Building the Evidence Base for Chronic Disease Self-management Support Interventions Across Canada

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ABSTRACT

Objective: The objective of this project was to determine how to improve evaluation of self-management support (SMS) in Canada to generate high-quality evidence to guide policy-makers, implementers, providers and participants.

Methods: This project used a multi-method approach, including a scoping and a focused literature review, an internet scan, interviews with key stakeholders, a review of existing theoretical evaluation frameworks and a consensus meeting with experts.

Results: Four themes were identified through the collection and analysis of data: 1) diverse SMS interventions are identifiable; 2) emerging evaluation activity in Canada is limited to mostly disease-specific, clinic-based programs; 3) there is little evaluation capacity among program implementers in Canada; and 4) there is a gap between the evidence and expectations.

Conclusion: Policy-makers, community organizations and health care teams, regional health authorities and, most importantly, people living with chronic conditions, need better evidence about how to support self-management in their communities. Measuring outcomes must be an explicit part of program implementation and development and requires coordinated support. A common evaluation framework may provide researchers, practitioners and decision- or policy-makers with a systems approach to understanding the possible structural and process factors that can affect self-management outcomes, and could support capacity building in evaluation.

Key words: Self-care; self-management support; chronic disease; program evaluation

Self-management support (SMS) interventions are proliferating across Canada. They aim to decrease the growing burden of chronic diseases on individuals, families, communities and the health system. Their goal is empowered patients with the skills and confidence to better manage their conditions.[1]

Many measures of effectiveness are used across SMS programs,[2] making comparisons difficult. Additionally, SMS is patient-centred and community-oriented, and must acknowledge the unique socio-ecological context in which disease management and support programs occur.[3] The purpose of this project was to determine how to improve evaluation of SMS in Canada to generate high-quality evidence to guide policy-makers, implementers, providers and participants.

METHODS

This project used an iterative, multi-methods approach including scoping and focused literature reviews, internet scan, systematic review, interviews, a review of existing evaluation and chronic disease management frameworks, and a meeting of experts. The project was approved by the Ottawa Hospital Research Ethics Board.

Scoping review

A scoping review of the international literature identified the range of approaches to evaluation of SMS interventions. This review built on a 2008 systematic review[4] of chronic disease self-management interventions conducted by team members, searching multiple databases and grey literature sources for additional reports or discussions of evaluation methods until 2010. The scoping review methods are listed in Table 1. Seventy-eight studies or reports (see Supplemental Appendix A) met inclusion criteria, and evaluation methods and reported outcomes were identified for each of these.

Systematic review

A systematic review was conducted to identify SMS interventions reported for Canadian populations. Medline was used in order to capture the most mainstream articles from 2005 until July 7, 2012. The review methods are listed in Table 2.

A total of 289 articles were returned by the search, after removing duplicates. Abstracts were reviewed to apply the inclusion and exclusion criteria and 20 articles received full review. Sixteen articles were included in a narrative synthesis of population, intervention, evaluation methods, and reported outcomes (see Supplemental Appendix B).

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Table 1. Scoping Review Keywords Used, Inclusion and Exclusion Criteria

Databases searched	Medline, Embase, CINAHL, HealthSTAR, and Google Scholar, other grey lit sources
Keywords used	Self-management; self-management support; chronic disease; disease management; patient care management; program evaluation; patient care team; patient-centered care; chronic care model; integrated care; evaluation
Inclusion criteria	• Deliberately loose to encompass more • Studies of SMS intervention or described as SMS (though no fixed criterion regarding required elements imposed) and the evaluation methods are included and described (methods of evaluation at least) • Discussions of evaluation approaches in SMS • All study types • Citations up to December 2010
Exclusion criterion	• Not primarily a SMS intervention but another primary purpose, e.g., patient education alone, no description of evaluation methods

Table 2. Systematic Review Search Strategy, Inclusion and Exclusion Criteria

Databases searched	Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE® 1946 to Present
Search strategy	(self-management.tw or self care/) and (Canada.tw or Canada/ or Quebec.tw or Quebec/)
Inclusion criteria	• All types of studies evaluating a SMS intervention • No requirements as to components of the program, target population or disease versus generic orientation • English language
Exclusion criteria	• Studies reporting on interventions described as primarily other than self-management (such as patient education or physical activity trials) • Studies not describing evaluation methods or not reporting outcomes • Studies published before 2005 • Reviews

