in focus backgrounder

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Leading knowledge exchange on home and community care

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Supporting Self-Managed Care

Introduction

Supporting self-managed care means having the appropriate knowledge, skills and opportunity to be an active and effective partner in one's health with adequate supports from health and social service providers, health educators and health policy planners.

This *In Focus* looks at how people with chronic health conditions can better manage their care, as well as the different ways health and social care providers and the system can support people managing their chronic health conditions.

Chronic health illnesses are conditions that:

- "usually develop slowly, last a long time, and in most cases, have no cure" (Health Council of Canada, 2007b, p. 14);
- require ongoing adjustments by the person needing care and ongoing interactions with the health care system (MacColl Institute for Healthcare Innovation http://www.improvingchroniccare.org/);
- can affect Canadians of any age (e.g., children with complex care needs).

Why self-managed care?

Demographic trends

- Nearly two in five (39%) of Canadians have one of seven chronic health condition (arthritis, cancer, COPD, diabetes, heart disease, high blood pressure and mood disorder) (Health Council of Canada, 2010).

- Statistics Canada estimates that by 2031, the proportion of Canadians over 65 is expected to grow from the current 13 percent to about 24 percent (Bélanger, Maron & Caron-Malenfant, 2005).

- Today's older people are generally healthier and more active than their counterparts in previous years. Nonetheless, they do experience greater incidences of chronic health conditions and make greater use of health care services than other age groups (Canadian Council on Learning, 2007; Health Council of Canada, 2007a) particularly in the last stage of their lives.

- Advances in medical technology have resulted in an increase in the number of children surviving birthing complications and serious illnesses. These children now require ongoing health care and/or technological support for the rest of their lives. Whereas in the past these children would have spent their lives in institutions, many are now living in their homes and communities where parents and other family members take a significant role in directing and managing their care (Spalding & Salib, 2008).

Changing values and increasing awareness

There is increasing public and professional awareness along with changing social values that many people have both the capacity and desire to be more active and engaged partners in their care. Advances in internet and other communications technologies mean that people now have instant access to tremendous volumes of information which they use to make care decisions. While health professionals remain the primary and trusted source of health expertise, more and more people are using other sources of information such as the internet to augment their knowledge. Along with readily available knowledge is the expectation for immediate and highly personalized health care (Forkner-Dunn, 2003). People want care that meets their needs and

responds to their unique life conditions (e.g., educational, economic and housing situation).

It is also important to recognize that people with disabilities have for decades successfully managed and directed their care. For example, Cheshire, a non-profit organization supports the care needs of people with physical disabilities in the London, Ontario area by providing attendant services which enable individual responsibility, independence, activity, participation and integration into community life (http://www.cheshirelondon.ca/). People with chronic health conditions are becoming more aware of models long used by people with disabilities. They, and their health and service care providers are beginning to recognize the benefits of self-managed care and are adapting these models to address the unique needs of chronic health conditions.

Changing values among clients is matched by attitudinal changes among providers. Across the health, home and community care continuum, health and allied health professionals working in multi-disciplinary health teams recognize that "client- or patient-centred care" is a critical component of quality healthcare (Institute for Alternative Futures, 2004; Health Canada, 2004).

Just as clients require support to manage their chronic conditions, providers who care for chronically ill patients see that they too can benefit from clearer guidelines, specialty expertise and integrated information systems.

Technological innovations

Many treatment options which previously could only be supported technologically in hospitals are now regularly supported in home and community care (e.g., dialysis and some forms of cancer treatment).

Internet and information communications systems enable people to access their electronic files. People can self-monitor health conditions and can send ongoing care issues and test results to their health providers.

The internet may also enable people with the same health conditions to connect as virtual online support groups (Forkner-Dunn, 2003). For example, *Teen Connector*, a social networking and informational resource site allows teens with cancer to share both anonymously and at their convenience, their experiences with a broad range of health and social issues relevant to their age group. The site also matches users with an older teen or young-adult mentor who has gone through a childhood cancer experience (http://teenconnector.ca/Terms.aspx).

