

Building Knowledge in Literacy and Health

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ABSTRACT

Health and literacy share an interesting relationship. The complexities of the relationship between literacy and health need to be recognized by policy-makers and practitioners to dispel myths, reduce stigma attached to low literacy, and empower disadvantaged groups. As we engage in building knowledge in the field, there is a need for multi-sectoral collaboration, both quantitative and qualitative information, and more effective ways to communicate with and educate people with low literacy. At the Second Canadian Conference on Literacy and Health, research reported indicates that in terms of what we know, the field has focussed on: linking literacy and health; examining intervention programs; exploring e-health and rural health; evaluating programs; and empowering people. In exploring what we need to know, researchers at the conference identified the need to understand: the extent of literacy sensitivity among health care providers in diverse settings; the impact of using plain language and readability formulas; the effectiveness of approaches to instructing literacy; and the incorporation of health content and health literacy goals into literacy instruction. Further, we need to create accessible ways of sharing knowledge in the field to build and strengthen existing multi-sector partnerships within and between communities.

MeSH terms: Health care facilities; manpower and services; health promotion; health care quality, access, and evaluation; health services research

Recent research led by the University of Toronto Centre for Health Promotion and the Canadian Public Health Association has resulted in heightened awareness around health and literacy issues. An environmental scan and needs assessment of Canadian research and practice in literacy and health were conducted through the National Literacy and Health Research Program.¹ The objectives of the research were to identify gaps in knowledge, current and proposed initiatives, and resources or opportunities for research in literacy and health in Canada. Interviews and focus groups with stakeholders in literacy and health found that, although there is a large number of literacy and health projects, such as plain language services, there is a need for focussed research. The study also revealed that the complexities of literacy need to be recognized by policy-makers and practitioners to dispel myths, reduce stigma attached to low literacy, and empower disadvantaged groups. There is a need for multi-sectoral collaboration, both quantitative and qualitative information, and more effective ways to communicate with and educate people with low literacy. Another outcome of this research was an inventory of Canadian researchers interested in literacy and health issues, as well as a compilation of publications on the topic. A conceptual framework was introduced to research participants during the focus groups at a national workshop in 2002. Their feedback and suggestions, in combination with those offered during the workshop, resulted in a revised conceptual framework. It provides the broader context of this paper.

The conceptual framework shows the complex and interactive relationships between: determinants of health (education, early child development, aging, personal capacity, living/working conditions, gender, and culture); actions to promote health (communication, capacity development, community development, organizational development, and policy); literacy (general, health, and other); and the indirect and direct effects of literacy. These all impact a person's overall health.

This paper shows what we know, what we need to know, and future directions for building knowledge in literacy and health in Canada. More specifically, the following three components that fit within the conceptual framework are addressed: 1) defini-

