

**REPORT**  
**Canadian Graduate Student Workshop on Literacy and Health Research**  
Ottawa, October 16-17, 2004

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**Background**

Investigators on the SSHRC-sponsored National Literacy and Health Research Project decided to organize a national workshop on Literacy and Health Research for Canadian graduate students in advance of the Second National Literacy and Health Conference in Ottawa. Funding was obtained from three CIHR Institutes (Gender and Health; Aboriginal People's Health: Population and Public Health) to hold the workshop on October 16 and 17. Canadian graduate students were invited to apply to attend the workshop and conference and 22 graduate students from across Canada were accepted. There were in addition, nine faculty, and seven others who attended the workshop.

**Purpose**

The purpose of the workshop was "to encourage young Canadian researchers to conduct research in literacy and health by providing them with an opportunity to meet and interact with researchers and practitioners in this field and with other graduate students with similar interests."

**Objectives**

The objectives were to:

1. conduct a one-day orientation and training session with Canadian graduate students interested in research on literacy and health;
2. provide them with the opportunity of attending the Second National Conference on Literacy and Health and playing a supportive role at the conference;
3. provide them with the opportunity of sharing their experiences with researchers and practitioners as well as with each other following the Conference;
4. establish a network of Canadian graduate students interested in Literacy and Health Research

**Agenda**

The agenda for the workshop was:

1. Buffet lunch and informal meeting and discussion
2. Welcome and overview of workshop and field

3. Roundtable discussions about current and planned research on literacy and health
4. Presentations to plenary
  
5. Briefing regarding roles in conference
  
6. Roundtable discussions on issues and directions in literacy and health research
  
7. Presentations to plenary and discussion of next steps

### **Organization of Roundtables**

In the first set of roundtables, participants were grouped according to the following issues: (1) Technology and health literacy; (2) Aboriginal literacy and health; (3) Education and literacy; and (4) Health and literacy. In the second set, participants were divided randomly into six groups.

### **Presentations**

Dr. Irving Rootman of the University of Victoria, the Chair of the Workshop welcomed participants and presented the purpose and objectives of the workshop. He then gave an overview of the state of research in literacy and health in Canada followed by Dr. Rima Rudd of Harvard University who provided an overview of the state of research in literacy and health in the United States.

### **Roundtable 1**

The following were the conclusions of the first roundtable discussions by each table:

#### **1. GROUP FOCUS: Technology**

##### **What do we hope to get out of the workshop?**

- General knowledge/update of health literacy
- Tools to address the health literacy issue
- Identifying underlying assumptions
- Culture and acculturation and assimilation issues (re: learning and adaptation for immigrants)
- Get to know people's research interests
- Diversity and richness of multidisciplinary input

##### **Current Involvement in Research**

- Knowledge in electronic texts – understanding and linking gender and SES
- Observation on the logical thinking and reasoning of people using computers
- Evaluation of the appropriateness of information tools given to people

- Demands and skills related to learning environments
- Education based on adult education

### **Issues/Topics of Interest**

- Issues with parent/child language skills and translation among immigrant families
- Aiming education/teaching to the right learner → Assessing who should know the information and how it should be given
- How to involve the client in active learning and evaluate effectiveness of intervention
- Involving many sensorial stimuli as teaching tools
- Analysis of the media's presentation of medication and the public's understanding of the of medication
- Expanding methods beyond traditional methodology

### **Challenges**

- Funding
  - Lack of opportunities
  - Often tied to outcomes
  - Need of a multidisciplinary team to facilitate the process
  - Tailoring proposals to funding is often difficult
  - Most studies required data

### **Opportunities/Positive Circumstances**

- Graduate students can get → OGS, SHHRC, Health Charities and HC

### **Solutions**

- Generosity
- Sharing and collaboration → Devotion to research
- Invest time and knowledge into younger generations (legacy)
- Use non-institution based research opportunities
- Involves work with rigor but reframing of structure
- Participatory research
- Teaching → Development of Ideas
- Lobbying Funding Agencies

### **Key Issues/Questions**

- A specific agenda for studying context in which people search, find and use health information
- What is the capacity of individuals to acquire the skills to use technology for their health?