Concerns about the impact of chronic diseases on the sustainability of the health care system

A key driver of supporting self-managed care for chronic illnesses is the potential to sustain the health system through cost savings.

- Chronic diseases account for almost half of the annual cost of illness in Canada, approximately two-thirds of direct health care costs, and almost 60% of indirect costs (Canadian Coalition of Public Health). Overall, chronic diseases cost the Canadian economy about 77 billion dollars.

- 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 (Health Council of Canada, 2007b).

- Treatment for chronic illnesses such as diabetes and related conditions such as heart disease, stroke and kidney disease currently cost Ontario over $5 billion each (North Simcoe Muskoka Local Health Integration Network, 2010).

- In the Wagner Chronic Care Model, supporting self-management is one component of a much broader range of health renewal initiatives which may help alleviate the burden on acute care providers. See http://www.improvingchroniccare.org/index.php?p=The_Chronic_Care_Model&s=2

- Primary health teams of diverse health professionals who can help clients become knowledgeable and capable partners in caring for their chronic conditions can lead to better quality of life (e.g., diminish pain and improve ability to handle daily living) and system efficiencies (e.g., reduce emergency department visits and

avoidable hospital admissions (Health Council of Canada, 2010).

What do we mean by supporting self-managed care?

Keeping people as healthy as possible requires determining the type of care needed, making sure care management roles are clear and ensuring any necessary follow-up care or consultation is available. For higher level needs, clients may require more intense and frequent case management.

The different ways that the support of self-managed care is conceptualized share the philosophy that people with chronic diseases and disabilities are at the centre to direct their care. Although self-management requires clients to take an active role in managing their health and illnesses, advocates are clear that the objective is to engage clients as partners in the prevention and management of chronic diseases, rather than to offload responsibilities from health professionals to clients.

The MacColl Institute defines self-management support as "the care and encouragement provided to people with chronic conditions and their families to help them understand their central role in managing their illness, make informed decisions about care, and engage in healthy behaviors" (Group Health Research Institute, 2010a).

Others similarly define supporting self-managed care as "the systematic provision of education and supportive interventions by health care staff to increase patients' skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting, and problem-solving support" (Adams, Greiner, & Corrigan, 2004, p. 57).

Ontario's model for Chronic Disease and Prevention and Management model takes a systems approach to prevention and management that:

- is centred on individuals, empowering them to play a greater role in managing their health or illness and to become an integral part of the care team;
- incorporates prevention at every stage to keep people as healthy as possible for as long as possible;
- mobilizes interdisciplinary, integrated care teams so that individuals get the right care from the right provider in the right setting at the right time;
- supports proactive, continuing care with regular follow-up to ensure that care is coordinated and that individuals have help navigating through the system (Ontario Ministry of Long-Term Care, 2009).

The Chronic Care Model (Group Health Research Institute, 2010b) emphasizes that it is essential for health care providers to build relationships with clients and prepare them to manage their own illness actively. This collaborative care approach (Bodenheimer, Lorig, Holman, & Grumbach, 2002) values the providers' professional expertise as well as the clients' own knowledge, attitudes, values and preferences (Picker Institute, 2007). Collaborative management is achieved when clients and care providers understand their roles and responsibilities, share the same goals, and have the skills to carry them out within a working relationship (Von Korff, Gruman, Schaefer, Curry, & Wagner, 1997).

Von Korff et al (1997) indentify four crucial aspects of collaborative chronic illness management.

1. Clients and care / service providers must define problems together and come to a common understanding.
2. Clients and care / service providers must collaborate in targeting, planning and setting goals.
3. Care / service providers must create a range of training and support services that teach clients self management skills.
4. Health care providers must actively follow-up with clients.

Health providers in an interdisciplinary team setting can also support effective self-management (Coleman & Newton, 2005). This arrangement can not only alleviate the workload of overburdened physicians in a medical setting (Kaanan, 2008) but also provide opportunities for self-management initiatives in the community, such as having community health workers run education programs (Victoria Department of Human Services, 2009).

