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# **THE IMPACT OF LOW HEALTH LITERACY ON CHRONIC DISEASE PREVENTION AND CONTROL**

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This report was adapted from *Increasing Understanding of the Impact of Low Health Literacy on Chronic Diseases Prevention and Control*, researched and written by Lynn Chiarelli, July 2006.

## **WHAT IS CHRONIC DISEASE PREVENTION AND CONTROL?**

This report defines chronic disease as any physical condition associated with a decrease in health lasting more than six months, and for which contact had been made with one or more health care professionals.

The World Health Organization's definition of disease prevention includes primary, secondary and tertiary prevention.<sup>1</sup> Based on this definition, primary prevention is directed towards preventing the initial occurrence of a chronic disease. This includes efforts to reduce risk factors for one or more chronic diseases, such as through smoking cessation programs or promoting healthy lifestyle practices such as regular exercise and healthy eating. It would also include promoting access to the basic resources needed to ensure health, such as adequate income, housing, social inclusion and a healthy environment.

Secondary prevention seeks to arrest or retard existing disease and its effects through early detection and appropriate treatment. This would include efforts such as screening and management of diabetes, heart or respiratory diseases or early detection of cancer.

Tertiary prevention is aimed at reducing the occurrence of relapses and applies primarily to acute conditions that recur, although preventing the recurrence of acute complications of a chronic disease would be considered tertiary prevention.

Within these three levels of prevention, there are important links to integrated chronic disease prevention, which targets risk factors common to a number of chronic diseases. There are also important links to health promotion, health education, primary health care and patient education for chronic disease care and self-management

## **CHRONIC DISEASE RATES IN CANADA**

In March 2006, a summary report was released examining chronic disease in Ontario and Canada.<sup>2</sup> It draws from a review of major chronic diseases and their associated risk behaviours: smoking, unhealthy eating and physical inactivity.<sup>3</sup>

Chronic diseases are the leading causes of death in Canada. In 2002, more than 75% of all deaths were due to one of five chronic diseases: cancer, heart disease, diabetes, kidney disease and respiratory diseases.<sup>4</sup> The number of new cases of chronic disease and rate of death change over time. Table 1 summarizes chronic disease trends.<sup>2</sup>

**Table 1 –Chronic Disease in Canada**

|                     |   |
|---------------------|---|
| Cancer              | <p>In 2005, there were approximately 149,000 new cases of cancer expected. Three types of cancer account for at least half of the new cases:</p> <ul style="list-style-type: none"> <li>• prostate, lung and colorectal cancers in men</li> <li>• breast, lung and colorectal cancers for women</li> </ul>  |
| Heart Disease       | <p>Heart disease continues to be the leading cause of death, although the number of deaths and the death rates are decreasing over time. The number of deaths due to heart disease is expected to increase for women until 2015 and to remain stable for men until 2025. Almost 80% of the Canadian population has at least one of the most common risk factors for heart disease:</p> <ul style="list-style-type: none"> <li>• smoking</li> <li>• being physically inactive or overweight</li> <li>• having high blood pressure or diabetes</li> </ul>   |
| Respiratory Disease | <p>Asthma is a chronic disorder with symptoms of cough, shortness of breath, chest tightness and wheeze.</p> <ul style="list-style-type: none"> <li>• over 2.2 million Canadians report being diagnosed with asthma</li> <li>• the number of deaths from asthma has decreased between 1984 and 2001</li> <li>• Chronic obstructive pulmonary disease (COPD) is characterized by shortness of breath, cough and sputum production due mainly to chronic bronchitis and emphysema.</li> <li>• an estimated 500,000 Canadians had COPD in 1998/99</li> </ul>                                       |
| Diabetes            | <p>People with Type 1 Diabetes cannot produce any insulin. With Type 2 Diabetes, the production is limited and not effective. Type 2 diabetes affects people after the age of 40 and is preventable.</p> <ul style="list-style-type: none"> <li>• diabetes risk factors, including physical inactivity, over-eating, and obesity, increase the risk of other chronic diseases like heart disease</li> <li>• more than 1.2 million Canadians are estimated to have diabetes.</li> <li>• the number of deaths from diabetes increased 35% between 1997 and 2002, to 3.5% of all deaths</li> </ul> |
| Mental Health       | <p>One in five Canadians will experience a mental illness in their lifetime.</p> <ul style="list-style-type: none"> <li>• in 2002-2003, mental illnesses accounted for 15% of hospital stays in Canada</li> <li>• approximately 8% of adults will experience major depression at some time in their lives</li> <li>• more women than men live with depression.</li> </ul>   |

