
Workshop report

International roundtable on the self-management support of chronic conditions

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Abstract

An international roundtable on self-management support (SMS) for persons living with chronic conditions (CCs) was held in Vancouver, Canada, in June 2009. It brought together 23 leading researchers, policy makers, health care practitioners and consumers from Canada, Australia, New Zealand, the United Kingdom and the United States. It also provided a forum for critically reflecting on SMS approaches and for building consensus on how to move forward in the self-management field. The deliberations resulted in a draft international framework that identifies key definitions, principles and strategic directions and also outlines sample strategies to guide those working to develop SMS capacities at the local, regional or national level. The framework is a mechanism for knowledge exchange that will hopefully act as a catalyst to shift SMS-related policy, practice and research directions to better serve the needs of all CC populations. More than 400 multi-level stakeholders in the Canadian and international community have been invited to review the framework using an e-consultation process. The final framework is scheduled for release in the late fall of 2011.

Keywords: *self-management, chronic disease, chronic conditions, health policy, health care reform, international collaboration, framework*

Introduction

Self-management support (SMS) has become an integral component of the management of chronic conditions (CCs) and has been promoted as an important part of the solution to the individual, social and economic consequences of CCs.¹⁻⁴ As an essential component of the Chronic Care Model,⁵ SMS activities have also become an important consideration in many health care reforms. Self-management includes the tasks that individuals engage in to manage their symptoms and treatments and the physical, emotional and social consequences of living with CCs everyday.⁶ SMS, on the other hand, is the broader domain of activities provided by

people, organizations and systems to support and increase people's ability to self-manage their CCs. SMS includes infrastructures and policies, supportive services and programs, and skills, resources and social networks.^{7,8}

A number of governments, health authorities, health care facilities, professional associations and non-profit organizations are promoting initiatives in SMS-related research, policies and programs to help reduce the various impacts of illnesses such as arthritis, diabetes, heart disease, multiple sclerosis, depression and HIV/AIDS. In Canada,

SMS activities are developing at local, regional, provincial and national levels. These include an environmental scan of Canadian-based CC SMS activities funded by the Public Health Agency of Canada⁹ as well as efforts to improve primary health care delivery (i.e. family health teams) to better align SMS activities with the needs of the CC population.⁹⁻¹¹

However, the development of new models and innovative approaches raises questions on the complex issue of the quality and effectiveness of programs, engagement of health care providers, integration with primary care, community participation in program development, potential harms and benefits of certain programs, and the limitations of some individuals to effectively self-manage their conditions. Gaps exist in integrating knowledge about self-management across fields of research; for example, the vast amount of qualitative literature on how people manage their CCs has not been well integrated with the literature and research on self-management. Similarly, knowledge on self-management from critical and social perspectives in medical sociology and related fields has largely *not* been incorporated into the body of literature on self-management. Gaps also exist in the exchange of knowledge and information between research, policy, and practice domains. For example, while there is mixed evidence on the effectiveness^{6,12,13} of the Stanford Chronic Disease Self-management Program,¹⁴ it remains the dominant policy approach being implemented in many

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provinces in Canada.⁹ There is also increasing concern that mainstream approaches to SMS may be meeting the needs of certain subgroups of the CC population, namely largely white, well-educated persons, to the exclusion of other disadvantaged groups and that this may be increasing inequities.^{9,15-23}

These challenges in SMS have been discussed at international seminars and conferences over the past few years.²⁴⁻²⁶ However, there remained a well-recognized need to convene a meeting dedicated to better understanding these issues and gaps and to use expert opinion and knowledge to develop a collective vision of how to address these challenges. As a result, an international roundtable on the SMS of CCs was held in Vancouver in June 2009.

International roundtable and consultation

The British Columbia Centre of Excellence for Women's Health hosted a three-day international roundtable on the SMS of CCs, entitled "'Minding the Gap': Building a Framework to Bridge Evidence, Policy, and Practice in Self-Management Support for People with Chronic Conditions." The roundtable, with Canada playing a leadership role, brought together international and interdisciplinary expertise in self-management from among leading researchers, policy makers, health care professionals and consumers from Australia, New Zealand, the United Kingdom and the United States as well as Canada. The 23 participants explored major initiatives in the current SMS field, identified key stakeholder perspectives and needs, analyzed strengths and opportunities and began developing a vision for advancing the field. The three-day process saw important differences in perspectives as well as divergent opinions and tensions between individuals, disciplines, sectors and countries; these high-lighted the challenges and opportunities of collaborative initiatives involving multiple countries and stakeholders at different levels. The self-administrated survey responses of 12 expert informants who were not present at the roundtable (including two health professionals working in Canada's First

Nations communities) added further opinions to the exciting debates.

The roundtable achieved its goal of furthering an interdisciplinary and intersectoral understanding of SMS and created a collaborative space for advancing SMS research, policy and practice. The participants were able to articulate a list of key values, principles, strategic directions and actions for addressing major gaps; these recommendations were summarized in a proceedings report.²⁷ The participants agreed that ongoing collaboration across sectors and disciplines and within and among countries was essential to disseminate evidence-based practices and evidence-informed policy. In order to continue the collaboration process initiated at the meeting, participants developed a plan to create an "SMS community of practice." The Canadian Institutes of Health Research (CIHR), which co-funded the roundtable, awarded a grant in January 2010 to further advance the development of the framework and community of practice.

Forwarding the field: international SMS framework development

After the meeting, transcripts were compiled and analyzed using qualitative methods (thematic analysis) and the findings were used in the framework development process²⁸ to create *Building Bridges: An International Framework for Chronic Condition Self-Management Support* ("CCSMS framework"). This draft framework was sent out for two reviews among the roundtable participants in April and September 2010 using a modified Delphi e-consultation process²⁹ (using a web-based survey created using SurveyMonkey) resulting in an 82% and 80% response rate, respectively. In December 2010, the framework was released via an adapted e-survey to more than 400 individuals and organizations in the SMS field for broad international review. In total, over 203 reviewers from 16 countries reviewed and gave their feedback on the draft framework: 194 completed the e-survey, and 9 gave detailed responses through email. The final framework will be broadly disseminated in the late fall of 2011. In order to strengthen the potential utility and impact of the framework

over the long term, supplementary documents may be developed; these will focus on evidence to support the identified strategic directions, implementation approaches in different contexts, and tools to facilitate knowledge translation between re-search, policy and practice.

The purpose of the draft framework is to help stakeholders in a variety of sectors influence policy, practice and research related to SMS for CCs. The framework identifies eight principles and seven strategic directions to guide those working to develop SMS capacities at the local, regional and national level. It also identifies sample strategies that suggest different ways of addressing each key area, recognizing that specific strategies must be developed in response to the needs, resources and systems in specific contexts.

Conclusion

As a result of its key involvement in the CCSMS framework, Canada is situated as a leader in building bridges, facilitating the development of a collective vision that can improve SMS. The collaborative process of developing the framework that began in Vancouver in 2009 has been instrumental in creating an international SMS community of practice that can continue to exchange knowledge and experience across countries and embark on mutually beneficial projects that aim to improve the health of CC populations and reduce inequities. As evidenced by the positive survey responses to date, the draft CCSMS framework is already acting as an important catalyst for expanding and strengthening research, policy and practice networks and knowledge translation capacities both in Canada and abroad.

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