Table 3. Chronic Disease Prevention and Management Frameworks Reviewed

Framework Title	Publication (Reference number)	Description
Chronic Care Model	(6)	The Chronic Care Model (CCM) provides health care teams with a guide to improve functional and clinical outcomes for chronic disease management. It is focused on the health care system and does not include prevention or health promotion. This model provides a general perspective on how self-management can be viewed in broad contexts of communities, structures, and organizations that provide the base for self-management, the resources and supports that are available to people and the self-management behaviours that can result.
Expanded Chronic Care Model: Integrating Population Health Promotion	(7)	This expanded model builds on Wagner and colleagues' CCM and was developed with the goal of better representing the roles of prevention and health promotion into chronic disease self-management.
Tri-Level Model of Self-Management	(8)	The Tri-Level Model builds on the Chronic Care Model to highlight the specific health care system and community elements within the CCM that provide an organizational base for patient self-management and other important components of patient-centered clinical care.
Framework for Primary Care Organizations: The Importance of a Structural Domain	(9)	This framework can be used as a template for a systematic evaluation of primary care. The framework blends organizational theory with existing concepts of service delivery and clinical care. The framework outlines two main domains: structural and performance.
A Proposed Evaluation Framework for Chronic Disease Prevention and Management Initiatives in Ontario	(10)	This proposed model is based on several pre-established models, including the CCM and the Expanded CCM, and creates a model that identifies areas that should be included when evaluating chronic disease management. 13 domains are included addressing prevention and management at the levels of health care, community organization, specific program or health system.
The Agency for Healthcare Research and Quality (AHRQ) Evaluation Toolkit	(11)	The toolkit provides project teams with a step-by-step guide for developing evaluation plans for health information technology projects. The guide includes a list of measures one may use to evaluate a project, suggested data sources, cost considerations, potential risks, general notes regarding each quality domain and links to available literature.
RE-AIM Framework	(12)	The RE-AIM framework includes five steps to translate research into action. These steps include: Reach, Effectiveness, Adoption, Implementation and Maintenance.

Internet scan

An exploratory scan of online information about SMS programs in Canada was conducted to capture unpublished examples of program evaluation. Websites of provincial health ministries, patient advocacy groups, disease-specific organizations, etc., were reviewed for a total of 202 sites in ten provinces and one territory. Keywords used were: self-management, chronic disease, evaluation, and Canada.

Stakeholder interviews

National experts in SMS intervention and evaluation were identified through the literature review, contacts and the internet scan. Interview participants were selected to maximize diversity of perspectives, skills and geographical regions. Eighteen people were invited to be interviewed; seven agreed to participate. Interviewees included knowledgeable program implementers and key policy-makers and/or funders. A semi-structured interview guide was drafted based on the literature review and internet scan. Participants described the programs offered, outcomes expected and evaluation methods. Interviews were stopped when theme saturation was reached.

The interviews were recorded and transcribed. Each transcript was reviewed by two members of the research team using immersion crystallization technique,[5] involving a detailed reading and

Table 4. Examples of Self-management Support Programs Across Canada

Sample Programs by Province/Territory	Type	Brief Description
British Columbia: Chronic Disease Self-Management Program (CDSMP)	Stanford Model	A free 6-week group self-management program for all people with various chronic conditions.
Alberta: Aboriginal Diabetes Wellness Program	Disease & Population Specific	Culturally sensitive program focused on promoting diabetes self-management.
Manitoba: Get Better Together CDSMP	Stanford Model	Manitoba's version of the Stanford Program for individuals with various chronic conditions.
Ontario: Living a Healthy Life with Chronic Conditions CDSMP	Stanford Model	The Champlain LHIN's version of the Stanford Program for individuals with various chronic conditions.
Quebec: I'm Taking Charge of My Arthritis	Disease Specific	Aimed at older adults with arthritis who have a loss of autonomy. Similar to the Stanford program, however sessions are run by health care providers.
Nova Scotia: Self-Help Network for People with Multiple Sclerosis	Disease Specific	Provides a forum for individuals to share and learn from experiences, and receive support and understanding from a peer group.
Newfoundland & Labrador: West Coast Asthma Support Group	Disease Specific	Group that provides information and education on living with asthma.
Territories: Coronary Health Improvement Program	Disease Specific	A lifestyle enrichment program designed to reduce heart disease risk factors by educating about the importance of, and encouraging the adoption of, healthy habits and lifestyles.

reflection on the data to identify themes or critical statements. Interpretations were shared to identify common themes and disconfirming statements.

