



National Collaborating Centre
for Determinants of Health

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**NATIONAL COLLABORATING CENTRE
FOR
DETERMINANTS OF HEALTH**

**ENVIRONMENTAL SCAN OF INTERVENTIONS
TO IMPROVE HEALTH LITERACY**

FINAL REPORT

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By

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Environmental Scan of the Interventions to Improve Health Literacy

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Key Messages

- There is very limited information available about the effectiveness of health literacy interventions
- Health literacy is defined as, “the degree to which people are able to access, understand, appraise and communicate information to engage with the demands of different health contexts in order to promote and maintain good health across the life-course” (Rootman & Ronson, 2005).
- The methodology used for this paper included searching academic and grey literature and conducting key informant interviews.
- Barriers and enablers to evaluation of health literacy interventions include available funds, time and expertise.
- Despite the limited available information, there is some evidence to support the finding and general understanding that a participatory educational and empowerment approach is effective.
- Despite the limitations in the available information, health literacy as a general area - and specifically an inter-sectoral approach to health literacy interventions and evaluation - is an important area to continue to study.

Abstract

The question guiding the paper is: “What do we know about health literacy interventions and their effectiveness?” Synthesizing insights from a variety of research streams, the paper identifies factors enabling or inhibiting evaluation of interventions addressing health literacy as well as identifying needs and issues for future services.

The paper suggests that health literacy needs to be more concretely defined and placed within a conceptual framework that enables more efficient categorization of health literacy-specific programs. Due to barriers including time and money, evaluation of these programs is often skipped. Because of this, there is a strong need for increased knowledge of how effective programs are when it comes to improving health literacy. There is also a need for better dissemination of project information, for which we suggest the creation of an online clearinghouse. Health literacy needs to be integrated in all government programs and addressed in a collaborative, inter-sectoral way, with a greater emphasis placed on training health care providers to communicate effectively.

Health literacy interventions had evidence of effectiveness could be placed in several categories. Participatory education appears to be effective in health promotion and disease prevention, as is health promotion information designed for, tested with and revised by people with limited literacy. Participatory educational methods help learners identify and research health issues and improves most aspects of health literacy. Programs using these principles and underlying theories of empowerment appear to help parents access, understand and use health information for the benefit of their own health as well as the health of their children.

Executive Summary

Project

The main objective of this project was to conduct an environmental scan of the effectiveness of interventions to improve health literacy with analysis of findings including considerations for follow-up action provided.

Methodology

The methodology for this project consisted of four main components:

- A focused search and review of the academic literature related to health literacy interventions.
- A focused search and review of the grey literature related to health literacy interventions in Canada and around the world.
- Key informant interviews.
- Analyzing the information gathered and developing a report based on it.

Key Findings

Types of interventions

The definition of health literacy used in this report is as follows: “health literacy is the degree to which people are able to access, understand, appraise and communicate information to engage with the demands of different health contexts in order to promote and maintain good health across the life-course” (Rootman & Ronson, 2005).

Using this definition as a framework, the majority of health literacy interventions appear to involve accessing and understanding health information, with very few focused on appraising or communicating health information.

Effectiveness

Very limited information was found from the sources that informed this report about the effectiveness of health literacy interventions. Health literacy interventions that did have some evidence of effectiveness could be placed into the following categories:

Health Promotion/Disease Prevention Interventions

A participatory educational approach appears to be effective in health promotion, disease prevention programs, as demonstrated by the “Literacy and Health Promotion:

Four Case Studies” project from Heart Health Nova Scotia (Heart Health Nova Scotia, 2001).

Health promotion information that has been designed for, tested with and revised by people with limited literacy appears to be effective in behavioural change interventions, such as healthier eating and weight loss (O'Loughlin, Paradis, Meshefedjian, & Kishchuk, 1998)

Literacy Interventions

There appears to be some evidence from both American (Hohn, 2004) as well as Canadian (Norton & Horne, 1998) interventions – including the READ Saskatoon project (Townsend, 2003) – that using participatory educational methods for learners to identify, research and learn about health issues, results in improvements to most aspects of health literacy.

Parenting Skills

There is also some evidence to show that programs like “Literacy and Parenting Skills” (LAPS) and “Naître égaux - Grandir en santé” (To be born equal - To grow in health) appear to help parents access, understand and use health information for the benefit of their own health as well as the health of their children. These programs are which are built on participatory education principles and underlying theories of empowerment.

Culturally Appropriate Delivery of Health Information

Cultural appropriate videos appear to be effective in increasing awareness of health resources and health service utilization (Poureslami, Rootman, & Balka, 2007).

Barriers to evaluation

Not surprisingly, there were two main barriers to evaluation of any program: time and money. These two barriers were followed by a third barrier of lack of provider expertise in evaluation.

Enablers to evaluation

Also not surprising was that when program leaders had the time, money and expertise to carry out evaluations, evaluations were completed.

Future needs

To address the gap in health literacy intervention evaluations in Canada, a number of areas of further investigation are suggested. These include the areas of:

- health literacy interventions focused on appraising health information;
- cultural issues;
- health care professional training;
- sources of health information; and,
- learner and patient perspectives.

Recommendations

Based on the key findings of this report, recommendations for next steps include the following:

- establishing a clearinghouse for categorizing health literacy interventions;
- promoting a health literacy definition; and,
- using an intersectoral approach to health literacy interventions.

Conclusions

In summary, it appears there are a number of different types of health literacy intervention projects in Canada. Unfortunately, the effectiveness of the majority of these health literacy projects has not been evaluated.

1.0 Introduction

In fall 2006, the National Collaboration Centre-Determinants of Health (NCC-DH) decided to undertake an environmental scan to find national and international interventions that had been used to improve health literacy.

