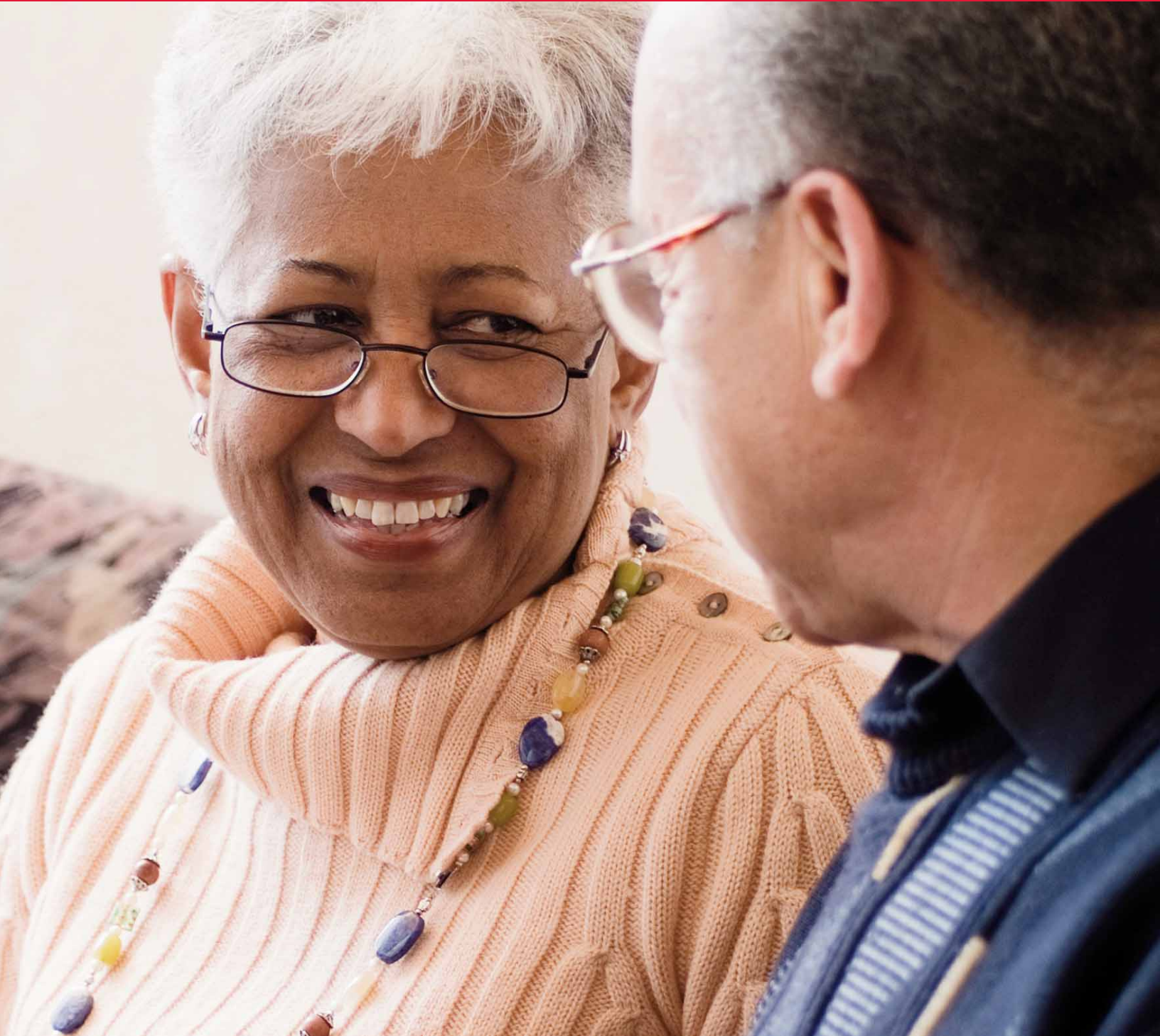


Helping Patients Help Themselves:

Are Canadians with Chronic Conditions Getting the Support They Need to Manage Their Health?



