- Link/curriculum with McGill Dept of Nursing
- Curriculum development with CPHA (proposal)
- Publications – Research reviews
  - Peer-reviewed articles
- Intranet file on HL at MUHC

## Accomplishments cont'd

- Peer-reviewed conference presentations
- Individual uptake- projects, initiatives
- Profile – in-house presentations at Quality Rounds, newspaper articles, in-house news, displays on literacy days, research conferences, national/international

# Interests that emerge internationally

## Convergence:

- Conceptual frameworks derived from Nutbeam
- Focus on patient needs/ differences
- Incorporating health literacy into areas of prevention, treatment, quality and safety
- Acknowledgement of cultural and systemic factors
- Interest in concepts of compliance and empowerment
- Interest in intersection of health and media literacies
- Balance between quantitative and qualitative measures

## Divergence:

- Use of literacy tests/acceptance of dominant model
- Which end of the patient spectrum to focus attention on
- Distinguishing among various communication barriers:  
What weight does “literacy” carry in each?

# Lessons learned

- **Need to take a long-term view**
  - Time to build understanding and support among front-line providers
  - Time to “sell” the concept to leadership and policy-makers
  - Not a quick-fix issue
- **Need for more systematic research – clear agenda that promotes the links identified by IOM**
  - in past and currently, too many short-term projects

# Lessons learned cont'd

- Need to “Make a Case for Health Literacy” in terms that speak to varied interests in health care sector
  - Nurses, physicians, social workers, ....
  - highlight links to corporate concerns (mission, bottom lines) as well as to best practices
  - Document cost/benefit of specific HL practices
  - recognize differences between institutional and public health practices
- Need to cultivate institutional champions

# Lessons learned

- Need to link to institutional assessment and certification

US: JHACO

Canada: AIM

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# WEB SITES

- **The Centre for Literacy of Quebec**
- [www.centreforliteracy.qc.ca](http://www.centreforliteracy.qc.ca)
  
- **National Literacy and Health Program - Canadian Public Health Association (CPHA)**
- [www.nlhp.cpha.ca](http://www.nlhp.cpha.ca)
  
- ***How Literacy Affects the Health of Canadians.* Health Canada**
- [www.hc-sc.gc.ca/hppb/healthpromotiondevelopment/pube/literacy-health](http://www.hc-sc.gc.ca/hppb/healthpromotiondevelopment/pube/literacy-health)