## HOW MIGHT HEALTH LITERACY AFFECT CHRONIC DISEASE PREVENTION?

Understanding what we know about preventing chronic disease helps to explain the impact of low literacy and low health literacy on health outcomes and on the effectiveness of prevention efforts.

Research shows that changing individual health behaviours can reduce risk factors and reduce the likelihood of developing a chronic disease. At the same time, there is growing attention being paid in the field of chronic disease prevention to the pathways linking chronic disease and inequity in health of the population.<sup>5</sup> There is a solid evidence base demonstrating the impact of cultural, social and economic factors on the prevalence of chronic disease and on the outcome of chronic disease prevention and management interventions.

## CHANGING HEALTH BEHAVIOURS TO REDUCE RISK

Research shows that physical inactivity and unhealthy eating are factors that increase a person's risk of developing the most common chronic diseases, as well as smoking, alcohol and other drugs.

Everyone has different interests or motivations for changing their behaviour. People move through different stages of change which lead to taking action to improve their health. A model of these stages of change is commonly used to help design prevention interventions. See Table 2.

**Table 2 - Stages of Change<sup>6</sup>**

|                   |   |
|-------------------|---|
| Pre-Contemplation | Person is not yet interested in changing their health behaviour |
| Contemplation     | Person starts to think about the need for change                |
| Preparation       | Person starts to plan for change and take small steps           |
| Action            | Person takes action for to change their health behaviour        |
| Maintenance       | Behaviour change becomes part of day-to-day living practices    |

This way of looking at change sheds light on how low health literacy may be a barrier to reducing risk factors for chronic disease such as physical inactivity and unhealthy eating/weights.

- Without access to health information that is clear, easy-to-understand and meaningful to the individual, there will be limited knowledge and/or motivation to change.
- To plan for change, information about realistic, achievable options is needed, reflecting the home, work and community contexts.
- To take action, practical supports may be required at the individual and community level to overcome barriers.
- Information, options, the ability to take action and make healthy choices are limited by social, economic and cultural factors.

## **SOCIAL AND ECONOMIC FACTORS**

Prevention efforts are limited if the focus remains on changing individual health behaviours without looking at the social, economic and physical environments where people live and work. Behaviours are strongly influenced by family, school, neighbourhood and work environments, as well as by social networks and social supports, the organizations and institutions in the community, and the public policies of all levels of government. This is the social ecological approach to health promotion.<sup>7</sup> Interventions that address all of these factors may be more effective at changing health behaviours and improving health.<sup>8,9</sup>

Chronic illnesses are more prevalent in poorer regions of Canada. The evidence linking inequity and chronic disease was summarized in a discussion paper focused on Atlantic Canada:<sup>5</sup>

In both 1986 and 1996 census data, Canadians living in the poorest 20% of urban neighbourhoods had strikingly higher mortality rates for cardiovascular disease, cancer, diabetes, and respiratory diseases than those living in higher-income neighbourhoods. Low-income groups such as Aboriginal peoples, visible minorities, and single mothers and their children consistently have worse health than the rest of the population. They have higher rates of smoking, poor diet, obesity and physical inactivity, which also are symptoms of deeper underlying social and economic factors. Strategies to reduce inequities need to increase social and economic inclusion within these groups.