Theoretical framework review

Theoretical frameworks for chronic disease management programs were identified through the literature review and internet scan (see Table 3), and reviewed for relevant theories, common outcomes and evaluation methods. The data from the literature review, online scan, interviews and framework reviews were triangulated for common findings to affirm interpretations and for disconfirming findings.

Expert review meeting

A meeting of Canadian experts was convened to review the findings from the previous steps and initial interpretations. Thirteen experts attended: three policy-makers (two federal, one provincial), four program implementers and six program researchers. A new framework of evaluation methodology for Canadian SMS interventions linking potential outcomes to measurement approaches and tools was presented (see Supplemental Appendix C). Additionally, the team presented an integrated model (see Supplemental Appendix D), cataloguing health system and community elements that might affect chronic disease self-management and their relationship to potential outcomes of SMS initiatives. The proceedings and interviews of participants were audio-taped and the transcripts were reviewed by at least two research team members to identify common issues. We compared themes from the meeting transcripts with the findings and interpretations from the previous steps.

RESULTS

Analysis and triangulation of the data collected revealed that:
1) Diverse SMS interventions exist.
2) Emerging evaluation activity in Canada is limited to mostly disease-specific, clinic-based programs.
3) There is little evaluation capacity among program implementers in Canada.

4) There is a gap between a wide range of expected outcomes for diverse populations and limited evidence.

Diverse interventions across Canada

SMS programs are being initiated in all provinces and territories targeting diverse populations (see Table 4). Program leaders include disease-based organizations, specialty medical clinics, as well as provincial and local health authorities. Programs range from the internationally renowned and standardized Stanford Chronic Disease Self-Management Program (a six-week, group-based course for all chronic conditions),[13] to disease-specific and/or locally responsive programs, for example one engaging Aboriginal elders to assist in leading programs.

The Stanford SMS program was the most frequently reported intervention. Several implementers cited the support and ease of implementation as well as evidence supporting the program's effectiveness to be reasons for its adoption.

Emerging evaluation activity in Canada is limited to mostly disease-specific clinic-based programs

The literature review identified 16 Canadian SMS studies reporting outcomes since 2005 (see Supplemental Appendix B). All published studies were conducted within health care clinics; all but one involved specialty clinics; and all but one were single disease-focused.

In 2009, Paterson et al. described the limited evaluation of SMS in Canada as consisting mostly of short surveys, typically administered at the program's end, developed by the leaders, and not based on any validated tool, theory, or outcomes.[14] Eleven of the seventeen studies included in the literature review were published since 2009, indicating an emerging body of increasingly rigorous evidence. Nonetheless, despite data showing that SMS programs are proliferating across the country, often as community-based programs, there is very little published evidence of the effect of SMS interventions delivered outside specialty clinics.

Table 5. Examples of Self-management Outcomes Expected by Canadian Implementers and Policy-makers, Reported in International Literature, and Reported for Canadian Populations

Outcomes	Expected by Canadian SMS Implementers	Expected by Canadian Policy-makers/Funders	International Reported	Canadian Population Reported
Patient/Family				
Learning – skills/knowledge	+	+	+	+
Healthy eating	+	+	+	
Being active	+	+	++	+
Monitoring	+	+	+	
Taking medication	+	+	+	+
Problem solving	+	+	+	
Healthy coping	+	+	+++	+
Reducing risks		+	+	
Attitudes/self-efficacy/health literacy	+	+	+++	++
Clinical improvements	+	+	+++	++
Change in health status/Quality of life	+	+	+++	++
Patient perspective of self-management process				+
Change in health system interactions – quality, frequency, type, appropriateness	+	+	++	+
Change in community interactions	+	+		+
Organization/Provider				
Improved structure and processes	+	+		+
Provider perspective of self-management process		+		+
Community				
Improved resources and policies	+			
Improved supportive informal networks				
# of participants in SMS programs	+			
Health system				
Reduced inappropriate health care utilization	+	+	+++	++
Cost savings		+	+	+
Access and equity		+		

+ 1-3 studies report this outcome.
++ 4-10 studies report this outcome.
+++ More than 10 studies report this outcome.

