



LESSONS IN LEARNING

Patient self-management:
Health-literacy skills required

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Treating and managing chronic conditions is one of the main components of health-care provision in Canada. This type of health care puts tremendous pressure on the health-care system, but patients who engage in their own self-management can benefit from improved health outcomes while decreasing their reliance on the health-care system. Patient self-management requires solid health-literacy skills, yet few Canadians possess these skills.

Chronic conditions and the health-care system

Increasingly in Canada health care is provided to people with chronic conditions such as diabetes, asthma, congestive heart failure, renal failure and chronic obstructive pulmonary disease. A large proportion of the available health-care resources is devoted to treating chronic conditions and, in Canada, 67% of all health-care costs are incurred as a result of caring for those with chronic conditions. More than half of Canadians aged 12 or older report at least one chronic condition¹ and at age 65, 77% of men and 85% of women have at least one chronic condition.²

Chronic diseases often occur with co-morbidities—other concomitant but unrelated diseases—and co-morbidity further increases the demand for health care. For example, individuals with diabetes and very high co-morbidity are expected to use ten times the health-care resources of the population average.³ The number of people with diabetes in Canada is projected to increase from approximately 1.4 million patients in 2000 with a cost of \$4.66 billion to 2.4 million in 2016 with a cost of \$8.14 billion (1996 dollar values).⁴ Moreover, the increased prevalence of diabetes (and renal vascular disease with hypertension) has contributed to a rise in end-stage renal disease with patients requiring dialysis and sometimes organ replacement.⁵

In addition to diabetes, other risk factors such as smoking, physical inactivity, high blood pressure, and obesity contribute to the epidemic of heart disease and stroke in Canada at a time of constrained resources in health organizations. Heart disease and stroke are the leading cause of hospitalization for men (starting at age 45) and women (starting at age 55) in Canada. An increase in the number of seniors in the population who have risk factors will lead to an increased need for additional services.⁶

There is mounting concern that health-care providers will not be able to deal with increasing chronic illness with existing resources and decreasing numbers of people entering the health-care professions. Although treatments for chronic disease are becoming more effective, access to services is a growing problem.

Patient self-management

In the face of growing demand for scarce health-care resources, patients suffering from chronic conditions can contribute to their own care by engaging in patient self-management. Self-management includes all of the “tasks that an individual must undertake to live well with one or more chronic conditions. These tasks include gaining confidence to deal with medical management, role management and emotional management.”⁷

Recent evidence suggests that patients who engage in effective self-management experience positive health outcomes and place fewer demands on the health-care system. For example, based on a review of 14 randomized-control trial studies of patients taking oral medication for a chronic condition (covering a total of 3,049 patients), researchers concluded that patients who engaged in self-management saw increased treatment benefits and reduced harms relative to those whose care was entirely managed by health-care professionals.⁸ In a study of the economic benefits of patient self-management, researchers estimated that providing chronic patients with education on self-management as well as ongoing supervision by a case manager would yield a savings of over \$2,000 per patient per year.⁹

Health literacy

Health literacy plays a crucial role in chronic disease self-management. In order to manage chronic or long-term conditions day-to-day, individuals have to be able to understand and assess health information (often a complex medical regimen) plan and make changes to their lifestyles, make informed decisions and understand how to access care when they need it.^{10,11} However, according to the Adult Literacy and Life Skills Survey, more than half (55%) of working-age Canadians do not have adequate levels of health literacy and only one in eight adults (12%) over age 65 has adequate health-literacy skills.¹² This lack of skill prevents many patients from engaging in effective self-management: the review of randomized-control trial studies noted above revealed that 62% of patients were unable or unwilling to engage in self-management.¹³

Populations most likely to experience low-literacy levels are among those being asked to manage their conditions—older adults, ethnic minorities, people with low levels of educational attainment, people with low income levels, non-native speakers of English, and people with compromised health status.¹⁴ Low functional health literacy has been identified as an issue even for those elderly who are more affluent and educated than the national norm.¹⁵ Also, those with low literacy skills are not likely to attend voluntary peer-led self-management programs even if they are aware they exist. In 2003, the Institute of Medicine in its priority areas for national action, identified self-management/ health literacy as an area that cut across many health problems. “Improved health literacy was put forward as a condition necessary to enable active self-management by patients for most conditions.”¹⁶