There is evidence of high rates of low literacy and low health literacy in low-income populations. Looking at social and economic factors is relevant to the design of interventions for chronic disease prevention to accommodate health literacy challenges. Lower rates of education for Aboriginal peoples in Canada have been linked to the socio-economic challenges facing Aboriginal communities. Literacy and socio-economic conditions are intertwined with a holistic definition of health that includes physical, mental, spiritual and social aspects and that promotes self-knowledge, self-expression, self-affirmation, healing from colonization, and self-determination.<sup>10, 11</sup>

Prevention research suggests that interventions need to focus on where people live, learn, work and play. The various sub-groups that make up the population with low health literacy in Canada also have distinct patterns in where they find health information, their ability to navigate the health system, and the supports they have in place to act on health information. The policies of organizations and of government can have a major influence on reducing barriers and enabling people to access information and resources for healthy living.

## **CULTURAL FACTORS**

A review of the way in which health and social services have served diverse populations identifies inequalities between Canada's ethno-racial minority populations and the general Canadian population for each determinant of health (e.g., gender, income, social support networks).<sup>12</sup> There are differences among Canadian-born and immigrants

and there are differences among ethnic groups, regardless of how long they have been established in Canada. The reasons for the disparities remain poorly understood.

Important disparities have also been documented with regard to specific illnesses and/or immigration status. Refugees have higher incidence and mortality rates for cardiovascular, infection and respiratory diseases and cancer than other immigrants.<sup>13</sup> Membership in an ethno-racial minority group or being a recently arrived immigrant increases a person's likelihood of being poor.<sup>14</sup> Ethno-racial minorities, whether Canadian or foreign born, face greater economic difficulties than other Canadians and are disproportionately represented in jobs with long hours and low pay. These realities create conditions conducive to stress-related illnesses.<sup>15</sup>

Culture-based literacy for Indigenous peoples appears to be about self-determination through programs designed to cultivate literacy as a process of recovering a sense of positive Indigenous identity.<sup>10</sup> Language and literacy include important cultural symbols that give meaning, which goes beyond the ability to read and write.<sup>16</sup> Loss of language and cultural symbols for many Aboriginal peoples in Canada has resulted from colonization and government policies such as the residential school system.<sup>17</sup> For this reason, language, culture, values, and beliefs are essential considerations in improving the health and well-being of Aboriginal peoples.

Cultural beliefs and practices form the foundation of our behaviours intended to protect and promote good health and to treat health problems. Despite the wide range of services available, research documents the barriers faced by members of ethno-racial minority or immigrant communities in making use of these services.<sup>12</sup> Health status indicators for Aboriginal peoples in Canada have been consistently and significantly lower than for the general population and inequitable access to health services has been documented.<sup>17</sup>

Community-based strategies for health promotion have long-recognized the need for culturally-appropriate strategies to address access barriers. The role of health literacy in these disparities is just beginning to be explored in Canada.<sup>18</sup> This is increasingly recognized as an important factor in chronic disease prevention and management, and has implications for policy and program development.

## **LOW HEALTH LITERACY AND CHRONIC DISEASE MANGEMENT**

In many cases, chronic disease prevention and management efforts overlap. Strategies to increase physical activity and to encourage healthy eating/weights not only prevent chronic diseases from developing, but also can improve health outcomes and prevent complications for those living with a chronic disease. There are a number of characteristics of chronic disease management that explain how low health literacy affects outcomes and may influence the effectiveness of interventions. When a person with low health literacy is living with a chronic disease, serious barriers to self-care can arise.

## **COMPLEXITY OF CHRONIC DISEASE MANAGEMENT**

In many cases, people living with chronic disease have more than one condition and may have a complex care plan involving multiple medications and medical instructions. Keeping track of all that is required for treatment is difficult, even for people who have no challenges with reading, writing and applying information in other aspects of their life.

## **MULTIPLE PROVIDERS AND CARE SETTINGS**

Not only can medical instructions be complex, but, typically, patients come into contact with many different service providers. There are often challenges with the coordination of care. Patients may receive inconsistent messages from different providers as they make their way through the system. It may also be difficult to determine where to go for information and support.