1.1 Background

The field of health literacy has grown exponentially in the last few years in Canada. This growth has resulted in a number of excellent reports that have looked at the field of health literacy, including:

“A report on the state of the field: Adult Literacy” (Quigley, Folinsbee, & Kraglund-Gauthier, 2006).

“Health and learning environmental scan 2006” (Folinsbee, Kraglund-Gauthier, Grégoire, Quigley, & the Adult Working Group, 2007).

“Increasing Understanding of the Impact of Low Health Literacy on Chronic Disease Prevention and Control” by the Canadian Public Health Association coordinated by Lynn Chiarelli (Canadian Public Health Association, 2006).

“Literacy, Health Literacy and Health: A Literature Review,” prepared by Hauser and Edwards (2006).

“State of the field report for health and adult learning” (Folinsbee, Kraglund-Gauthier, Grégoire, Quigley, & the Adult Working Group, 2006).

Common to all these reports is a section on health literacy interventions. Unfortunately, the content within this section provides limited information on how effective these interventions are in improving health literacy. For example, the lack of evaluated literacy and health/health literacy interventions was a knowledge gap identified in the recent literature review conducted for the Expert Panel on Health Literacy (Hauser & Edwards, 2006).

1.2 Scope of the Project

The following questions guided the scan:

1. What interventions are taking place in Canada or elsewhere that have implications for Canada?
2. What do we know about their effectiveness?
3. What don't we know?
4. What do we need to know?
5. What are the factors enabling and inhibiting evaluation of interventions addressing literacy and health literacy as determinants of health?

The objectives of the environmental scan were to:

1. Develop an annotated bibliography of the existing health literacy interventions in Canada for funded and non-funded activities and providers, and summarize the results in a report.
2. Develop an overview of the existing health literacy intervention frameworks in applicable countries for comparative purposes.
3. Assess the health literacy intervention and evaluation needs and issues for future services in relation to priority groups.

1.3 Definitions

Definitions were used to help limit the scope of this scan. The Expert Panel on Health Literacy is also using the same Health Literacy definitions.

Health Literacy

- *Health literacy is the degree to which people are able to access, understand, appraise and communicate information to engage with the demands of different health contexts in order to promote and maintain good health across the life-course (Rootman & Ronson, 2005).*
- *La littératie en santé est la capacité pour des individus de repérer, comprendre, évaluer et communiquer de l'information pour être capables de composer avec les divers contextes de santé afin de promouvoir la santé tout au long de leur vie » (Rootman et al., 2005) [traduction libre] (Rootman, Kaszap, & Frankish, 2007).*

Although the above definitions were used to identify health literacy interventions for this scan, many people did not use a health literacy definition or held a different interpretation.

Intervention/Programs

To make sure that as many interventions as possible were uncovered, a broad definition of health literacy interventions or programs was used. Any interventions that were in place to make it easier for people to access, understand, appraise and communicate health information, which in turn would help people make health-related decisions, were included. These interventions/programs may or may not have been identified as health literacy interventions by the providers of the interventions.

Measurement of Health Literacy

A few of the research projects and interventions reviewed used a health literacy measure as a component of the evaluation of the project. The two main tools were the Rapid Estimate of Adult Literacy in Medicine (REALM) and the Test of Functional Health Literacy in Adults (TOFLHA). Please refer to Appendix 1 for a brief overview of these assessment tools and their psychometric properties.

1.4 Limitations of Environmental Scan

Limitations of this environmental scan include the following:

The information in this scan represents the health literacy interventions as of early 2007. Although a focused search was carried out in both the academic and grey literature, some interventions may have been missed. Certainly, a challenge was to actually find programs that might have been health literacy interventions. Many of these programs may be embedded in other programs and were therefore not located.

Given that this scan took place in December 2006 and early 2007, many key informants were unavailable for telephone interviews and correspondence thus occurred through email.

2.0 Methodology

This report was developed by an external consultant (Judy King) under the guidance of Dr. Lars K. Hallstrom, Acting Director of the National Collaborating Centre for Determinants of Health (NCC-DH), and Doris Gillis, a Health Literacy Advisor.

Information was broadly sought through a number of channels to identify health literacy interventions as well as programs that might have had a health literacy component embedded within them.

The methodology of the project consisted of three main components:

2.1 Literature Review - “Academic”

A focused literature review was undertaken to identify any published reports in academic literature that focused on interventions or programs that were examined to look at health literacy. Relevant research studies were sought via various databases including:

- the Cumulative Index of Nursing and Allied Health Literature (CINAHL);
- Dissertation Theses;
- Educational Resources Information Centre (ERIC);
- MEDLINE;
- EMBASE;
- PsychINFO;
- MLA international; and,
- Sociological Abstracts.

The search terms were limited to the years of 1990 to present, with no restriction placed on language. Key word searches included various combinations of: “health literacy”, “literacy and health”, “health information, program(s)”, “intervention(s)”, “programme(s)”, and “effectiveness”. A critical review of the search results combined with the examination of sources cited in other reports (e.g. Berkman et al., 2004; Canadian Public Health Association, 2005; Hauser & Edwards, 2006) and suggestions of key informants are discussed in the subsequent review.

2.2 Literature Review - “Grey Literature”

A focused review of grey (or non-academic) literature was also conducted. This included a search of the internet using search engines such as Google, Google Scholar, Yahoo, and others, with the above search terms. A search of the National Adult Literacy Database (NALD) was also completed, as was a review of conference presentations/publications and sources suggested by key informants.