Little evaluation capacity among program implementers in Canada

While all interviewees supported evaluation to ensure that investment and implementation are guided by evidence, they reported a lack of capacity to collect, analyze and use information on the effect of their programs. Lack of funding and expertise and inability to recruit providers and patients into evaluation efforts were frequently reported barriers.

A gap between limited evidence and wide-ranging expectations

Interview participants expected a wide range of outcomes from SMS programs (see Table 5). Interview and meeting participants noted that stakeholders need to re-evaluate, narrow and agree on expected outcomes for SMS as well as what they need to know about SMS in order to tailor evaluations. Table 5 compares the outcomes for which there is evidence of effect and the much greater number of outcomes expected by Canadian stakeholders, highlighting the gap between evidence and expectations.

Decreased inappropriate health care utilization was a focus for policy-makers investing in SMS programs, though this finding has been reported in Canada for disease-specific interventions for COPD patients only.[15,16] Behavioural changes, such as increasing physical activity, eating healthy foods and self-monitoring were frequently cited as expected outcomes during interviews, and yet peer-reviewed evaluations have reported primarily on clinical improvements, and attitudes or self-efficacy. (See Table 6 for outcomes reported in Canadian population studies.)

Some implementers believed international evidence would translate into their target populations and did not feel their programs required further evaluation. As Interviewee 5 (a decision-maker) stated: "We know that we have [reached our desired outcomes] … because we delivered it and Stanford set it up, and it's been proven to achieve those outcomes." Several participants noted that there is little evidence to guide policy-makers and program implementers seeking interventions other than Stanford.

Canadian studies reporting SMS program outcomes used diverse tools and methods for evaluation; even studies focusing on the same diseases did not use the same tools to measure and report on similar outcomes.[17,18]

The Integrated Model of SMS Outcomes (see Supplemental Appendix D), drafted for presentation at the experts' meeting, was seen as a useful tool for highlighting the many outcomes of SMS programs possible at different levels, and the many areas where efforts to promote SMS might be aimed.

DISCUSSION

The importance of local context in SMS, such as cultural norms, health system access or community resources, means that improving the generation of evidence on the effect of SMS programs in Canada's diverse populations is essential to justify investment in any given approach. A significant body of evidence now exists supporting positive effect of the Stanford program across countries on outcomes such as self-efficacy and health distress.[19] However, given the growing number of innovative SMS programs across Canada, targeting increasingly diverse populations – often different from study participants – and the perceived limited capacity for evaluation outside academic-affiliated medical clinics, efforts to improve evaluation capacity where investment is occurring are needed.

Generating capacity for evaluation at the grassroots level needs skill-building, dedicated resources, and partnerships with program implementers and existing academic and government experts. However, the burgeoning local SMS innovations and the fundamental importance of community context in understanding their

Table 6.   Canadian Literature: SMS Reported Outcomes

Outcome	Study (#) See Supplemental Appendix D as Legend
Patient/Family	
Learning – skills/knowledge	3, 10
Healthy eating	
Being active	11
Monitoring	
Taking medication	1, 2, 10
Problem solving	
Healthy coping	8, 12
Reducing risks	
Attitudes/self-efficacy/health literacy	3, 5, 6, 7, 10, 11
Clinical improvements	1, 5, 6, 8, 7, 11, 12, 13, 14
Change in health status/quality of life	3, 5, 8, 14
Patient perspective of self-management process	5, 7, 16
Change in health system interactions – quality, frequency, type, appropriateness	3
Change in community interactions	2
Organization/Provider	
Improved structure and processes	11
Provider perspective of self-management process	11
Community	
Improved resources and policies	
Improved supportive informal networks	
# of participants in SMS programs	
Health System	
Reduced inappropriate health care utilization	1, 2, 4, 5, 9, 14,
Cost savings	2
Access and equity	

effectiveness highlight the need to fill the gap between growing community-based practice and academic centre-based evidence to demonstrate effectiveness of interventions as delivered.[20-22] The theory of developmental evaluation, imbedding assessment into ongoing program development,[23] seems particularly well suited to guide interventions in these early stages of implementation and adaptation to community needs.

The Stanford Patient Education Research Centre[13] provides free tools, and offers support on how to use the tools. Their widespread uptake highlights the value of easily accessible support for program implementers, such as guidance on how to collect information, collate and analyze findings and interpret results.