Depending on the resources available in the community, a person living with a chronic disease in Canada may be followed by a physician or nurse practitioner in private practice or in another primary care setting such as a community health centre or clinic. In remote communities, particularly in the North, public health nurses may be the primary caregivers with the support of community health representatives.

In some locations, there are examples of integrated chronic disease management where multi-disciplinary teams provide the care, often including physicians, nurses/health educators, pharmacists, dieticians and social workers, and sometime including other health professionals such as rehabilitation therapists and respiratory therapists. For more complex chronic disease management, patients may receive treatment through specialists, hospital outpatient or inpatient services or through home care services. In addition to seeing providers for assessment and treatment, patients typically need to visit labs for tests to monitor their condition.

## **IMPORTANCE OF SELF-MANAGEMENT**

Unless they are in a care facility, Canadians living with chronic diseases are expected to manage their own care, under the periodic instructions of one or more health care providers, usually a physician. This means organizing lab tests and regular visits to a physician or other provider and taking medication as prescribed. This includes using monitoring devices to measure their condition and understanding how to modify their medication or other behaviours based on the results. Self-management also includes making changes to diet, exercise and other lifestyle factors that may affect their condition.

Important components of self-management include understanding the health condition and treatment, being able to track and communicate symptoms and other important personal information, learning skills for self-care, and knowing where to find the resources that are available for support.

## **LIMITED TIME FOR CARE AND PATIENT EDUCATION**

In spite of the complexity of care, and in the absence of a well-functioning integrated team, patients have limited time with their provider. For example, a typical physician visit to monitor diabetes takes place every 3 months unless there are serious complications. This visit typically lasts 12 to 15 minutes.<sup>19</sup> In that time, the provider must carry out an assessment, order any tests required, answer questions and provide instruction for self-care.

Under the best of circumstances, this can be challenging for both the provider and the patient. Time is an important factor in building trust and collaboration between provider and patient. For adults with literacy barriers, new skills for self-management are best learned through listening to verbal explanations, watching demonstrations and practicing over repeated visits. Limited time for direct contact gets in the way of this learning process.

## **LOW HEALTH LITERACY AND CHRONIC DISEASE MANAGEMENT**

A framework has been developed that introduces the ways in which limited health literacy might influence health care outcomes.<sup>20</sup> The framework was developed by Dean Schillinger, a researcher who has studied the relationship between limited health literacy and chronic disease management of diabetes and other conditions. This type of framework helps to identify points of intervention and shows the broader social context that affects the quality of care and health outcomes for people with limited literacy and/or limited health literacy.

Schillinger points out that literacy skills are necessary but not sufficient for health literacy. The problems that result from limited health literacy are most intense for people with limited literacy skills. He notes that reducing disparities related to health literacy revolve around:

- Directly addressing the problem of basic literacy; and/or,
- Creating a health care system in which the gap between the literacy demands of the system and the literacy skills of the patients served is significantly narrowed.