2.3 Key Informants

Key informants were identified through the academic and grey literature as well as through listings of participants from health literacy conferences, the expert panel on health literacy, and members of the Canadian Public Health Association and the National Literacy and Health Partnership. Key Informants were also identified through personal contacts in literacy groups, disability networks, adult education organizations, ethnocultural groups, women’s groups, labour organizations, and aboriginal and francophone associations.

Key informants were also identified through a recent electronic scan. As part of the larger consultation process of the Expert Panel on Health Literacy, a bilingual national electronic scan on health literacy was developed and circulated in December 2006. A total of 679 people completed the scan, which consisted of 23 questions - one of which was included to help identify health literacy interventions.

More specifically, the question was, “Are you aware of any evaluated projects or interventions addressing health literacy in Canada?” Only 14.2 per cent of respondents indicated that they knew of any evaluated projects. A follow-up question asked respondents to provide their email address if they were willing to share their knowledge of these programs. Thirty-eight participants provided contact information and were subsequently contacted.

The identification of key informants was an iterative process in which one key informant would identify other key informants who might be helpful. Key informants also identified relevant resources and programs.

Initial contact with the key informants took place through email (please see Appendix 2). When possible, key informants were interviewed by phone or in person. Due to the schedule constraints of the informants, phone interviews were not always feasible. Questions and answers were therefore shared through email correspondence (Please see Appendix 3 for a list of interview questions, Appendix 4 for a list of Canadian key informants, and Appendix 5 for a list of International key informants).

3.0 Findings - Academic Literature

A number of designs including controlled randomized, uncontrolled, and nonrandomized controlled studies, most of which have been conducted in the United States, have been utilized in recent years to examine the effectiveness of interventions developed for those with limited literacy (Berkman et al., 2004). The majority of the studies that have examined intervention effectiveness thus far have looked at short-term outcomes (e.g., Coleman et al., 2003; Kim et al., 2001) with fewer examining program effectiveness longitudinally (e.g., Gardner, Jones, & Peeler, 2005). Many of the studies that will be examined in the next several sections can be categorized under access, understanding, appraisal and communication – all components to the working definition of health literacy noted elsewhere in this report. (Please see Appendix 6 for specific information on each study.)

Access Information

The initial findings from a literacy and health program development study in Canada that sought to improve health care access in low-income women via language and literacy strategies are promising (Norton & Horne, 1998) with reported increases in knowledge, behavioral changes, and awareness observed. Other interventions have provided low-income residents with access to health information through mobile means. The Outreach on Wheels program, for example, provides on site access to health information via numerous computers with Internet access, educational software, and other forms of technology located within a van that visits areas of need in Washington D.C. (Downey, Pomerantz, & Abdullah, 2004). While the effectiveness of this program needs further examination, initial commentary provided by visitors to the van has indicated an increase in knowledge of and how to access available resources. Perhaps a contributing factor to the positive outcomes of the Outreach on Wheels program is the presence of staff members who provide assistance to van visitors. A recent study has shown, for example, that those with limited literacy may not be able to employ strategic string searches that return relevant results or decipher information without guidance regardless of whether they are provided with Internet access (see Birru et al., 2004).

Actual programs that provide teachers with strategies to assist learner accessibility to health information have also been reported. The Study Circle+ program (Soricone & Lawrence, 2004) and HEAL: BCC project (Kurtz-Rossi, Coyne & Titzle, 2004) focus on literacy and language skill development rather than health content. Both programs have reported preliminary positive results with teachers from the Study Circle+ program noting an increase in student engagement, question asking, and discussion, and with those from the HEAL: BCC project similarly noting positive student outcomes, such as an increase in literacy-skills; an important facet of patient access to relevant health information.

Access to health information has also been provided through other means, such as picture stories (Singleton, 2004) and Canadian researchers have found that culturally relevant videos are an effective means of increasing awareness and use of health

services (Poureslami, Rootman, & Balka, 2007). While the ability of these programs to increase access to health-related information in those with limited literacy is promising, further testing of their effectiveness is needed.

Understanding Information

The examination of various programs on the health-related comprehension and knowledge of participants has been examined in a number of studies. A breast cancer control program in California was found to have an impact on proficiency of breast-self examinations, self-efficacy, and increased ability to correctly identify symptoms and risk factors in Latina women (Mishra et al., 1998). The success of the program was attributed to an interactive educational approach that corresponded to the literacy level of the participants, combined with an informal style that was receptive to individual beliefs. It is important to note with this study and many others the approximate duration of the intervention and period of assessment. With only 10 weeks between pre and post-test measures, the long term effectiveness of the program is unknown.

Another component contributing to program success is the involvement of community members in identifying the problem and discussing possible solutions (Jahan, 2000). For example, the Sanitation and Family Education program effectively improved the hygiene practices of community members in Bangladesh where a previous program had failed. Community involvement and direct observation of actual behaviour rather than reliance on self-reporting measures partially contributed to the success of the program. Although the implementation of the program and its evaluation was time-consuming, requiring well-trained and committed facilitators, the program elicited behaviour changes that might have otherwise not have occurred (see Jahan, 2000). Indeed, the social network of a community in Paraguay was also believed to contribute to the effectiveness of a community-based program (Ohnishi, Nakamura, & Takano, 2005).