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TABLE I

List of Presenters in Order of Appearance Within This Paper

Name	Title	Affiliation
Irving Rootman	Professor and Michael Smith Foundation Scholar for Health Research	University of Victoria, British Columbia
Rima Rudd	Senior Lecturer, Society, Human Development, and Health	Harvard School of Public Health
Lyn Simpson	Assistant Dean and Director, Graduate Studies, Faculty of Business	Queensland University of Technology, Australia
Brenda Kwan	Research Assistant	Institute of Health Promotion Research, University of British Columbia
Luce Lapierre	Director	Fédération canadienne pour l'alphabétisation en français
Scott Murray	Director General, Social and Institutional Statistics	Statistics Canada
Linda Shoheit	Director	The Centre for Literacy of Quebec
Pamela Nuttall Nason	Professor, Early Childhood Education	Early Childhood Centre, University of New Brunswick
Pamela Ainsley Whitty	Associate Professor, Early Childhood Education	Early Childhood Centre, University of New Brunswick
Lucie Lemieux	Director of Public Health	Agence de santé et services sociaux de l'Outaouais
Lisa Merry	Research Coordinator	McGill University
Jodi Tuck	Research Assistant/ Nurse	McGill University
Julia Thomas	Research Coordinator	McGill University
Roma Harris	Professor, Faculty of Information and Media Studies	University of Western Ontario
Cameron Norman	A Joint Post-Doctoral Fellow	C2E2 at Vancouver Coastal Health Research Institute and Centre for Global eHealth Innovation, affiliated with the University of Toronto
Ellen Balka	Professor, Communications	Simon Fraser University
Tiffany Veinot	Doctoral Student	University of Western Ontario
Trudy Lothian	Coordinator	Literacy and Basic Skills Program, Ottawa-Carleton Catholic School Board
Elsie Petch	Community Health Promoter	South Riverdale Community Centre, Toronto
Norma Levitt	Involved Senior	South Riverdale Community Centre, Toronto
Al Levitt	Involved Senior	South Riverdale Community Centre, Toronto
Deborah Begoray	Professor (Education)	University of Victoria
Elizabeth Banister	Professor (Nursing)	University of Victoria
Terrie Moar	Executive Director	Bookmates Family Resource Literacy Centre, Winnipeg, Manitoba
Candyce Jones	Facilitator	Bookmates Family Resource Literacy Centre, Winnipeg, Manitoba
Rick Wilson	Consultant	RW Consulting, Inc.
Deborah Gordon El-Bihbety	President and Chief Executive Officer	Council for Health Research in Canada

tions of literacy, health, and health literacy; 2) access to health information and services; and 3) empowerment.

What we know

Health and literacy share an interesting relationship with various complexities. The Second Canadian Conference on Literacy and Health provided a multi-sectoral forum for identifying and discussing some of the key issues for health and literacy. Through roundtables, panels, presentations, and workshops, the emphasis on building knowledge around health and literacy was strengthened and invigorated.

Literacy, health, and health literacy

The words "literacy," "health," and "health literacy" are used differently depending on who is using them, as well as the sector with which that person is associated. However, these terms need to be clarified and defined to create a common language. This is necessary to enhance the effectiveness of communication between sectors,

which is essential to successful collaboration.

It is important to realize that the terms "literacy," "health," and "health literacy" maintain specific meanings. They should not be used narrowly. Each term refers to distinct characteristics with differing assumptions. Literacy should be viewed as an interactive process involving an exchange of information and meaning through multiple sources. Literacy is a continual process that extends beyond a set of skills.

The word "health" is currently defined by the World Health Organization and others as a more holistic concept. It moves beyond the traditional physical model. It involves one's mental, spiritual, physical, and emotional well-being. Health must be extended beyond the absence of disease so that it reflects the complexities of health determinants as well.

Irving Rootman² noted that literacy is the necessary foundation of health literacy. Rootman and his co-investigators define

health literacy as "the ability to access, understand, and communicate information to engage with the demands of different health contexts to promote good health across the life-course." Rima Rudd³ emphasized the extent to which health literacy pervades people's lives. Health literacy impacts people in medical institutions and in homes, workplaces, and communities. Lyn Simpson⁴ suggested that health literacy includes the cognitive and social skills that indicate a person's ability and motivation to access information. Brenda Kwan⁵ highlighted the importance of viewing health literacy as a two-way interaction within different contexts.

The way these terms are conceptualized has implications for health and literacy research and intervention. Luce Lapierre⁶ drew attention to the need for ongoing interaction between education and health practitioners. Literacy programs should address health content within their literacy activities. Communities need increased access to health services for people with

varying literacy skills. Health information is no longer limited to hard copy and traditional print materials. Therefore, alternate forms of communication need to be considered. The content of health material can also go beyond disease-specific information to include general information for healthy living.

Linking literacy and health

Rootman provided conference participants with important background information on the Canadian Literacy and Health Research Program, which began in 2002. This project was funded by the Social Sciences and Humanities Research Council of Canada. It involved developing a national program of research on literacy and health. An environmental scan of Canadian research and practice in literacy and health was conducted. A needs assessment on future research opportunities was also done. Rootman shared a clear language edition of this report with conference delegates.