With the right kind of supports from their health care providers, patients can build knowledge and confidence to help reduce the physical and emotional impact of chronic disease. Ideally, they will feel they have some control over their health condition, rather than having *it* control *them*.

Survey reveals gaps in care

Many Canadians with chronic conditions such as diabetes and heart disease say they don't regularly receive some types of support recommended to help them better manage their health.

This is the main finding of the Health Council of Canada in a survey of Canadians about their primary health care. The Health Council's analysis focused on Canadians with chronic conditions.

Helping patients manage chronic disease is an increasingly important part of primary health care in Canada. Chronic conditions are on the rise due to unhealthy lifestyles and the aging of our population.¹ Along with prevention, one of the best ways to reduce the impact of chronic disease on people's lives and on their need for expensive health care services is through a partnership of patients, their family doctor, and other professionals.^{2,3}

However, the survey suggests disturbing gaps in the delivery of what's known as self-management support, which is intended to give patients the knowledge and skills to manage their health problems between visits. This support includes such things as asking patients about their goals in caring for their

chronic conditions and referring them to community services that might help them reach those goals.

Although patients with three or more chronic conditions are more likely to receive self-management support, compared to those with just one chronic condition, this good news is dampened by the low levels of support that patients reported overall.

This bulletin takes a closer look at these data, which are based on the responses of more than 5,000 adults with chronic conditions to the 2008 Canadian Survey of Experiences with Primary Health Care, a collaborative project by Statistics Canada, the Canadian Institute for Health Information, and the Health Council of Canada (see "About the survey"). We then look at the thinking behind self-management support, and at the changing role of primary health care for people with chronic conditions.

We also want to hear from readers about your experiences with self-management. Your responses will help inform our future work in this important area of primary health care in Canada. Visit www.healthcouncilcanada.ca and click on Canada Values Health.

ABOUT THE SURVEY

The **Canadian Survey of Experiences with Primary Health Care** provides cross-Canada population-based estimates on topics related to access, use, quality and outcomes of primary health care and of chronic illness care. The Health Council of Canada collaborated with Statistics Canada and the Canadian Institute for Health Information in developing the survey.

Statistics Canada conducted the survey by telephone from April 14 to June 30, 2008. The 11,479 adults aged 18 and older who participated were selected from respondents to the 2007 Canadian Community Health Survey. This sample represents people living in many kinds of communities across Canada, but does not include people living in institutions (such as very ill people in long-term care), in some remote areas and on First Nations reserves, as well as members of the Canadian Forces.

Of these respondents, 5,137 reported having been diagnosed with at least one of seven select chronic

conditions (arthritis, cancer, chronic obstructive pulmonary disease (COPD), diabetes, heart disease, high blood pressure, and mood disorders including depression) and having seen a doctor at least once in the previous 12 months. This group is the basis for the data about patient self-management reported in this bulletin.

More information about the survey, including the questionnaire, is available at Statistics Canada's website, www.statcan.gc.ca, under "Definitions, data sources, and methods." Requests for custom tables or access to data should be directed to Statistics Canada (ssd@statcan.ca).

All differences discussed in this report are statistically significant. A technical appendix describing the statistical analyses and 95% confidence intervals for data in this bulletin is available on request from the Health Council of Canada (information@healthcouncilcanada.ca).

At least two in five Canadians have a chronic health condition

Nearly two in five Canadian adults (39%) have at least one of seven common chronic health conditions (arthritis, cancer, chronic obstructive pulmonary disease (COPD), diabetes, heart disease, high blood pressure, and mood disorders including depression), the survey found. These conditions were selected for the survey because they affect many people (high prevalence) and/or they often lead to the intensive use of health care services (high impact).