Behavioural outcomes. Behavioural changes have been observed in some interventions (Bill-Harvey et al., 1989; Hartman, McCarthy, Park, Schuster, & Kushi, 1997; Kalichman, Cherry, & Cain, 2005) while others have yielded none (e.g., Murphy et al., 1996). Studies conducted by Kalichman and colleagues (2005) and Hartman and colleagues (1997), for example, lacked a participant control condition limiting the conclusion that behavioural changes were a result of the intervention alone (Berkman et al., 2004). Moreover, many of the interventions noted in this report used author-developed measures that did not appear to have undergone psychometric evaluation, further inhibiting the extent to which their outcomes could be generalized. A study in inner-city Montreal aimed to increase the awareness of healthy eating and weight ranges while downplaying diet and weight loss in adults of low education and socioeconomic status. Eighteen pamphlets were designed to be highly accessible to persons of low literacy who have few sources of social or clinical support. The pamphlets were adapted based on feedback from focus groups with residents from the neighbourhood, and then sent out by mail to an intervention group. This inexpensive, low-intensity intervention was effective in supporting change processes among volunteers who wanted to learn about weight control, to improve

eating habits, and to improve health (O'Loughlin, Paradis, Meshefedjian, & Kishchuk, 1998).

Literacy levels. The role that one's literacy level plays in program effectiveness appears to be variable. A recent study conducted by Rothman, DeWalt and colleagues (2004), for example, examined the role that patient literacy had on the effectiveness of a program designed to aid in the management of diabetes. The program was informed by low-literacy teaching techniques (e.g., "teach back") with a different outcome noted for those with a lower literacy level. These results suggest that literacy status may determine the benefits that can be obtained from intervention programs (Rothman, DeWalt et al., 2004). Other studies have also identified different outcomes among literacy levels (e.g. Gerber et al., 2005) while others have not (e.g., Meade, McKinney, & Barnas, 1994; Rothman, Malone et al., 2004; Wydra, 2001). Additional factors may therefore play a role in the success of various interventions on different literacy levels, such as the cultural appropriateness of the program content and readability of materials (Davis et al., 1998).

Readability. Resource materials targeted to specific groups of people have yielded positive results. Comparison of a breast self-examination pamphlet with drawings to a pamphlet with photographs developed for African American women with a low literacy level (Grade Three), revealed that women who received the pamphlet with photographs were able to detect more lumps in a silicone model. Subsequent distribution of the pamphlet containing photographs revealed greater knowledge, better examining techniques, and increased intent to perform breast self-exams among recipients (Coleman et al., 2003). Intervention patients who watched a videotape or read a booklet on colon cancer customized to their literacy level also exhibited increased colon cancer knowledge when compared to control subjects (Meade, et al. 1994). The effectiveness of the videotape and booklet intervention was also attributed to the Grade Five to Six reading level of the content.

Other studies that have used intervention brochures containing pictures and control pamphlets without pictures have shown differing results when literacy levels among participants are taken into consideration. Differences among only those with higher reading abilities (Davis et al., 1998) or no differences between intervention and controls (Wilson, Brown & Stephens-Ferris, 2006) have been found. Ease of readability and the inclusion of illustrations in educational pamphlets alone may not contribute to greater comprehension and recall.

Appraise Information

There were few appraisal-related studies (those that address the ability of people to decipher what is quality information), with those that were identified as such in this review also inclusive of understanding, access and/or communication-related content as well. Two educational programs noted positive outcomes in participant ability to appraise health information. More specifically, students involved in the Massachusetts adult basic education system showed improvement in their appraisal of reliable sources

of health information (Hohn, 2004). The affect of a CD-ROM shared decision making program on treatment preferences and intentions, level of satisfaction, and knowledge also resulted in the majority of those with prostate cancer selecting their own treatment preferences (Kim et al., 2001). Health care providers are also valuable resources for patients when determining the validity of health-related information (Levin-Zamir & Peterburg, 2001).

Similar to appraisal, the communication component of health literacy is in need of further consideration and evaluation, particularly in Canada where few examples of communication-related studies can be found (Canadian Public Health Association, 2006).

Communication Information

Interventions that address patient and/or provider communication, though few in number, are particularly noteworthy for the implications they have for Canada.

Provider communication

A recent examination of the effect of physician notification on patient health literacy prior to a doctors' visit revealed that physicians were more likely than control subjects to employ communication management strategies (such as involving family and friends in patient discussion) noted in the literature. Interestingly, physicians who were informed of patients' limited health literacy perceived their communication to be less effective than controls and were less satisfied with the visit. Moreover, patients did not score higher on a measure of self-efficacy post visit suggesting that although physicians exhibited communication behaviour changes, patients did not benefit from these changes in terms of their confidence in managing their disease (Seligman et al., 2005). Few physicians openly addressed the limited health literacy of the patient during their visit leading the authors to speculate that open acknowledgement of limited health literacy may result in better communication, benefiting the self-efficacy of the patient. Others have noted the importance of providers acknowledging the literacy level of the patient or parent of the patient so that individual needs can be addressed (Davis et al., 1998).

Patient Communication

The California Health Literacy Initiative has addressed patient communication through their *Ask Me 3* campaign. The use of wallet-sized cards that contain useful navigation information for before, during and after a doctor's visit is noteworthy. Patient communication is particularly important given provider acknowledgement of the lower quality of care they believe those with limited literacy receive (Rothschild & Bergstrom, 2004). Other communication resources, such as picture stories (Singleton, 2004) and educational programs (Hohn, 2004), have also been developed to improve patient communication and have been positively received.

Canadian Research

While a number of health literacy programs have been implemented across Canada (Canadian Public Health Association, 2005), few have been found in the literature. The initial findings of a study conducted by Norton and Horne (1998), for example, reported

that learning had taken place with changes in exercise, diet, self-assertion, sharing of support, stress management, the expression of anger in a healthy manner, and the recognition of the link between social conditions noted. While a recent study conducted by Davachi and Flynn (2005) did not examine intervention effectiveness, their diabetes screening program in Calgary, Alberta underscores the importance of community support in the success of a program (Davachi & Flynn, 2005). O' Loughlin and her colleagues (1998) study found that health promotion materials designed to be accessible to persons of low literacy were effective in helping people make behavioural changes. And Poureslami and his colleagues (2007) found that using culturally-relevant videos are an effective means to increase awareness and use of health services.