Canadian implications for research done in the US were explored at the conference. Rudd presented findings from the reports *Literacy and Health Outcomes*, *Health Literacy: A Prescription to End Confusion*, and *Literacy and Health in America*.⁷⁻⁹ Rudd suggested that these reports have moved the topic of literacy and health onto the US agenda in unprecedented ways. The first and third reports listed above profile the limitations created when health literacy is conceptualized within a framework of language structure and complexity of printed text. *Literacy and Health in America* characterizes the need for health-related literacy skills. It created a task-based Health Activity Literacy Scale that captures the complexity of tasks that people are expected to perform as they negotiate health information. The second report listed above, *Health Literacy: A Prescription to End Confusion*, expands the definition of literacy and identifies the need to move the scope of health literacy into the home, workplace, and community. Rootman argued that the American reports will likely have the impact of raising the public and political profile of health and literacy in Canada. He also said that a similar need to expand the work in health literacy outside of health care exists in Canada, and that the responsibility for health literacy needs

to move away from the individual to involve a complex, interactive societal process.

Research from the US, outlined in the Institute of Medicine report *Health Literacy: A Prescription to End Confusion*, has shown that when measured by reading skills, low literacy is associated with lower levels of health. Rootman and T. Scott Murray¹⁰ predict that these correlations may also prove true for Canada. Murray pointed out a detailed analysis of Canadian literacy and health data that showed wide variations in health literacy levels when analyzed by province. Overall, literacy and educational levels correlate with health literacy. Murray, who has been a leader in developing the International Adult Literacy Survey (IALS),¹¹ noted that Canadian data have shown a relationship between health literacy (measured through a subset of the IALS data) and self-perceived wellness. According to the survey, a person's educational level accounts for 60% of his or her health literacy level. Age is correlated with health literacy. Senior populations tend to lose literacy skills as they age; they also generally have lower levels of education. Murray pointed out that further refinement and expansion of the data base would provide further insight into health literacy scores for specific populations in Canada and the US.

Access to health information and services

An important distinction must be made between the availability and the accessibility of health information. Although there may be much information about health issues on the Internet or in clinics, there is no guarantee that people have the ability to locate, understand, evaluate, and apply that information. Thus, there is a need to make health information more accessible to wider populations. Certain interventions have been put in place to address this issue. These include embedding health information within the context of literacy programs, altering print materials, and enhancing educational opportunities for health care consumers and practitioners.

Interventions

As noted in the recent US Institute of Medicine report on health literacy, key points for intervention include the educa-

tion and health care systems, as well as society and culture. Linda Shohet¹² and her colleagues have done important research on health literacy. Among other things, the Centre for Literacy of Quebec at Dawson College held plain language workshops for 300 health care practitioners between 1995 and 1998.¹³ As a result of this work, further needs were identified and addressed through multiple phases. There were: literature reviews and interviews with health care providers and patients; development and testing of the readability of health information; conceptualization of a framework for health literacy; and the creation of a four-year project proposal to include action research, development of print resources, and ongoing assessment of materials with patients.

Pamela Nuttall Nason and Pamela Whitty¹⁴ discussed literacy activities within the context of two programs for parents and children – the Canada Prenatal Nutrition Program and the Community Action Program for Children. Through concrete examples, the complementary intertwining of literacy activities and health-related information became evident. The study's results were shared in an accessible format. The researchers reported their work using plain language with accompanying graphics in a layout similar to that of a magazine.

Lucie Lemieux⁶ addressed how high school completion rates are a concern in some communities. In response to the high numbers of people who leave school before graduation, early childhood programs have been established for children living in low socio-economic conditions. This may help foster those children's future educational success, so they may be more likely to complete high school.