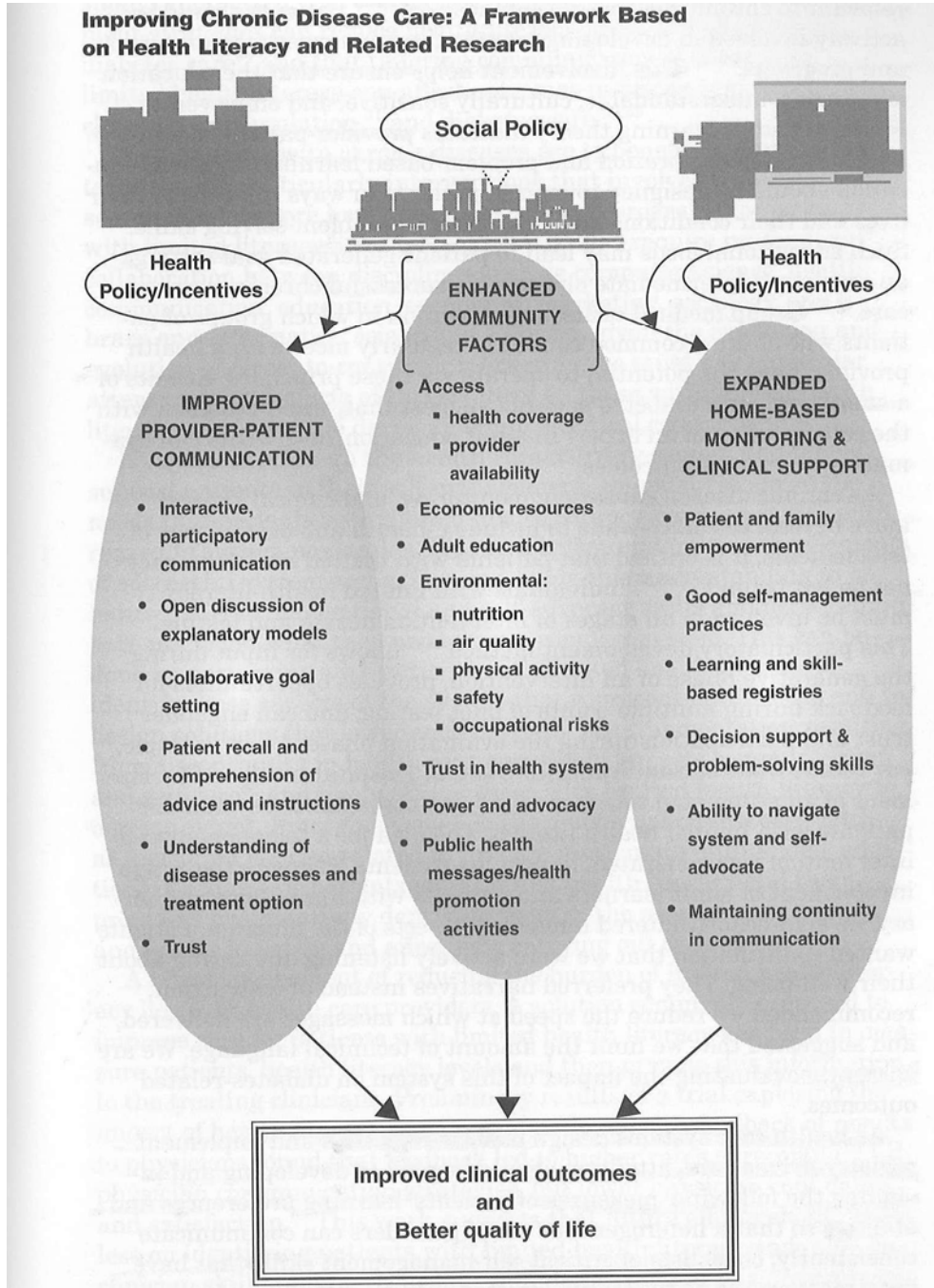
The framework developed by Schillinger is based on elements of an accepted model for restructuring chronic disease management.<sup>21</sup> This model was adapted to create the BC Expanded Chronic Care Model, which includes health promotion and disease prevention.<sup>22</sup> It recognizes the importance of productive interactions between the patient and health service providers. Productive interactions require informed patients and trained, well-prepared health service providers.

The patient-provider interaction is influenced by factors outside the health system such as healthy public policy, supportive environments, and strong community action. It is also affected by health system factors such as self-management skills for the patient and required skills and resources for the provider to deliver quality care.

Limited health literacy may affect the interaction between patient and provider and the patient and health system. It may also impact the ability of the individual with their community and environment to take care of their health. Without paying attention to

the challenges of limited health literacy, improvements in chronic disease management may not reduce health disparities experienced by vulnerable populations.