Conclusions of Academic Literature

It appears that interventions using materials that are culturally-relevant and presented in forms matching the interests of the intended recipient are particularly successful in achieving positive outcomes (e.g., Coleman et al., 2003). Indeed, developing materials geared towards specific audiences, such as those with limited literacy, should involve the representatives of the group to ensure that the end result is reader relevant (Rudd & Comings, 1994). Interactive education models where skills development rather than health content is the focus have also yielded successful results (Mishra et al., 1998). The use of videos (e.g., Wydra, 2001) and picture stories (e.g., Singleton, 2004) have also been recommended as effective teaching approaches. Such materials can be constructed to reflect the characteristics and colloquialisms of the intended reader (Rudd and Comings, 1994).

Early identification of limited literacy during initial patient/doctor visits should also take place to ensure that health care providers employ appropriate communication techniques (Wilson et al., 2006). Although the findings are somewhat unclear, evaluators should also examine whether differences among literacy levels and outcome exist. While the immediate assessment of intervention effectiveness is more often than not the most feasible method of choice, controlled designs that are longitudinal in nature are particularly valuable for their insight into whether short-term outcomes translate to sustained knowledge and behavioural changes over time. Moreover, while many of the studies discussed in this review yielded statistically significant increases in knowledge and comprehension, these increases may not be sufficient for the management of one's health in the health care environment (Davis et al., 1998). This means continued research and evaluation of program effectiveness is necessary.

3.1 What interventions are taking place in Canada?

Interventions were uncovered either through key informant contacts or grey literature. Although many key informants suggested programs, the actual program coordinators acknowledged that unfortunately many of these programs had not been evaluated.

Interventions that closely match the definition of health literacy are highlighted in this report. While other programs have a health component, such as the discussion of health

issues and the health care system in a literacy class, these types of activities were not included unless they were part of a formalized program or project.

A geographical framework will be used to frame the different interventions that are taking place in Canada. The province or territory in which the intervention is based will be used. However, for many of the programs, although interventions may be based in one province, their health literacy resources can be accessed by anyone in the world. These programs can be found in Appendix 7.

Please refer to Appendix 8 for an annotated bibliography, provided in a tabular format, of evaluations of health literacy interventions from Canada.

3.2 What interventions are taking place in other countries that have implications for Canada?

Health literacy is not only a Canadian issue, but an international topic. In fact, the World Health Organization recognizes that improving people's access to health information and their capacity to use it effectively is essential to promoting and maintaining good health. By improving people's access to health information and their capacity to use it effectively, health literacy is critical to empowerment (World Health Organization, 1997). The following section highlights international health literacy interventions.

Australia

Research Projects

A group of researchers at the Screening and Test Evaluation Program, School of Public Health, The University of Sydney, Sydney Health Decision Group, are looking at the use of written decision aids. Their project is entitled "Understanding the information needs and preferences of low and high literacy consumers in the development of a decision aid (DA) for colorectal cancer screening." The researchers are Sian Smith, Kirsten McCaffery, Lyndal Trevena, Alex Barratt, and Don Nutbeam.

The findings of their project indicate that "Both literacy groups expressed the need for scientific information to be simplified. Regardless of literacy ability, participants reflected upon additional factors (organization of sections, use of topic headings, role of the DA, and complexity of medical terms) which influenced how they processed the information. This, in turn, was shaped by their prior knowledge, expectations and experiences, as well as values and preferences" (p. 1, 2007)

A second phase involved testing the acceptability of the new version of the decision support tool with the health literacy of different participants measured by the TOFHLA and the Newest Vital Sign (Weiss et al., 2005).

The third phase of the project will involve a randomized controlled trial of the decision

aid designed for people with low literacy skills, compared with standard government information about bowel cancer screening.

Israel

Interventions

The majority of health services in Israel are provided by Clalit, which is the 2nd largest health maintenance organization in the world. Clalit provides health services to over 3.7 million people, close to 57 per cent of the population. It includes general teaching hospitals, specialty hospitals, community primary care clinics, pharmacies, and well-baby clinics.

Within the Clalit organization, health literacy interventions are a part of every program. Although it may not be their main objective, all national health promotion programs include an aspect of health literacy.

The focus of many of the interventions is to increase and improve the ability, for example, of patients to ask questions to their health care provider. Health information resources are available in plain language in Hebrew, Arabic and Russian.

Current interventions include:

- Development of a model for assessing health literacy as it relates to mass media among adolescents from Grades Seven to 11.

- An assessment initiative working with Jewish and Arab people with diabetes, using focus groups in the primary care clinics across the country.

- Health Promotion in the Elderly - with the aim to improve self-efficacy by learning, 1) how to keep a personal record of their own health, 2) how to ask questions to the health care providers, 3) how to express their needs to caregivers, and 4) how to look for health-related information.

- Youth Program - has similar aims to that of health promotion of the elderly in that it provides training about how to decipher good health information. A component of the media literacy section of the program includes encouraging critical thinking. In addition, the youth develop the materials that serve as the basis for the interventions.

All programs take into consideration relevant intercultural needs, especially among new immigrant populations, as well as age groups (i.e. adolescents, elderly, etc.).

Evaluation

An evaluation, a component of all programs, is usually completed by external people in an effort to be more ethical and non-biased. Having outside evaluators also saves time for those who actually provide the program. Workshops on how to conduct evaluations are often available for regional programs.