Lisa Merry¹⁵ addressed the effectiveness of using questionnaires translated into other languages to collect health data from diverse communities. She found that design, word choice, and cultural bias impacted the accuracy of the collected data. As a result of this work, a need for adaptable questionnaires is evident. This will enable people of various cultures to accurately convey their health care needs. The work of Jodi Tuck¹⁶ and Julia Thomas¹⁷ also explored important issues around cultural sensitivities when researching health and literacy. All of these

research projects led to the conclusion that cultural sensitivity is necessary for successfully gaining knowledge about the health and literacy of various populations.

E-health

Given that access to the Internet is increasing, people are able to locate health information more readily than ever before. However, simple access to the technology itself does not ensure the understanding of information. Heather Hemming² emphasized the need to examine the electronic communication of health information. She also identified the importance of collaboration among researchers from various disciplines to more thoroughly investigate issues around health and literacy.

Simpson drew attention to the importance of focussing on social inclusion and community mobilization within health literacy programs. For programs that incorporate technologies, Simpson further advocated for a broadened definition of the "digital divide." This definition would move beyond access to technology. It would focus on how technology is embedded within a specific social context.

Roma Harris¹⁸ found that rural women accessed health information from a variety of sources, including the Internet. Although the women sought assistance from a hospital or doctor in urgent situations, they addressed less threatening concerns via the Internet. However, the women still want to discuss the online health information with their trusted doctor.

The Internet has provided people with more health information than was available in the past. Although many websites that involve medical information come with a warning to consult one's doctor, this advice often goes unnoticed or is disregarded. This may have repercussions for a person's health. For example, medical information may be misinterpreted or misunderstood by those who do not seek further clarification from their doctors.

Although the assumption that younger generations are computer-savvy often underlies various programs, Cameron Norman¹⁹ found this to be inaccurate. In response, he and his colleagues developed the eHealth Literacy Scale. It is a tool for assessing young people's ability to locate,

evaluate, and apply electronic health information.

Ellen Balka²⁰ presented information around using the Internet as a tool for health literacy. She also addressed issues related to public access to health information on the Vancouver Public Library and the BC HealthGuide OnLine Website within the context of the ACTION for Health project. This project focusses on the changing role of information technology in the field of health.

Rural health

Simpson emphasized the importance of the community's role in health and literacy. Harris raised important issues around the health of women living in rural Ontario. Her research found that those women shared an increased risk for poor health for a variety of reasons: limited access to information; barriers to health such as distance to health clinics and a low number of female doctors; and the most significant factor was identified as the need for social networking to reduce isolation.

Tiffany Veinot²¹ raised some concerns about the health of people living in rural areas. She has done research on how people in rural communities view HIV/AIDS. She has also looked at the implications of limited anonymous testing and the varying knowledge of family health practitioners.

Evaluating literacy and health programs

During a panel presentation, Rudd noted that most interventions address the accessibility of health information by those with limited literacy skills and involve the altering of print materials. However, Rudd emphasized that such improvements alone do not constitute a program.

Drawing from the findings of the three reports, Rudd noted that evaluating literacy programs was problematic. Funders often associate success with program completion rates. However, the socio-economic nature of program attendance is not reflected in this measure. There is a need for funding bodies to better recognize and consider the complexities around the determinants of health when assessing programs.

Empowering people

When people have the ability to access and use information for self-perceived improve-

ments within their life contexts, they are empowered. To promote opportunities for empowerment, it is essential to recognize that literacy and health are interconnected. They have profound impacts on the overall well-being of a person and his or her family.

Veinot identified the "control individuals gain" as the central idea to empowerment in all contexts.²² Because of lack of funding and access to doctors in rural communities, many people have taken on responsibility for their own health. When empowered people are put in this position, they increase their use of alternative medicine, self-help, and mutual aid groups. Veinot also found mixed feelings among physicians and patients about seeking and obtaining health information outside of medical clinics. Nonetheless, there appears to be a discrepancy between health care providers' ideals and actual support for their patients' empowerment. This could be tied to the complexities that surround under-funded health care.