Nearly all respondents (at least 95%) with one or more of the select chronic conditions have a regular family doctor or other regular place they go for health care such as a clinic or community health

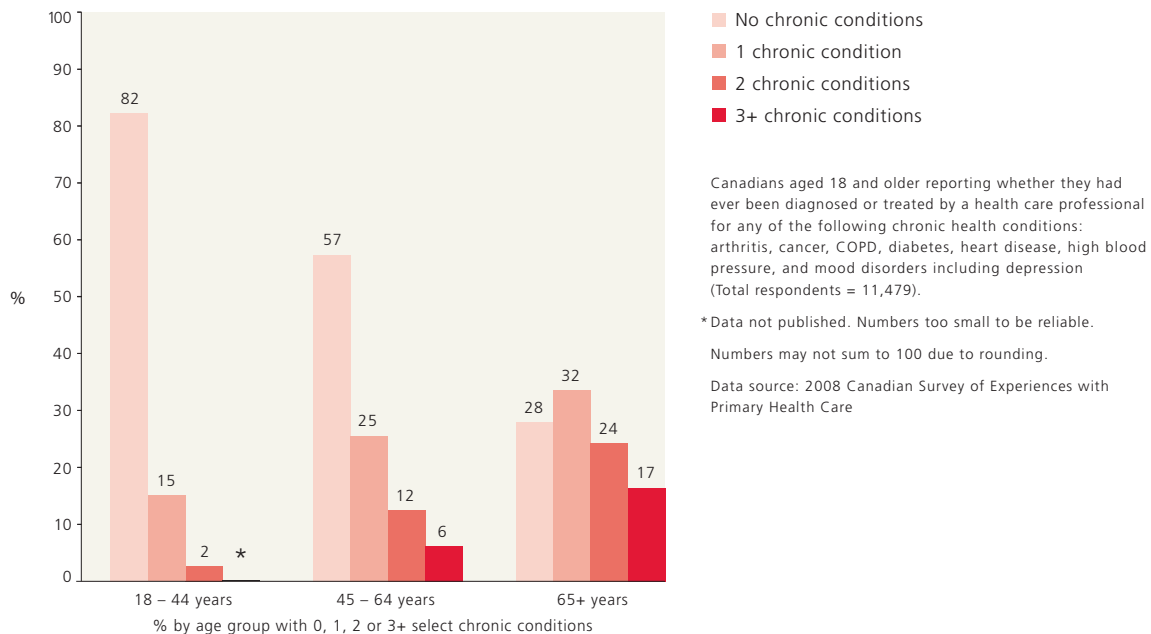
centre, said the Canadian Institute for Health Information (CIHI) in an earlier analysis of the same survey.⁴

Close to three-quarters (72%) of Canadians aged 65 and up report having at least one of the seven select chronic conditions. Older Canadians are more likely than younger age groups to have multiple chronic health conditions (Figure 1).

FIGURE 1

How many Canadians have chronic health conditions?

Chronic conditions are more common as people age, and having multiple chronic conditions tends to make people's health problems more complex. Older Canadians are significantly more likely than younger and middle-age adults to have two or more chronic conditions.



Support for patients varies a lot and is not high overall

Patients diagnosed with the select chronic conditions were asked about care they receive from their family doctor or regular place of care.

In our analysis, we grouped together people who answered “sometimes,” “most of the time” or “almost always” to questions about receiving specific kinds of self-management support during their primary health care visits during the past 12 months. And we looked at two high-needs groups – seniors (aged 65 and up) and people with multiple chronic conditions.

The proportion of people who report receiving various types of support differs by age group and by the number of chronic conditions they have.

Older Canadians are less likely to receive some kinds of self-management support, although they are the group most likely to have chronic health conditions (Figure 2). On the other hand, people with multiple chronic conditions are, regardless of their age, more likely to receive each type of support compared to those with just one condition (Figure 3).

But overall, the level of self-management support appears low (Figure 3):

- About half to two-thirds of Canadians with one or more of the select chronic conditions are asked to talk about their goals in caring for their chronic disease.
- About two-thirds are shown that what they do to care for themselves influences their health condition(s).
- About one-quarter to one-third receive a written list of things they can do to improve their health.
- At best, one-quarter are referred to a specific group or class to help them cope with their health problems. About the same percentage are encouraged to attend a community program (such as a support group or exercise class) that could help them.
- At best, one-quarter to under one-half are told how their visits to specialists or other doctors help their treatment.

WHAT PATIENTS WERE ASKED

Canadians with one or more chronic conditions were asked six questions about whether their regular primary health care provider (usually a doctor) offered them different types of support to help them manage their condition(s). Patients were asked the following.