Research Projects

Recently the s-TOFHLA was culturally translated in Hebrew and studied by Dr. Orna Baron-Epel, Director of the Health Promotion Department, School of Public Health, Haifa University. The new test is called the Hebrew Health Literacy Test (HHLT) with publication pending.

Switzerland

Switzerland boasts a few researchers that have started to work in the area of health literacy as a part of larger European projects. The Swiss offices of public health and health promotion have recently put health literacy on the agenda.

United Kingdom

Within the United Kingdom there are large national initiatives to address some of the issues surrounding health literacy. One of these initiatives is an adult literacy language and numeracy (LLN) strategy called “Skills for Life”. One component of this strategy is “Skills for Health,” a national approach to integrating health and learning skills (Department of Health and Department for Education and Skills, 2006). Eight pilot projects to assess this strategy were completed in phase 1, which linked health improvement with adult education to improve people’s ability to manage their lives and health, as well as begin the journey to become “lifelong learners.” The World Health Association’s definition of health literacy was used for this project.

Within the United Kingdom as well as in other parts of Europe exists a move to use a health literacy definition developed at a European Public Health Forum: “Health Literacy is the ability to make sound health decisions in the context of everyday life: At home, In the community, At the workplace, In the health and social care system, In education and learning, In the market place and In the political arena” (Kickbusch, Wait, Maag, McGuire, & Banks, 2006, p. 8).

United States

Highlighted in the academic literature review were findings from both health literacy research projects as well as programs in the United States, which might be applicable in the Canadian context. These include the work of Marcia Drew Hohn (1998) with “Student Health Teams,” the California Health Literacy Initiative (Rothschild & Bergstrom, 2004), learner developed materials (Rudd & Commings, 1994), developing health curriculum for ESOL learning (Singleton, 2004), and learning how to teach health literacy (Soricone & Lawrence, 2005).

The Medical Library Association of the United States is beginning a large national project to investigate hospital-based health care provider and administrators’ awareness and understanding of health information literacy and its value in support of patient care. The completion of this project is anticipated to take place in 2008 (www.mlanet.org/resources/healthlit/hil_project_overview.html).

Other types of health literacy interventions have included such things as a weekly radio show in Texas, “Brazos Valley Health” on KEOS 89.1, in which health topics are

discussed in plain English with a nurse host. The website for the radio station provides additional resources (www.BVHealth.org) and the radio station also works with Texas A & M's University Center for the Study of Health Disparities to discuss the latest research.

International Interventions

In addition to individual countries looking at health literacy, there exist a few international organizations that have also been involved with health literacy initiatives. One such organization is Proliteracy (www.proliteracy.org), a U.S.-based organization that funds partner programs to link literacy education with community development to encourage learner-initiated action in six areas: Economic Self-Reliance, Health, Education, Peace, Human Rights, and Environmental Sustainability. Program content is diverse and includes the following:

- Access to important health information
- Learning how to use local plants for healing
- Waging disease-prevention campaigns
- Becoming trained midwives or village health workers
- Negotiating for professional health care from municipal governments

Dominican Republic - Literacy education includes topics on vida (life), agua (water) and salud (health).

China - Publishes health materials geared towards rural women from reproductive health to child safety.

Zimbabwe - AIDS education is included in literacy instruction as well as topics on planting nutritious gardens without having to buy fertilizers.

Pictograms

A Canadian pharmacist, Dr. Regis Vaillancourt, has been working for a number of years on the use of pictograms to label drugs. These projects were first started when their need was identified in post-natural disaster areas. When medication from around the world was donated, it often was not labelled in the common language of the area where it would be used. Field testing of the pictograms has been examined in Gabon and Benin by Dr. Vaillancourt and the FIP Military and Emergency Pharmacy Section (Kassam, Vaillancourt, & Collins, 2004).

3.3 What do we know about their effectiveness?

Very limited information was found from any of the sources that informed this report about the effectiveness of health literacy interventions. The health literacy interventions that did have some evidence of effectiveness could be placed into the following categories.

Health Promotion/Disease Prevention Interventions

A participatory educational approach appears to be effective in health promotion, disease prevention programs as demonstrated by the “Literacy and Health Promotion: Four Case Studies” project from Heart Health Nova Scotia (Heart Health Nova Scotia, 2001).

Health promotion information that has been designed for, tested with and revised by people with limited literacy appears to be effective in behavioural change interventions, such as healthier eating and weight loss (O’Loughlin, Paradis, Meshefedjian, & Kishchuk, 1998)

Literacy Interventions

There appears to be some evidence from both American (Hohn, 2004) as well as Canadian interventions (Norton & Horne, 1998), including the READ Saskatoon project (Townsend, 2003), that using participatory educational methods for learners to identify, research and learn about health issues results in the improvement of most aspects of health literacy.

Parenting Skills

As well there is some evidence to show that programs like the “Literacy and Parenting Skills (LAPS)”, and “Naître égaux - Grandir en santé (To be born equal - To grow in health)” which are built on participatory education principles and underlying theories of empowerment appear to help parents access, understand and use health information for the benefit of their own health as well as the health of their children.

Culturally-Appropriate Delivery of Health Information

Cultural-appropriate videotapes appear to be effective in increasing awareness of health resources and increasing use of health services (Poureslami, Rootman, & Balka, 2007).

Evaluation

The projects that included an evaluation process did not necessarily evaluate their effectiveness in improving health literacy. For example, the evaluation component may have consisted of how many plain language pamphlets were requested, but not the impact or effectiveness of the intervention.

3.4 What don’t we know?

Unfortunately, there are many areas in which the effectiveness of health literacy interventions is unknown.

3.5 What do we need to know?

Increased knowledge on the effectiveness of health literacy interventions is needed.

3.6 What are the factors enabling and inhibiting evaluation of interventions addressing literacy and health literacy as determinants of health.