A person's life context impacts his or her relationship with health and literacy. Trudy Lothian²³ spoke about the varying life experiences of many people in literacy programs. With such diverse backgrounds, it is important to embrace each learner's experience and use it as a starting point in the program through the building of mutual understanding and respect. Age and culture also play a role in health and literacy issues. Elsie Petch, Norma Levitt, and Al Levitt²⁴ illustrated how these factors affect a group of people. They gave an example of how a community of English and Chinese seniors has emphasized the importance of plain text and language for communicating health information. Deborah Begoray and Elizabeth Banister²⁵ focussed on younger generations. Begoray was involved in research around students' literacy learning and development, while Banister's research focussed on dating among 15-year-old girls and its impact on their health and well-being.

Extending beyond individuals, health and literacy affects entire families. To address this, Terrie Moar and Candyce Jones²⁶ presented an approach to family literacy. It addressed health-related information within the context of literacy activities. They demonstrated the importance of community connections and involvement.

Future knowledge building in literacy and health: What we need to know

Outcomes of research done by participants at the conference, as well as others in Canada and beyond, are central to building knowledge around health and literacy. The research led by Rootman focussing on a conceptual framework of health literacy and an instrument for measuring health literacy in Canada will provide more information for future directions. Once there is a measure for health literacy, it may be used with various populations to build knowledge around health literacy in the many contexts unique to Canada. Research on the ways in which people locate health information, where it is found, understood, and communicated is also one of the important foci for building knowledge. The results of this important work will lead to valuable answers as well as questions and directions for further inquiry.

The National Literacy and Health Program successfully raised awareness and developed resources for health and literacy issues. However, research in the area is still minimal. Rick Wilson²⁷ identified three key areas of further study: the extent of literacy sensitivity among health care providers in diverse settings; the impact of using plain language and readability formulas; the effectiveness of incorporating health content and health literacy goals into literacy instruction.

Deborah Gordon El-Bihbety²⁸ proposed a study that would involve testimony from community groups and key informants on literacy and health research. She also emphasized a need for evaluating research and gathering information in accordance with a project-funding model based on the model for Health Canada's Population Health Fund. New research could also take place as a joint strategic initiative on literacy and health research between organizations and funding sources, such as the Canadian Public Health Association, National Literacy and Health Program, Canadian Institutes of Health Research, and the Social Sciences and Humanities Research Council. She also suggested the need for funding projects, developing capacity, and infrastructure. Specifically, she identified the following four priorities: 1) culture, literacy, and health; 2) evaluation; 3) cost benefits of literacy and health efforts; and 4) the role of technology in literacy and health.

There is a need to clarify the definitions of literacy and health within both the health and education sectors. According to Rootman, in Canada we tend to speak of "literacy and health," whereas in the US the term "health literacy" predominates to describe this new field of study and practice. Distinctions between health and literacy, and health literacy must be used with in future research and program development and evaluation. It is also important to gain understanding about the link between literacy and mental, spiritual, physical, and emotional health, within the more holistic concept of health and well-being extending beyond the absence of illness.

Criteria for measuring health literacy need to be clarified. These criteria can then be examined for various populations (e.g., based on language, culture, age, gender, geographic location, disability, etc.). Developing tools and methods for assessing health information is also needed once criteria for health literacy are identified. There is also a need for increased awareness of the need for two-way interaction between health care practitioners and patients. This will ensure accurate receipt and understanding of health information rather than a single-direction transmission of information from practitioner to patient.

As more research is done, it is important to create an easily accessible database. This way, information can be shared and further knowledge building can occur. This may facilitate the process of understanding literacy and health issues in Canada.

Building new and strengthening existing multi-sector partnerships within and between communities is a key factor in building knowledge in health and literacy. Ultimately, multiple sectors need to collaborate creatively to improve the health of all Canadians.

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