In the past 12 months, were you:

- asked to talk about your goals in caring for your chronic condition?
- shown that what you did to take care of yourself influenced your health condition?
- given a written list of things you should do to improve your health?
- encouraged to go to a specific group or class such as an educational seminar to help cope with your chronic condition?
- encouraged to attend programs in the community such as support groups or exercise classes that could help you?
- told how your visits with other types of doctors (e.g., specialists or surgeons) helped your treatment?

Adding to this picture is a report by CIHI, one of our partners in this survey, looking at many aspects of primary health care. CIHI found that:

- 40% of Canadians with one or more of the seven select chronic conditions did not make a treatment plan with their health care provider during the past 12 months.
- 40% of patients with three or more chronic conditions reported that, during the past year, they rarely or never talked to a health care professional about specific things they could do to improve their health.⁴

FIGURE 2

Who receives self-management support? Responses by age group

Although Canadians aged 65 and up are most likely to have chronic conditions, they are less likely to report receiving some types of self-management support during their primary health care visits. Compared to the other age groups, they are less likely to be referred to a specific group or class, or encouraged to make use of appropriate community programs. Older Canadians are also less likely than those 45–64 years old to be given a written list of things they could do to improve their health.

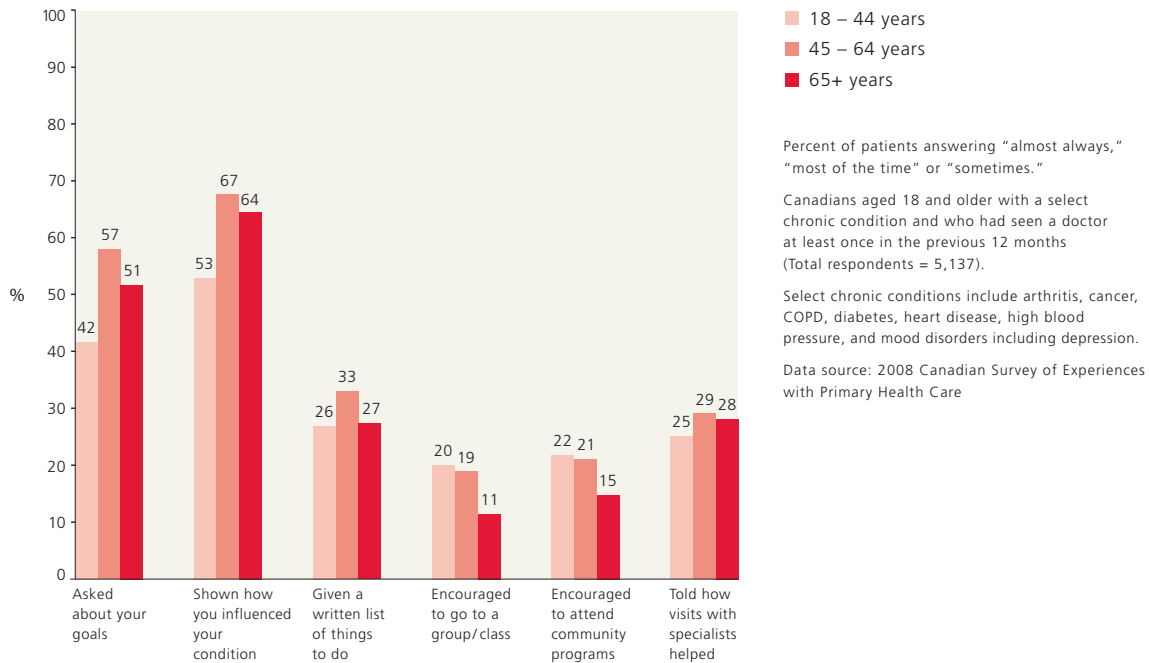
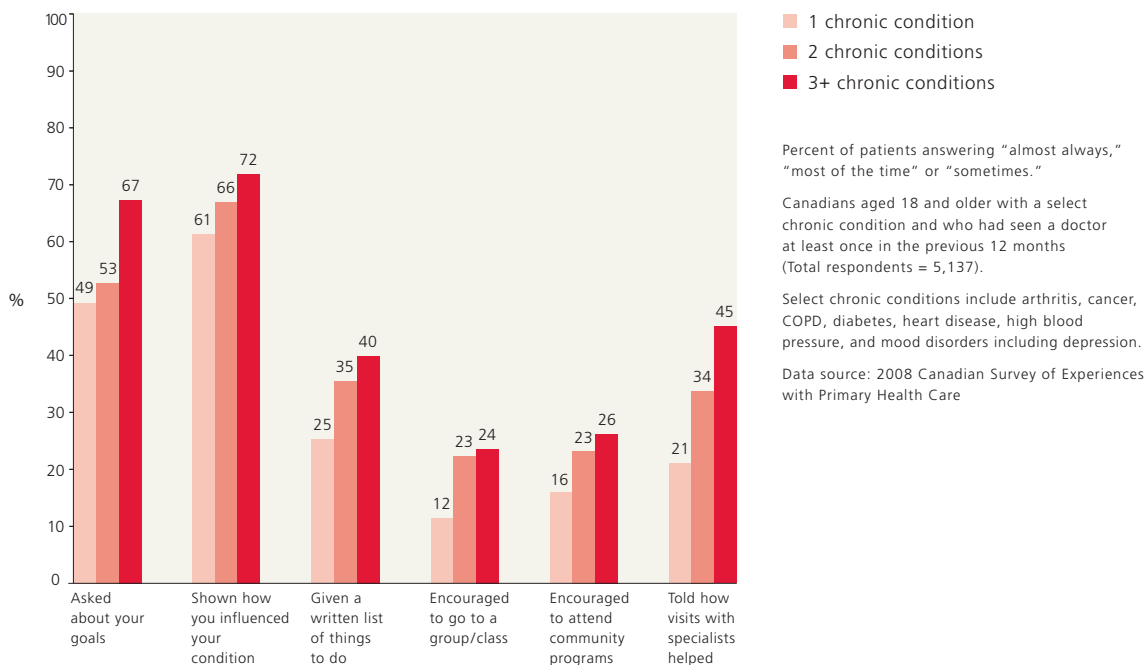