**SCHILLINGER FRAMEWORK<sup>20</sup>**



**REFERENCES**

1. World Health Organization. *Health Promotion Glossary*. 1998. Geneva: World Health Organization p.4.
2. Haydon, E., Roerecke, M, Giesbrecht, N., Riehm, J. and Kobus-Matthews, M. *Chronic Disease in Ontario and Canada: Determinants, Risk Factors and Prevention Priorities*, March 2006. Prepared for the Ontario Chronic Disease Prevention Alliance and the Ontario Public Health Association.
3. Harvey, Dexter, Hook, Ethel, Kozyniak, Jennifer, Selvanathan, Morgan *Building the Case for the Prevention of Chronic Disease*. Disease Intervention Division, Centre for Chronic Disease Prevention and Control, Health Canada, March 31, 2002.
4. Statistics Canada. *The Daily*. September 27, 2004. Catalogue 11-001-XIE.
5. Hayward, K. and Colman, R. *The Tides of Change: Addressing Inequity and Chronic Disease in Atlantic Canada*. A Discussion Paper prepared for the Population and Public Health Branch, Atlantic Region. July 2003.
6. Adapted from Prochaska JO, DiClemente CC, Norcross JC. In search of how people change. *Am Psychol* 1992; 47:1102-4.
7. McLeroy, KR, Bibeau, D, Steckler, A. et al. An ecological perspective on health promotion programs. *Health Education Quarterly*, 1988; 15(4):351-377.
8. Stokols, D. Translating social ecological theory into guidelines for community health promotion. *American Journal of Public Health*, 1996; 10(4): 351-377.
9. Hancock, L., Sanson-Fisher, RW, Redman, S, et al. Community action for health promotion: A review of methods and outcomes 1990-1995. *American Journal of Preventive Medicine*, Jul-Au 1997; 13(4):229-39.
10. Smiley, J., Williams, L, Cooper, N. Culture-based literacy and Aboriginal health. *Canadian Journal of Public Health*, 2006, S21-S25.
11. Canadian Public Health Association, *Summary Report: Second Canadian Conference on Literacy and Health*, September 2005, pp. 33-35.
12. Oxman-Martinez, J, Hanley, J. *Health and Social Services for Canada's Multicultural Population: Challenges for Equity*. Discussion paper prepared for Canadian Heritage, 2005.
13. Vissanjee, B, DesMeules, M. Cao, Z. Abdool, S. and Kazanjian, A. (2004) Integrating ethnicity and migration as determinants of Canadian women's health. *BMC Women's Health*, 4, S32
14. DesMeules, M. Gold, J, Kazanjian, A., Manuel D Payne, J, Bissandjee, Be, McDermott, S., Mao, Y: New Approaches to Immigrant Health Assessment. *Canadian Journal of Public Health*. 2004; 95(3):122-126.
15. Dunn, JR and Dyck, I (2000). Social determinants of health in Canada's immigrant population: Results from the National Population Health Survey. *Social Science and Medicine*, 51, 1573-93.
16. Korhonen, M. Literacy and Health: *The Importance of Higher-Level Literacy Skills: A Discussion Paper for Inuit Communities*. Ajunnginiq Centre: 2006.

17. Canadian Institute for Health Information, Canadian Population Health Initiative. *Improving the Health of Canadians*. Canadian Institute for Health Information: 2004, pp.75-104.
18. Zanchetta, M, Poureslami, I. Health Literacy Within the Reality of Immigrants' Culture and Language. *Canadian Journal of Public Health*, 2006, S26-S30.
19. Personal communication, Dr. Michael Cussen, March 2006.
20. Schillinger, D. A Conceptual Framework for the Relationship between Health Literacy and Health Care Outcomes: the Chronic Disease Exemplar. In *Understanding Health Literacy: Implications for Medicine and Public Health*, Schwartzberg, J., VanGeest, J., Wang, C. eds.. American Medical Association Press. 2005, pp181-203.
21. Wagner, E. *The Chronic Care Model. Improving Chronic Illness Care*; 2003. Available at [www.improvingchroniccare.org/change/model/components.html](http://www.improvingchroniccare.org/change/model/components.html).
22. Barr, V. et al. *BC's Expanded Chronic Care Model*. Accessed on May 22, 2006 at <http://www.hlth.gov.bc.ca/cdm/cdminbc/>