- Skills you need to thrive in your context
  - Critical Literacy: Who is at the table...bringing in multiple perspectives when looking at literacy more broadly (i.e., anthropologists, educational policy)?
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## **2. GROUP FOCUS: Aboriginal**

### **What do we hope to get out of the workshop?**

- General knowledge/update of health literacy; information seeking
- Assistance in developing framework and how it fits with existing frameworks
- Networking
- Inspiration, encouragement
- Information for research development

### **Current Involvement in Research**

- HIV/Diabetes research
- Relationship between literacy and health
- PAR/Interdisciplinary
- Use of theatre to convey findings
- Mobilizing language, literacy and culture
- Health, employment, development and literacy
- Language, literacy and culture as determinants of health – multiple literacies and community based work
- ‘Girl Talk’ using literacy as an art form (writing) to move towards emotional health
- Understanding history and articulating future direction – re-educate Aboriginal communities, prescription drug abuse; Understand the implications of cultural genocide and support change – identity and health

### **Issues/Topics of Interest**

- Ways to collect data and build cases for action (i.e., advocacy, go behind literacy to articulate public policy)
- Change within primary health care system – change practice/policy through a research process
- Assessing communication methods – bring awareness to public and policy makers to see literacy in a holistic viewpoint (rather than a deficit model) and acknowledgement of unique circumstances

### **Solutions**

- Focus on areas we are already literate in and value each equally

- Focus on areas of good health
- Increase communities' control over health and research (Ownership Control Access Possession)
- Policy makers need to recognize multiple literacies

### **Key Issues/Questions**

1. What aren't we seeing?
  2. How do we get policy makers to acknowledge indigenous knowledge?
  3. How do we ensure the community is engaged in all aspects of research including data collection, evaluation, dissemination and follow up (recommendations, action plans)
  4. How do you use/create a research process to make this happen?
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## **3. GROUP FOCUS: Education**

### **Issues/Topics of Interest**

- Wants more participatory research and literacy
- Child protection and the effects of literacy
- Involve library sciences
- Rural women's health and the internet
- Consumer health Information

### **Challenges**

- Trying to evaluate literacy – lack of tools and the need for more empirical work – develop criteria for a useful tool
- Quality markers for kids – visual appeal and friendly
- Outcomes – what are good websites?
- Contexts specific instrument development
- Understanding varying definitions of health and health needs
- Lack of money for IT health interventions and evaluations

### **Solutions**

- More money – development and evaluation of IT health, as well as more research on context and patient involvement
- Attract CIHR attention to this area and need for research development and outcomes measurement
- Create a network of those involved in technology as a factor in health literacy
- Education opportunities to evaluate resources

### **What do we hope to get out of the workshop?**

- Development of individual workplans/responsibilities
  - What do you need to know?
  - What skills do you need in order to do that work?

### **Key Questions/Issues**

1. What are our responsibilities as a researcher?
  - Reflection, dialogue, ownership, dissemination and activation
  - Usually we end with writing the report – what are our responsibilities after the report is written
2. How do we do this?
  - Identify question – the interplay of identify and location;
  - How does this help/hinder health?
  - How would it look different if put in a different context (e.g., French in Nova Scotia vs. French in Quebec)
3. How do we prioritize research?
4. Critical Literacy: Who comes to the table? Social anthropologists; trends/stigma; educational policy
5. How do we best blend qualitative and quantitative to achieve the best outcomes? How do we educate our funders that there is rigour in qualitative research and that it needs to be valued as a legitimate research.
  - Increase communities' control over health and research (Ownership Control Access Possession)
  - Policy makers need to recognize multiple literacies

### **4. GROUP FOCUS: Health**

#### **What do you hope to get out of the workshop?**

- General knowledge/update of health literacy
- Get to know people's research interests
- Identify potential partners
- Identify funding opportunities

#### **What kind of research would you like to be involved in or would you like to see happening?**

- Literacy work with homeless youth

- Examining long-term outcomes
- Work that is sensitive the context of client/study population (i.e., there is often difficulty in measuring literacy with some groups)
- Evaluation
  - Providing evidence to policy makers/service providers
  - Best practices around interventions for literacy
- Training Opportunities
  - Creating awareness of appropriate communications between providers and clients (i.e., nursing, physician) and assess curriculum/training of professionals in this area
  - Understanding how people take care of themselves and use the information that is given to them by health professionals
- Points of Intervention
  - Better understand how to reach and make a difference in populations with lower literacy levels. What are the effective points of intervention?
- Population Gaps
  - Adolescent and Young Adults
  - People with disabilities/sensory impairments
  - Gender/Cultural Diversity
  - Pre-Schoolers with language delays – successfully helping parents of these children (who may have literacy problems themselves) access and care for their children

### **Challenges:**

- losing the context; understanding the co-existing determinants (meaningful, holistic measurements)
- Continue to develop, define and apply a theory of literacy and health
- There is a danger in limiting our definition of literacy to skill-based measures (explore other contexts, definitions, measurements, outcomes, etc.)