FIGURE 3

Who receives self-management support? Responses by number of chronic conditions

People with three or more chronic conditions are significantly more likely to report receiving each type of support from their provider, compared to people with only one diagnosed condition. Overall, however, many Canadians with chronic conditions are not receiving self-management support.



What is patient self-management?

For patients, self-management means having the skills and opportunity to be effective partners in their own health.⁵ Patients with self-management skills can recognize when they have a problem and have the confidence to take appropriate action.⁶ As some observers have noted, the issue is not *whether* patients with chronic conditions manage their health, but *how well* they manage it.^{3,6} What people eat, how they exercise, whether they take appropriate medication, and how they cope with stress – these are among the many self-management challenges Canadians with chronic conditions face every day.

With the right kind of supports, patients can build the knowledge and confidence they need to help reduce the physical and emotional impact of their disease. Ideally, they are able to keep up important everyday activities such as a job and family life, and they feel in some control over their health condition, rather than having *it* control *them*.

For health care providers, self-management support involves more than educating patients about their condition,^{7,8} a role family doctors have traditionally played. It includes asking patients about their goals, checking in with them on their progress, and connecting them with support programs specifically designed for people with chronic conditions. Self-management also involves giving patients tools that can help them at home, such as a written list of things they can do, and talking to them about how the different components of their health care, like visits to specialists, are (or should be) working together.