Health-care professionals and health literacy

Health professionals often overestimate patients’ literacy. One study at a women’s health clinic found that physicians only identified a small proportion (20%) of patients considered to have low literacy.¹⁷ Among elderly patients, many with chronic conditions, researchers found that four out of five were unable to read and understand basic medical instructions.¹⁸ “Patients typically cover up by faking it, avoiding situations that require reading, leaving their glasses at home and asking family and friends for help. Even the most poised and articulate patients may have trouble reading, and...are unlikely to step forward and ask for help.”¹⁹

Despite growing evidence of the link between health literacy, patient self-management, and health outcomes, some health professionals are reluctant to adopt a role in health literacy. A project in Nova Scotia discovered that it was important to begin by increasing awareness of health-literacy issues among health-service providers.²⁰ In a survey of allied health professionals in the U.S., less than one third of the respondents were aware of the issues surrounding health literacy or that health-literacy resources were available. They also did not have institutional or policy goals to address health literacy in their organizations.²¹ Another survey by the American Medical Association Foundation, in 2003, found “that the issue of health literacy is just a blip on many physicians’ radar screens.”²²

Literacy Partners of Manitoba, a provincial umbrella group, committed to raising literacy levels in Manitoba, emphasized the connection between literacy and health in all its community outreach activities. They implemented 16 training sessions for health-care workers and found in their evaluation that “...the links between literacy and health were a revelation to some health professionals. It was a link that needed to be made again and again.” Two-thirds of the respondents in the evaluation reported that they had changed the way they did things after they became aware of the issue.²³

In B.C., health-care providers were asked about challenges related to providing support for patient self-management. In addition to a number of health-system issues, some of the responses focussed on providers’ skills and competencies:

- Health-care providers do not have the skills to use self-management support strategies.
- Limited self-management support training is available for practicing health-care providers.
- Some did not believe that health-care providers had a role in providing self-management support.

Lessons in learning

Low levels of health literacy present a formidable challenge to the widespread and effective use of patient self-management. There is good evidence, however, that this challenge can be met. A study of asthma self-management found that inadequate health literacy was a surmountable barrier to learning and remembering key asthma self-management skills in one-on-one, written and oral instruction.²⁴ In another study in which communication to diabetes patients was individualized and delivered to enhance comprehension among patients with low literacy, these patients were found more likely than control patients to achieve goal levels.²⁵

Fostering better conditions for successful self-management must begin with health-care providers. The education of health professionals needs to include information on the high prevalence of inadequate functional health literacy and its relationship to poor health, and to incorporate training on how to be effective in addressing the needs of low health-literacy patients.²⁶ As well, health-care providers “need to be supported to develop the competencies to provide self-management support and to have options for self-management support available to match the needs of the patients.”²⁷

The Canadian Public Health Association's Expert Panel on Health Literacy has identified a number of health literacy initiatives across Canada, some of which help health-service providers and institutions promote health literacy with plain language and picture manuals.²⁸ Nova Scotia has gone even further and adopted a policy on health literacy. The Rural Nova Scotia Research Project identified a number of actions, two of which are: to increase awareness of literacy as a determinant of health, and to increase awareness of literacy issues among primary health-care providers. The Guysborough Antigonish Strait Health Authority presented health literacy awareness sessions to 185 primary health-care providers followed by a survey to evaluate how well the sessions raised awareness. Health literacy awareness orientation sessions were also held using a government video and audits were to be carried out annually using a health-literacy environmental-assessment tool.²⁹ Building on that work, the Nova Scotia Departments of Health and Education developed a Health Literacy Awareness Initiative to raise awareness among primary health-care providers about literacy issues and how they can help their patients to understand health information better.

Increased patient self-management has been shown to improve health outcomes, but it is also an important sustainability issue for the publicly funded health-care system. Patient self-management support has been recognized as a necessary and evolving role for health-care providers. Addressing health-literacy challenges of patients is a component of patient self-management support. Health-care providers need to enhance their capacity to support the patient self-management agenda.

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