Some barriers to supporting effective self-managed care

- Some self-management support programs are time and resource intensive. This can be challenging for organizations and people with limited economic means.
- A collaborative approach assumes buy-in from physicians, providers and clients.
- Self-management support programs work best within the context of care that is integrated across the continuum where supports are less likely to fall through the cracks as would be the case in a fragmented system.
- It is important to consider diversity and equity issues. For example, self-management support programs need to be linguistically and culturally appropriate. Furthermore, the very concept of self-managed care may in some cultures be deemed "second rate care." In this case, more basic front-line education to communicate the value of self-managed care is likely necessary.

How is education in self-managed care different from traditional patient education?

While an educational component is central to supporting self-managed care, this education is different from traditional forms of patient education.

Traditional patient education emphasizes teaching the medical management skills people need to take care of their chronic health condition (Bodenheimer, Lorig, Holman, & Grumbach, 2002).

Self-management education emphasizes teaching people how to problem-solve so they can adapt to issues that may arise in the future (Lorig, 1993). Unlike traditional approaches that educate clients on the knowledge of their condition, a self management approach seeks to enhance clients' abilities to generate their own solutions to chronic health problems and behaviour changes (Coleman & Newton, 2005).

Support for self-management models

There is no "best" or "one-size-fits all" self-management support model. While all self-management support models promote client-centered care and collaborative problem-solving, they may have different philosophies, emphases and practices. Approaches need to be adapted and modified to ensure a "best-fit" with an organization's missions, goals, structures, capacities and philosophies of care. Some self-management approaches target the client or family members with chronic conditions themselves, while others are aimed at changing the way that providers deliver care within a new integrated care model.

Core skills
Despite differences among the various chronic care models, there are some common core self-management skills.

1. **Problem solving:** supporting the capacity to define problems, implement solutions based on available resources and evaluate outcomes.
2. **Decision-making**: providing enough information to enable decision-making in response to changing health conditions.
3. **Finding and utilizing information:** promoting knowledge exchange and enhancing access to information on specific health conditions from a variety of reputable sources.
4. **Partnership development**: developing ongoing relationships with health care providers to jointly care for the condition.
5. **Taking action**: educating people on how to set up action plans and enable them to take action (Lorig & Holman, 2003).

The following self-management teaching models have become popular.

Chronic Disease Self-Management Program (CDSMP) or "Stanford Model" (US)

- Developed in the 1990s originally for individuals with arthritis, this model is now applied to a wide variety of chronic conditions.
- It consists of a structured course offered to groups (10-15 people) for 6 weeks and covers

various aspects of managing chronic conditions such as exercise, nutrition, communication with strong goal setting and problem solving focus.

- **Benefits**: The group setting reduces isolation, facilitates peer learning, experience sharing and bonding with other people with the same conditions. **Drawbacks**: It is not tailored to individual learning styles or experiences with illnesses; the group setting can be intimidating for some individuals.

Flinders Model (Australia)

- This model claims to be applicable to a wide range of conditions.

- **Benefits:** There is a one-on-one relationship between client and care provider. The individualized support may be highly beneficial to some clients (Lawn & Schoo, 2009). **Drawbacks:** This model is time and resource intensive and may seem confrontational for clients not ready to change. As well, there is little focus on providing skills for medical/social/emotional management.

Motivational Interviewing

- Deriving from principles of behavioral and cognitive psychotherapy, the model was first used in addiction counselling.
- Its directive, client-centered counselling approach elicits behaviour change by helping clients explore and resolve ambivalence toward chronic conditions (Rollnick & Miller, 1995).

- **Benefits:** It suits people with different chronic conditions and goals who are at different stages of readiness for change. **Drawbacks:** The model requires staff with counselling background. The program tends to be unstructured and may require significant training and changes to the existing practices of many health providers.

Health Coaching

- This is a relatively new approach adapted from psychology, counselling and coaching. It is designed to assist people to make and maintain behavioural changes which lead to positive health outcomes.

- **Benefits:** It is highly flexible and adaptable to wide variety of clients and needs. **Drawbacks:** There has been little empirical testing of success and effectiveness of this model in comparison to other more established models. Furthermore, as with the case of other models with a counselling focus, providers need time and resources for training.