Some chronic disease management programs in Canada give patients a take-home binder loaded with information about how to manage their condition. The binder may include charts to track things like diet, exercise, medication concerns, blood sugar and blood pressure, and these items are updated at every visit and by patients at home. This kind of personal health record can be empowering for patients, providing them with resources and opportunities to stay in control.^{9,10}

A number of studies have looked at whether self-management programs are effective. There is good evidence they can reduce emergency department visits and hospital admissions^{3,11} and can pay for themselves by saving health care costs.¹²

Patients have also reported that self-management programs have reduced their pain and improved their ability to handle daily living, though the research evidence is not as strong here.¹³ Some studies suggest that self-management programs can be particularly effective for patients with severe illness,¹⁴ and that adapting programs for people with low literacy can benefit socially disadvantaged patients.¹⁵

Why primary health care in Canada is changing: doctors can't do it alone

Governments and health care organizations across Canada are concerned about the growing prevalence of chronic disease among their populations. Health care spending is steadily climbing,¹⁶ and a large portion goes to diagnose and treat people with chronic conditions. In a 2007 report, we showed that Canadians with chronic health conditions used at least half of all consultations with family doctors and nearly three-quarters of all nights spent in hospital.¹⁷ This is echoed in a 2007 survey of Canadian family doctors. Four out of five reported growing demands on their time due to the management of patients with chronic conditions and the increasing complexity of their patient caseload.¹⁸

Like chronic conditions, government spending on health care per Canadian rises with age. It increases slowly from age 1 (about \$1,000 per person in 2007) to age 64 (about \$3,800), and then sweeps up to more than \$7,700 per person for ages 70-74 and even higher for older age groups.¹⁶ How will we afford the explosion of costs as older Canadians become a larger share of our population? Experts believe that our growing economy will be able to handle these trends – if we can prevent and delay the impact of chronic diseases.¹⁹

That's why improving chronic disease management is a key element of primary health care renewal underway in every jurisdiction.^{10, 20} Governments that fund most of our health care and the organizations that deliver the care see that primary health care needs to be a target of efforts to better manage our health resources and help Canadians lead more active and healthy lives.

And there is increasing recognition that better chronic disease management cannot be accomplished by doctors alone. The idea that primary health care should be re-organized around patients who are considered partners in a health care team has been gaining ground over the past 10 to 15 years.^{3, 21} As we illustrated in our 2009 report, *Teams in Action: Primary Health Care Teams for Canadians*, health care renewal initiatives are embracing diverse teams of medical, nursing, and other professionals, along with networks of community services. These teams can better help patients with chronic conditions become knowledgeable, motivated, and capable participants in their care, and they can better support people with complex social and economic challenges that may hamper their ability to get the health care they need.^{10, 22}

In a family doctor's office, change may be as simple as having an assistant (after appropriate training) spend a few minutes with patients asking how they are doing with their goals for their chronic illness care. This approach, part of a larger strategy to improve care for people with chronic conditions, is described in physician-education videos available on the website of Impact BC, a health care quality-improvement agency in British Columbia.⁹

Chronic disease "collaboratives" are another strategy featured in our 2007 report *Why Health Care Renewal Matters: Lessons from Diabetes*. By joining a collaborative, family doctors gain access to a range of support mechanisms organized by their provincial ministry of health, medical

association, or local health region – things like seminars about patient self-management and electronic tools to monitor how well their practice is caring for patients with chronic disease. Collaboratives aim to improve patients' quality of life and help doctors by fostering care that better matches expert guidelines.^{7, 23}

It takes a village

How can patient-focused, team-based care for people with chronic illness lead to better health outcomes? Research shows improvements such as better control of blood sugar among people with diabetes, many fewer hospital admissions, and much less use of emergency room visits.^{24, 25} It's no coincidence that successful initiatives in Canada and other countries tend to be based on an evolving concept called the Chronic Care Model (Figure 4).

Developed in the US in the 1990s, the Chronic Care Model describes how health care should be redesigned to more effectively and efficiently care for people with chronic conditions.^{2, 26} The model is based on a philosophy of patients taking an active role in their care, supported by their primary care providers working together with specialists within a supportive community. Basically, the Chronic Care Model says, "it takes a village" to reduce the personal and social impact of chronic health conditions.