### **Key Issues and Questions**

- Agreement on terms. What is literacy, how do we use this term and what is the context of developing literacy skills (i.e., in relationship to some challenge, or task, or issue)
- Issues of Power: Needing to recognize different forms of knowing. Accept that there are multiple views of literacy

## **Roundtable 2**

The following were the conclusions of the second roundtable discussions by each table:

### **GROUP 1**

- Definition of Literacy – we must recognize different types of literacy (‘multiple literacies’). **Implication:** reflect on various measures which probably only measure 1 or 2 different types of literacy
- Understanding what people bring in terms of context and how they function in their community?
- Recognizing learners’ knowledge and what they bring to the table.
- Performance Indicators: Some of the quantitative tools we use often focus on deficiency models rather than what people bring...we can use qualitative tools to bring learners’ strength and context to research
- There is a need to recognize variations in learning style and methods of delivery

### **Solutions**

- Engage in capacity development of care providers to recognize the variation in learners’ and learners needs, rather than the ‘deficits’ of clients.
- Recognize the cultural context of literacy

### **Feedback**

It is very difficult to access literacy tests. A need for better access to tools and measures

### **GROUP 2**

#### **Questions/Issues**

- What is healthy? Healthy traditions from the past and paying attention to competencies and strengths that are already there (strengths mode)
- Western education and health care system is not meeting the needs of Aboriginal communities – policy makers need to be aware of this and take action
- Importance of community leadership – there are problems in making the case for the benefits of community leadership to policy makers



- ‘Multiple literacies’ vs more limited definitions
- Political context of literacy – there is an economic impetus behind much of the literacy work

### **Key Question**

- How do we incorporate an understanding of context in research on health and literacy?

### **Solutions**

- We must realize a variety of contexts exist (political, geographic, economic)
- Study role of context in defining ‘deficits, handicaps, impairments’
- BUT:
  - Not every question is about context
  - Need for multidisciplinary lens
  - Work with manageable questions
  - Strengths model (multiple intelligences)
  - Look for solutions in context

### **GROUP 3**

- Emphasize the context of Language and Literacy. Think about literacy as it relates to ethno-linguistic communities, Aboriginal communities and communities in general
- Any research must start at context
- Must involve – community and a community approach to work

### **GROUP 4**

- How do you engage communities in health research? Each community needs to be viewed as unique
- Success comes from capacity building: obtain community feedback – understanding community priorities; engage leaders (both formal and informal community leaders); begin with strengths of individuals; challenge the notion of apathy. What are the barriers and enablers?

## **GROUP 5**

- Who should participate in research and how can the larger community be meaningfully engaged in the *entire* research process?
- How can research inform best practice and how can the community be part of this process? Ensure that PAR doesn't just become rhetoric
- How do we best identify our relationship with communities and the ideal roles for both community and researcher?

## **GROUP 6**

- Literacy is relatively new to French language – not well understood or used
- There is a lack of awareness of literacy issues among certain groups. There is a challenge in bringing diverse communities into discussions of literacy – the term may have different meanings of scope within certain groups.
- Information about health should be provided through multiple means – literacy is about information AND relationships

## **Solutions**

- We need to know what other types of care people access?
- How can we make better use of existing resources (i.e., libraries)

## **Proposed Actions**

The workshop proposed the following short-term actions:

- Send out overheads
- Send out evaluation questionnaire
- Prepare and send out report
- Collect and send out short bios
- Prepare and send out participant list
- Compile bibliography
- Bring back information to our organizations
- Get permission to use e-mail addresses
- Develop mentoring matches
- Compile list of list-serves/websites

The following medium-term actions were proposed:

- Develop Conceptual Map
- Develop ways to collect and distribute tools
- Dialogue on Questions
- Web-based briefcase
- Establish Listserve
- Disseminate information to providers
- Develop mission statement
- Produce fact sheets, plain language versions

The following long-term actions were proposed:

- Organize annual/biannual Institutes/ Workshops
- Develop capacity for research
- Obtain funding for network
- Establish plain language Academic journal
- Establish Regional Clusters to do research on Literacy and Health

### **Recommendations**

The following recommendations were made to the Conference:

- Research on Literacy and Health interventions require financial support for interventions and long-term funding. CPHA and NLHP advocate (jointly to parliament and funders) for this kind of support for LAH Research to develop a program of regionally supported research on LAH
- That CPHA and the NLHP approach the Canadian Institutes of Health Research and the Social Sciences and Humanities Research Council to undertake a joint strategic initiative on literacy and health research.

### **Conclusion**

The workshop was concluded with thanks to the funders ( CIHR (Gender and Health, Aboriginal People's Health and Population and Public Health) and SSHRC) and members of the planning Committee (Jim Frankish, Gail Hammond, Heather Hemming, Judy King, Cameron Norman, Nigwakwe (Priscilla George) and Irving Rootman). The contribution of Lynn Chiarelli, Maggy Razafimbahiny and the Canadian Public Health Association was also gratefully acknowledged. Darryl Quantz was also thanked for recording during the workshop.

### **Participation in Conference**

Graduate students received training to act as session chairs and recorders thorough out the conference. Most chaired and recorded in several sessions during the conference.