Five A's Model

- Originally developed to help clients quit smoking; the model has been adapted for more general self-management education.
- It consists of the following steps.
    - **A**ssess client beliefs, behaviours, knowledge.
    - **A**dvise and educate client about disease.
    - **A**gree about goals and action plans.
    - **A**ssist with problem solving.
    - **A**rrange follow-up evaluations.

- **Benefits:** This model acknowledges the knowledge clients have of their own conditions and provides only as much information as desired. **Drawbacks:** Providers require training, support and time to reflect on their practices.

Supporting self-management across Canada

Here is a brief overview of some of the many programs implemented in different jurisdictions.

Ontario has adopted the Chronic Disease Prevention and Management Framework (CDPM) to manage the rising incidence of chronic health conditions within its population. Accordingly, various Local Health Integration Networks (LHINs) have funded a number of self-management support initiatives. For example:

- **Central-East LHIN***: Living a Healthy Life with Chronic Conditions* is a community-based workshop (Central East Local Health Integration Network, 2009).

- **South West LHIN**: *Self-Management Tool Kit website*. The website details self-management support tools developed in collaboration with

international self-managed care experts. These comprehensive tools can be used by organizations and health care teams (South West Local Health Integration Network, 2009).

- **Mississauga Halton LHIN***: The Halton Renal* Program demonstrates the successful application of Chronic Disease Self-Management Program principles. The multidisciplinary collaboration modified the entire program by conducting a self-assessment of the program; collaborating to identify opportunities where self-management would fit into existing programming; and, creating new formats of care management and delivery to help patients (Institute for Optimizing Health Outcomes, 2009).

In addition to the LHINs, several Ontario community organizations provide information for self-management support programs which are targeted to specific needs groups.

The Ontario Patient Self-Management Network: provides links to programs offered by their member organizations. There are links giving people access to resources to self-manage anemia, arthritis, Parkinson disease, the aftermath of a stroke and other complex chronic conditions. For more details see http://www.ontpsm.net/partners.php.

Sherbourne Health Centre (Toronto) has tailored the chronic disease management model to meet the needs of three marginalized communities it serves-lesbian, gay, bisexual, transgendered clients (LGBT), homeless populations and newcomers. For example, it is part of an interdisciplinary collaborative program to help people manage Hepatitis C virus (Read, 2009).

Carefirst Seniors and Community Services Association (Toronto) orients its Diabetes Education and Maintenance Program for people with Type II diabetes in the Chinese community. Responding to the lack of language and cultural-specific teachings, this program provides culturally and linguistically appropriate diabetes education through individual and group teachings through the perspective of Chinese medicine (Carefirst Seniors and Community Services Association, 2009).

Centre for Addictions and Mental Health (Toronto): The Training Enhancement in Applied Cessation Counselling and Health (TEACH) Project is an accredited certificate training program for health care providers working with tobacco-using clients. TEACH has developed a community of practice which links trained clinicians and experts in tobacco counselling, education and research together using educational workshops, videoconferences and other opportunities for networking (Centre for Addiction and Mental Health, 2009).

Other provinces have also implemented self-management support programs.

British Columbia is recognized as a leader in self managed care in Canada. The province has adopted The Expanded Chronic Care Model (ECCM) as a means by which to address individual and community needs as well as system integration and sustainability. The model builds on the Chronic Care model to include health promotion strategies. By integrating aspects of prevention, health promotion, and community collaboration, the model moves beyond the individual and the practice team to "an activated and informed community and prepared and proactive community partners" (Barr et al, 2003, p.75). For a detailed account of this model, see http://www.primaryhealthcarebc.ca/phc/pdf/eccm_article.pdf.

Impact BC is a strategic alliance between BC Ministry of Health Services, the BC Medical Association and provincial health authorities. A not-for-profit organization, Impact BC has adopted the Expanded Chronic Care model. An important aspect is the Practice Support Program which helps physicians who wish to incorporate the collaborative principles of the Expanded Chronic Care model in their practices (MacCarthy et al. 2009). See http://www.impactbc.ca/ for more details.