A recent report from the Canadian Senate, *A Healthy, Productive Canada: A Determinants of Health Approach*, further reminds us that formal health care accounts for only about 25% of the things that influence Canadians' health. The other 75% of factors are determinants of health that lie outside of the health care system. Income, education, circumstances in early childhood, social supports, and other factors, along with individuals'

genetic makeup and physical surroundings, all affect whether or not people are healthy and how well they can manage their health problems.²⁷

In the face of this reality, the Senate report advocates a “whole of government” approach – coordinating many kinds of social policy changes – to reduce health disparities within Canada’s population and to improve more people’s chances of living long and productive lives.²⁷ Thirty-five years ago, a similar call came from Marc Lalonde, then Minister of National Health and Welfare. In his famous report, *A New Perspective on the Health of Canadians*, Lalonde said, “Marvellous though health care services are in Canada,” they are only part of the picture, and a relatively small part at that.²⁸

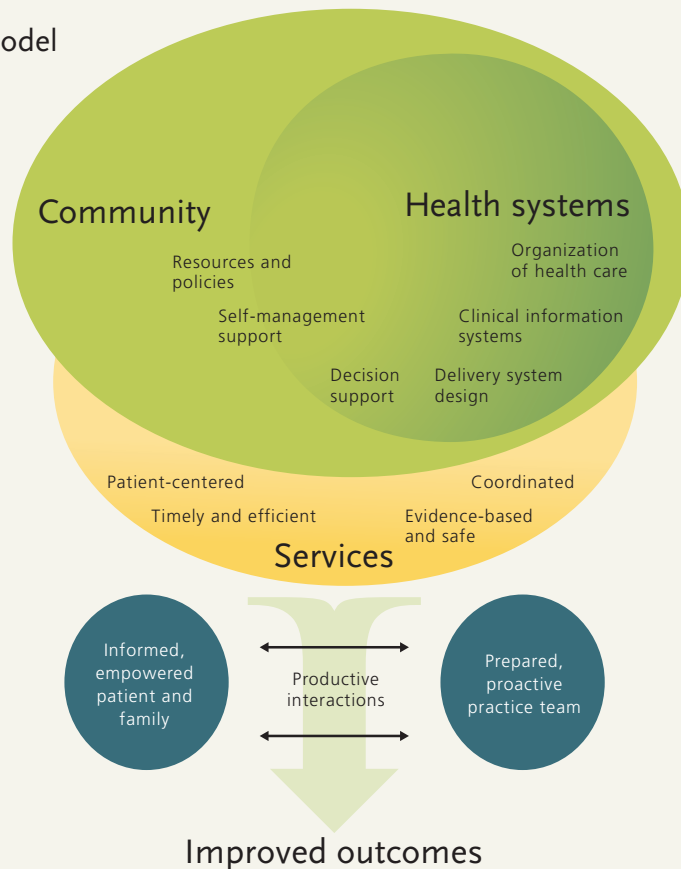
This broad perspective is critical in addressing chronic disease in Canada. Social determinants affect whether or not someone has a chronic condition (for example, rates of diabetes are much higher among lower-income and Aboriginal Canadians),^{17, 23, 27} and they play a crucial role in people’s capacity to effectively manage those health problems. An excellent self-management tool will not be much help if it is in a language or reading level that patients can’t understand. Self-help classes are not much use if people can’t get to them because of transportation issues or problems at home. Primary health care providers need time, information, and team support to be able to tailor their self-management approaches to the life circumstances of each individual patient.

FIGURE 4
The Chronic Care Model

Source:
www.improvingchroniccare.org.

The Improving Chronic Illness Care program is supported by The Robert Wood Johnson Foundation, with direction and technical assistance provided by the MacColl Institute for Healthcare Innovation at Group Health Research Institute.

Reproduced with permission. The Chronic Care Model was originally published in: Wagner EH. (1998). Chronic disease management: what will it take to improve care for chronic illness? (Figure 1). *Effective Clinical Practice*; 1: 2–4.



Why is self-management not a basic fact of Canadian health care today?

It's important to keep in mind that the survey data presented here are just a snapshot of one aspect of the reforms in primary health care and chronic disease management underway across Canada. The survey included people with seven common chronic conditions, but there are others. Patients were asked about the support they received from primary care providers, but not from other professionals or peer helpers who may already be engaged in their care. And patients were asked about some key features of self-management support, but not all. We recognize that our analysis represents some pieces of a more complicated puzzle.