Barriers to Evaluation

Barriers to evaluation appear to fall into the following categories: 1) type of program, 2) time, 3) money/funding, and 4) expertise.

1) Type of program

If the intervention is part of a community program or project-funded program, its evaluation will most likely not take place due to the factors listed below. As well, because many of the health literacy interventions uncovered in this scan were one-time only projects, they often did not continue after the funding for the pilot project was exhausted because no infrastructure was in place to sustain the project, even if it appeared to be effective.

2) Time

Time is a major barrier to completing an evaluation. As many key informants remarked, people are too busy providing services and do not have time to evaluate them. Often, unless it is a research project, the evaluation component of a program has not been budgeted into the funding and therefore the organization must take time and money away from something else for its completion.

3) Money/Funding

Further to the issue of the amount of money is the barrier of how the money can actually be used. For example, with project-based year-by-year funding, which is the case for most of the community programs, the money is to develop the resource/program. Sometimes it is the responsibility of others to actually implement the program and if evaluation is needed a new proposal has to be submitted to acquire money for the evaluation. As well, the organization must often spend their budget before the year-end or lose the money altogether.

4) Expertise

Many of the key informants provided comments that often those who are involved in health literacy interventions begin the projects due to their passion of the content area (e.g., health literacy, or the social justice aspects of the field). These same people, however, may not have any passion for administration, policy or evaluation. Moreover, people may not have the skills and experience to undertake an evaluation. For example,

one key informant mentioned that he “didn’t know to ask for money for evaluation” until after the project was finished and it was too late.

Enablers to Evaluation

1) Type of program

If the intervention is part of a research project, it will be evaluated. With research, the research questions are linked to the evaluation – they go hand in hand. Further, programs from large organizations are more likely to be evaluated because it is part of the “culture” of the organization and the organization has the monetary resources to undertake the evaluation.

2) Time

If there is time allocated in the operating budget of an organization, the evaluation will occur. As well, having external evaluators execute evaluations saves time for those who provide the interventions.

3) Funding

Funding for research projects will always have a component designated for evaluation.

4) Expertise

Some funding organizations have recognized the issue of expertise and are using a method called “research friends” to address the problem. Students with masters degrees are assigned to a grant recipient to help with the evaluation component. Another method is for organizations to link with partners that have the desired knowledge. The challenge with this approach is in finding the right partner.

4.0 Recommendations

Clearinghouse

Many informants mentioned that it was sometimes difficult to find out about health literacy interventions going on in Canada. There is a definite need to have some sort of clearinghouse to help both literacy and health practitioners find information about health literacy interventions. On the whole, it appeared that many of the literacy practitioners had a better sense than health care practitioners of what other health literacy interventions were in place. The clearinghouse could help with knowledge exchange and, of course, dissemination of health literacy intervention project information.

Of course, this clearinghouse needs to be maintained on a website. Many of the key informants suggested that the Canadian Public Health Association National Literacy and Health Program would be the most appropriate website for the location of the

clearinghouse due to its long history of working in the area. Provincial and government agencies would then need to provide a link to this clearinghouse website.

Definition/Conceptual Framework

Even though there are a number of excellent reports about health literacy interventions, it was at times very challenging to find them. Interesting to note is that challenges were encountered when trying to encourage some key informants to be interviewed because they felt they did not know of any health literacy programs and they had not categorized what they were doing as health literacy interventions. This sometimes seemed due to the fact that they did not appear to know about health literacy as a concept.

A more well-known definition and conceptual framework for health literacy might make it easier for people to identify and categorize programs. As referenced previously, the four components of the health literacy definition used for this scan were: 1) accessing information, 2) understanding information, 3) appraising information and, 4) communicating information. These four components could be used as a basis to build a conceptual framework.

Often, interventions may be focused on more than one component of the health literacy definition. Each component builds upon the other. One must first find information or access it, and then understand what they have found. It's necessary to appraise or analyze the information to see if it is helpful and trustworthy.

The component of communication may be intertwined throughout the other three phases or as a final phase in making an informed decision with a health care provider. In the first three phases, the person may not actually have interaction with a health care provider. Instead, they may be looking at issues of health promotion and disease prevention, such as smoking cessation or weight loss.

Inter-sectoral Approach

Another recommendation that emerged from the scan is for future health literacy interventions to be designed using an inter-sectoral approach, not just to isolate projects in one aspect of the health care or education system. There is a need for community agencies to come together to identify what needs to be done in terms of health literacy across and between organizations and to collaborate on shared programs.

Integrating literacy throughout all government programs instead of having specific health literacy interventions is an approach being used in Quebec. The whole governmental approach to health literacy issues is one that is inter-sectoral. Therefore initiatives in health, for example, need to be linked with initiatives in adult education.

Given that people have multiple entry points into health care, health literacy cannot only be a public health issue, but needs to be addressed in primary care, acute care, and

chronic disease management. Clalit in Israel has recognized this reality and has approached health literacy throughout its large health maintenance organization.

At the same time, there is a need to make sure that the health literacy intervention is appropriate for the community. As Canadians, we often try to provide the same type of program coast to coast to coast, but that might not be possible when it comes to health literacy intervention. The smaller regional community programs work well because the people understand their context and the community that they are living and working within.

5.0 Future Needs - Health Literacy Interventions

Appraisal of Health Information

Health literacy is a relatively new topic area in which there is not a large community of practice. This may be the reason that many of the projects discovered in this environmental scan appeared to be one-time projects, unconnected to others. The interventions uncovered fall into the access, understanding and communication components of health literacy. Although there are a few interventions that are geared toward improving people's ability to appraise health information, more are needed. One area that might be related is the use of decision-making tools. Over the last few years with the development of decision-making tools, the ability to make health-related decisions has improved for patients. Investigating the use of decision-making tools with the issue of health literacy may be helpful.