Alberta has developed local community-based self-management programs such as the *Living Well with a Chronic Condition - Row your Own Boat* Program for Chronic Disease Management, the Stanford Self-Management Leadership Training, as well as pain management programs (Health Canada, 2009).

Manitoba has established the CareLink program, an e-health pilot initiative that builds on existing e-health services. It responds in part to inconsistent access to health care for geographically dispersed populations, and frequent use of walk-in clinics, specialists and emergency rooms for acute episodes and multiple health complications associated with chronic disease (Wasilewski, 2009).

The initiative uses Health Links–Info Santé and Telehealth videoconferencing to support patients to manage their care needs without having to travel to a doctor's office or hospital. Another provincial initiative is the *Safe to Ask* program to improve patient empowerment (Manitoba Institute for Patient Safety, 2007).

Nova Scotia's ANCHOR (A Novel Approach to Cardiovascular Health by Optimizing Risk Management) is a one-year intervention study being conducted by 6 community and health care partners and stakeholders. The model consists of health risk assessment, review and goal setting, counselling or intervention, education, community programs, medication review, and specialty referral. Interventions are determined by the client's risk category (Courtney-Cox & Campbell, 2009).

International examples

The **United Kingdom** aims to achieve system-wide reforms beginning with investments in programs for clinicians, patients, and local sites of health care provision (Health Foundation, 2008).

The *Co-Creating Health* initiative is a three-part program consisting of the Advanced Development Programme for Clinicians, the Self-Management Programme for Patients, and the Service Improvement Programme to support local co-creating health sites.

The Expert Patient Program (EPP) is based on the Chronic Disease Self Management Programme (CDSMP). It was first piloted through the NHS and then launched through the Primary Care Trusts throughout England. The program offers free self-management courses, the majority of which are delivered by trained tutors who live with a long-term health condition. Programs include chronic pain, substance abuse, chronic mental health and a supporting parents program.

Program evaluation studies demonstrated significant patient benefits (e.g., increased knowledge and advocacy skills, increased attainment of preferred treatment needs from health care professionals and increased positive outlook) and systems benefits (e.g., decreased GP consultations, outpatient visits and emergency room visits and increased pharmacy visits) (Expert Patients Programme Community Interest Company, 2009).

Germany has introduced several disease management programs based on Wagner's Chronic Care Model intended to improve "the management and coordination care of patients with chronic conditions" (Greß, et al., 2009, p. 82).

The Netherlands has also put in place similar disease management programs where a team-based approach is the norm, particularly when providing self-management support (Greß et al., 2009).

Australia's "Sharing Health Care" initiatives provide grants to organizations to assist establishing self-management support programs in communities (Australian Government. Department of Health and Ageing, 2008). National Evaluations of these initiatives, conducted since 2004, recommended additional self-management programs throughout Australia (Australian Government. Department of Health and Ageing, 2005).

In the **United States**, the MacColl Institute's model identifies core components of a sustainable self-management support program for both clients and the health system. At the client level, these include:

- emphasizing the patient's central role in self-managed care;
- including family members at the patient's discretion;
- respecting patient's values, preferences, and cultural and personal beliefs;
- developing goals and action plans collaboratively;
- providing follow-up on action plans;
- connecting the patient with community programs to sustain healthy behaviors.

At a system level, components include:

- a proactive Delivery System Design which focuses on health promotion and specifies roles and tasks to ensure patients get necessary care using structured, planned interactions or intensive care management;
- Decision Support that promotes evidence-based care while taking into account patient preferences;
- Clinical Information Systems that provide timely reminders for needed services; help track, monitor and plan care; and, identifies groups of patients requiring additional care while facilitating performance monitoring and quality improvement efforts (http://www.improvingchroniccare.org/).

For more information

Group Health Research Institute - Improving Chronic Illness Care
http://www.improvingchroniccare.org/

Health Council of Canada
www.healthcouncilcanada.ca

Impact BC
http://www.impactbc.ca/

Ontario Ministry of Health and Long-Term Care - Chronic Disease Prevention and Management
http://www.health.gov.on.ca/english/providers/program/cdpm/index.html

Picker Institute Europe
http://www.pickereurope.org/

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