## **Evaluation**

A questionnaire to evaluate the workshop was developed and e-mailed to all participants in the workshop. Fifteen responses were received, mostly from graduate student participants. The following were key findings:

### **Expectations**

Almost all of the respondents to the survey indicated that the workshop did meet their expectations and every respondent rated the workshop as having been 'very successful'.

Many of the participants indicated that they hoped to have networking opportunities and to learn about current research and issues in the area of health literacy. Respondents strongly felt that this goal was achieved. Many indicated that the success of the workshop was enhanced by the diversity of the participants and the various disciplines and roles that they represented. The content of the workshop provided participants an opportunity to assess and identify potential research ideas and topics, and even motivated one student to produce a colloquium on health literacy. Networking opportunities were noted as a particular area of success. Many survey respondents indicated that they would take further action to increase their network in the field through the contacts that they had made at the workshop.

For some participants with a limited background in this area, the workshop provided a knowledge foundation that facilitated their participation in the remainder of the conference. Additional general comments on the workshop were that it was well managed, the time frame was appropriate, there was an interesting agenda and that it was well recorded.

A few respondents stated that the workshop did not fully meet their expectations. One individual noted that they had hoped to discuss research issues in greater depth and found that there was not enough distinction being made between practice/policy issues and research during the small group sessions. Two respondents felt that the background of participants was not fully captured. They suggested that a brief opportunity for participants to present their work or planned research prior to the workshop would have allowed individuals a chance to better grasp what others were doing. Finally, one individual expected the workshop to focus more on the required readings.

### **Assessments and Comments**

In terms of overall format, the combination of focused presentations with small group discussion was viewed very positively. This format created a number of opportunities for response and dialogue around the issues being presented. The

small group discussions and the clustering of participants by interest were also very much appreciated. The subsequent mixing of groups also gave people a chance to meet and work with additional participants. Many respondents indicated that the diversity (geographically and discipline) and size of the groups facilitated the discussion. Finally, one participant noted their appreciation for the informal and relaxed atmosphere of the workshop process.

Respondents also made comments on a few elements that they felt could be improved. A number of participants felt that the focus of the small group discussions became lost at times and that it was difficult to develop a consensus or coherent strategy for next steps. At times, one respondent noted, it was like participants were speaking a different language about the same issue. Additionally, two respondents indicated that additional time was needed or should have been committed to formalize the recommendations that were made during the workshop sessions. Finally, one respondent felt that a formal presentation on literacy and health in Canada should have been made prior to the workshop.

A number of comments were also made with regard to the assignments that were carried out during the conference. A few respondents felt that the recording was difficult and could have been better served if presenters were better organized (i.e., handouts, outline, more attendant participation as opposed to lecture style). One person indicated that the recording did give them practice at clear writing skills and summarizing presentations. The opportunity to chair sessions was viewed as beneficial for several reasons. First, it created an opportunity to meet and network with presenters. Second, students learned more about the various themes under which presentations were grouped and applied these connections during their facilitation of post-talk discussions.

## **Recommendations**

### **a. Process/Content**

- Provide a brief biography of all workshop attendees before the meeting.
- Get a dialogue happening via the web or email before the conference to provide opportunities to become familiar with others and their work.
- Have a component of the workshop that teaches the linkages between practice and policy in literacy and health.

- Provide opportunities aimed at students who are at different stages of graduate work. This creates a chance for new students to talk about possible topics, supervisors etc., and for students who are further along in their studies to discuss methods, publishing and grant applications. Consider a mentor to work with various student groups.
- Consider grouping people into themes and complimentary subgroups ahead of time
- Provide an overarching topic or theme for the workshop.

#### **b. Participants**

- Invite government representatives (i.e., from Health and Education) and create opportunities for partnership building.
- Ensure that graduate students of all ages are encouraged or able to attend
- Provide opportunities for undergraduate students to attend.

#### **Topics/Areas of Focus for Future Workshops**

- Technology as it relates to literacy and health
- Developing a research agenda and defining the core areas of work that are needed to move a national research program further
- Population-specific comparisons and assessments of literacy and health (i.e., age, gender, psychiatric population, First Nations or gender)
- Building research capacity for students and for community based research
- Cultural context of literacy and its impact
- Increasing awareness of issues in the health care field
- Intergenerational perspectives and impacts of literacy and health (i.e., the population whose first language is English, but who struggle in a health context because of intergenerational low literacy)

## **General Comments**

- The lunches were not very good. Ensure that cookies are labelled as many people are allergic to nuts, etc.
- Ensure that there is representation at the conference from those with low literacy levels. This could also provide an opportunity (i.e., focus group) to evaluate the outcomes/interventions presented at the conference
- Consider making the workshop an annual event
- The number of Aboriginal people present was appreciated
- Create opportunities for debate on issues
- Continue to promote the possibilities for literacy and health research outside of medical/public health settings

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