Cultural Issues

As with the need for health literacy intervention effectiveness research, there is also a need to investigate interventions that are targeted at improving health literacy for members of Aboriginal, Francophone and multicultural communities.

Although there are a few projects that are looking at issues of health literacy with people who are immigrants or refugees, most are based in large urban centers. There is also a need to undertake projects in smaller communities, where there maybe more recent populations of new Canadians who may be trying to access health information and services but are unable do to health literacy barriers.

Health Care Professional Training – Inter-professional

Although this scan's goal was to identify health literacy interventions that helped individuals access, appraise, understand and communicate health information, it also identified the continued need to raise awareness of the issue amongst health care providers. Many of the key informants mentioned there is still a large gap between how health care practitioners view health literacy and how literacy practitioners view the issue.

To help reduce the burden of health literacy barriers for individuals, health care providers need not only to be aware of the issue. There is a need for a “cultural shift” to occur in health care away from putting the onus on the patient to try to figure out health information to making health information more accessible in terms of health literacy. Many key informants felt that a greater emphasis on training health care providers on effective communication skills would help reduce some of these barriers. As well, the key informants mentioned that to be consistent in approaches it would be helpful to use an inter-professional educational approach when teaching about health literacy and communication so that all health care providers have the same set of knowledge and skills.

Sources of Health Information

Canadians have multiple sources of health information. These sources include people, (friends, family, health care providers, volunteer caregivers, nontraditional health care practitioners), the Internet, consumer health information, health charities’ information, television, magazines etc. There is a need to investigate the delivery of this health information, as well as the use of other method, such as sign language, translators, videos and websites.

For example, the Canadian Health Network website (www.canadian-health-network.ca) provides health information for consumers on a number of health topics in both English and in French. As well, there are some articles about literacy and health on the website.

Other organizations, such as the Patient Self-Management program in Ontario, provide health information to help people with chronic diseases to manage their conditions (www.ontpsm.net).

There have been evaluations of these websites in terms of readability, visual appeal etc., but not with regard to the effectiveness of these interventions.

There is a lack of health literacy interventions in place to help people appraise and sort out all of these different sources of health information.

Learner/ Patient Perspectives

Although many of the interventions reviewed in this scan included needs assessments to find out the health information needs of learners or patients, there is a lack of learner and patient perspectives about what they feel are the health literacy interventions that would be most helpful for themselves and their families.

Recently the Canadian Council on Learning conducted a Survey of “Canadian Attitudes toward Learning” (Canadian Council on Learning, 2007). One aspect of the survey was to investigate people’s attitudes and experiences in health-related learning. One of the major findings was that people can find information but that it can be conflicting.

As well, in the past few years there have been several studies that have explored the experiences of adult literacy learners with the health care system. Although this might be helpful as a starting point, it appears that people require help in all aspects of health literacy, in accessing, understanding, appraising, and communicating health information.

Participants in a recent qualitative study that investigated the patient education experiences of adults living with limited literacy and chronic illnesses suggested that health care professionals try several different learning approaches and methods with a person, including visual material with props or pictures, verbal instruction and a written pamphlet or handout. It was evident the participants had determined their own optimal learning methods after frustrating and difficult experiences, and were eager for health care providers to accommodate these learning methods through different teaching methods and media (King, 2007).

Regardless of the method of delivery, participants thought that health care professionals must check patients' understanding of health information and advice through follow-up questions at later appointments. Participants emphasized that such education and follow-up must be delivered using a non-threatening and nonjudgmental approach (King, 2007).

To help with communication, participants suggested that paid or volunteer translators be made available during health professional visits when the patient is less comfortable in the language of the health care provider. This person could be a friend, family member or even someone from the government (King, 2007). In their study, Gillis and Quigley (2004) found that people recommended the use of what they termed "client advocates" who would "help people move through the health care system and to interpret when English is not the first language (p. 33)."

Participants in the Canadian Public Health Association's second Canadian Conference on Literacy and Health shared their experiences living with limited literacy. Their personal stories, their expertise, and their views about dealing with the health care system were recorded through focused workshops conducted in French and English (Canadian Public Health Association, 2005). There was also a Learners' Gallery which showcased the participants' stories, art and poetry based on their experience with health and the challenges and barriers they encountered (Canadian Public Health Association, 2005). Suggestions included using simple words, talking slowly, using both oral and written information, showing respect, including pictures and videos, having the patient attend appointments with someone else, and telephoning within one week's time to check up on the patient. Conference participants also recommended that learners speak to health care students, use videos in waiting rooms, and slow down to build trust (Canadian Public Health Association, 2005).

6.0 Conclusions

This environmental scan uncovered a variety of very exciting health literacy interventions which appear to show a growing interest and commitment to the field. Unfortunately, not many of these interventions have been evaluated. For the interventions that have been evaluated there is a major gap in knowledge exchange and it was very challenging to uncover these programs.

Even though a health literacy definition was used, many people contacted for this scan had very different views of what health literacy is. For example, some key informants assumed that health literacy meant providing information only for literate people – they did not perceive it as having something to do with people with limited literacy. Others viewed health literacy as the same as health information or patient education.

Many of the key informants expressed concern that this confusion and clouding of the issue may result in projects that are geared toward people with limited literacy being lost because programs are trying to address issues of health literacy for everyone.

Although the focus of the environmental scan was on interventions designed to help individuals, individuals must interact with many systems. Therefore there is also a need to address and improve the practice and models of service delivery to reduce all health literacy barriers for Canadians.

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