That said, our research suggests some good news. Compared to patients with only one condition, people with multiple chronic illnesses are more likely to receive self-management support during their primary health care visits. And the proportion of patients receiving support is moderately high for at least some components of self-management. These are hopeful signs that primary health care is beginning to make the shift from the single-disease focus of the past to an approach better suited to the increasing complexity of chronic disease.

At the same time, the survey also points to concerning gaps in self-management support for Canadian patients with chronic conditions, and it raises many questions such as:

- Are the patients receiving self-management support the people who need it most?
- Who is falling through the cracks, and why?
- Are appropriate programs available and accessible?
- What barriers are preventing primary health care providers from making self-management support a regular part of their chronic illness care?

High-quality primary health care and supportive social policy to help patients prevent and manage chronic illness is a cornerstone of sustainable health systems. This will continue to be a focus of reporting by the Health Council of Canada in the coming months.

READ MORE

The Health Council of Canada has focused much of our research and reporting on chronic conditions because of their huge impact on the health care system and on Canadians' lives. We have highlighted the evidence from research showing that much of this burden can be prevented through changes in health care and public policies related to health. All of the following reports are available in our online library at www.healthcouncilcanada.ca:

Teams in Action: Primary Health Care Teams for Canadians (2009)

Getting It Right: Case Studies of Effective Management of Chronic Disease Using Primary Health Care Teams (2009)

Fixing the Foundation: An Update on Primary Health Care and Home Care Renewal in Canada (2008)

Population Patterns of Chronic Health Conditions in Canada: A Data Supplement (2007)

Canadians' Experiences with Chronic Illness Care in 2007: A Data Supplement (2007)

Why Health Care Renewal Matters: Learning from Canadians with Chronic Health Conditions (2007)

Why Health Care Renewal Matters: Lessons from Diabetes (2007)

We want to hear from you.

The Health Council of Canada wants to hear from Canadians about your experiences with chronic conditions and the role of self-management in your treatment.

- Do you receive self-management support from the people you see for primary health care? If so, what specific types of support do you get?
- Are there programs and resources accessible to you in your community to help you manage your chronic conditions? If so, which did you find most helpful?
- What types of support from your providers would you find most useful?
- Are there types of support that have been mentioned or that you receive that are not helpful to you?
- If you were to set one goal to improve your health or better manage a condition you have, what would that one goal be?
- What would help you achieve your goal?
- What would be most likely to get in the way?

Please share your experience at www.healthcouncilcanada.ca by clicking on Canada Values Health.

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As always, the analyses and conclusions of this bulletin are the responsibility of the Health Council of Canada and do not necessarily reflect the views of external reviewers or consultants, or the organizations with which they are affiliated.

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ABOUT THE HEALTH COUNCIL OF CANADA

Canada's First Ministers established the Health Council of Canada in the 2003 *Accord on Health Care Renewal* and enhanced our role in the 2004 *10-Year Plan to Strengthen Health Care*. We report on the progress of health care renewal, on the health status of Canadians, and on the health outcomes of our system. Our goal is to provide a system-wide perspective on health care reform for the Canadian public, with particular attention to accountability and transparency.

The participating jurisdictions have named Councillors representing each of their governments and also Councillors with expertise and broad experience in areas such as community care, Aboriginal health, nursing, health education and administration, finance, medicine and pharmacy. Participating jurisdictions include British Columbia, Saskatchewan, Manitoba, Ontario, Prince Edward Island, Nova Scotia, New Brunswick, Newfoundland and Labrador, Yukon, the Northwest Territories, Nunavut and the federal government. Funded by Health Canada, the Health Council operates as an independent non-profit agency, with members of the corporation being the ministers of health of the participating jurisdictions.

The Council's vision

An informed and healthy Canadian public, confident in the effectiveness, sustainability and capacity of the Canadian health care system to promote their health and meet their health care needs.

The Council's mission

The Health Council of Canada fosters accountability and transparency by assessing progress in improving the quality, effectiveness and sustainability of the health care system. Through insightful monitoring, public reporting and facilitating informed discussion, the Council shines a light on what helps or hinders health care renewal and the well-being of Canadians.

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