The SMS Intervention Evaluation Framework (see Supplemental Appendix C) developed by our team links potential or desired outcomes with measurement approaches and validated tools identified in the literature, and provides a systems approach to understanding the structural and process factors that can affect self-management outcomes. It also offers a comprehensive set of methods by which to evaluate all SMS factors and effects. This Framework could support capacity building in evaluation, especially for exploratory evaluation – essential to understanding new outcomes for which validated measurement tools do not exist – which must accompany the locally innovative programs reaching out to more and more diverse groups. In order to generate usable evidence efficiently, given limited capacity and resources, stakeholders including funders, implementers and participants should agree on priority outcomes to pursue and evaluate. The Integrated Model of SMS Outcomes (see Supplemental Appendix D) could also help stakeholders identify common outcomes of interest and build consensus on what to measure to narrow the gap between evidence and expectations.

An easily accessed online SMS resource site sharing intervention descriptions and reporting available results for Canadian populations would also help generate awareness of different interventions and evidence that supports them. A Canadian professional associ-ation, academic institution or federal, provincial or regional health agency might establish such a resource centre similar to ones hosted by the Stanford Patient Education Centre, the American Academy of Family Physicians, and the Ontario Champlain LHIN.[13,24,25]

Finally, coordination for evaluation by program implementers is needed to generate usable evidence. Meaningful follow-up times for outcomes such as behavioural change or hospitalizations might require a year or more. Few organizations would be able to gather data from enough participants, or follow them for long enough, to report outcomes with statistical significance in a time frame useful to decision-makers. While trends and smaller sample sizes may guide implementers in adapting or developing programs, some outcomes of interest are likely to need large samples. However, key population groups – such as cultural or linguistic minorities, people who are homeless, or individuals with less common conditions, such as lupus – may not be served in large numbers in a single organization. Using an evaluation framework to guide the selection of common outcomes and measurement instruments would help pool data across regions and interventions, as exemplified by the Peers for Progress Model to study the effect of peer support for people managing diabetes.[25]

Limitations

The small sample for interviews in this study may limit the generalizability of our findings. However, identified interview themes were compared to multiple sources of data, and there were many common themes across interviewees despite differences in roles, focus and provincial affiliation. While most expert-meeting participants were leaders in SMS, it is likely that the barriers they revealed for evaluating outcomes would be more acute for less-experienced implementers or decision-makers.

CONCLUSION

Policy-makers, community organizations and health care teams, regional health authorities and, most importantly, people living with chronic conditions, need better evidence about how to support self-management in their communities. Measuring outcomes must be an explicit part of program implementation and development and requires coordinated support. The next generation of SMS programs in Canada should benefit from the lessons of the many approaches flourishing across the country.

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RÉSUMÉ

Objectif : Déterminer comment améliorer l'évaluation du soutien à l'autogestion des soins (SAS) au Canada afin de produire des preuves de haute qualité pour guider les responsables des politiques, les exécutants, les fournisseurs et les participants au SAS.

Méthode : Nous avons utilisé plusieurs méthodes, dont une étude de champ et une revue de la littérature spécialisée, une exploration d'Internet, des entretiens avec des acteurs privilégiés, un examen des cadres d'évaluation théorique existants et une réunion de concertation avec des spécialistes.

Résultats : Quatre thèmes sont ressortis de la cueillette et de l'analyse des données : 1) diverse interventions en SAS sont identifiables; 2) les activités d'évaluation émergentes au Canada se limitent en gros aux programmes cliniques axés sur certaines maladies; 3) les capacités d'évaluation sont minimes chez les exécutants des programmes au Canada; et 4) il y a un écart entre les preuves et les attentes.

Conclusion : Les responsables des politiques, les organismes communautaires et les équipes de soins de santé, les offices régionaux de la santé et, surtout, les personnes vivant avec des maladies chroniques ont besoin de meilleures preuves sur les moyens de soutenir l'autogestion des soins dans leurs communautés. La mesure des résultats doit faire partie intégrante de l'élaboration et de la mise en œuvre des programmes de SAS, et elle exige un soutien coordonné. Un cadre d'évaluation commun pourrait fournir aux chercheurs, aux praticiens et aux décideurs ou responsables des politiques une approche systémique pour comprendre les facteurs structurels et liés aux processus qui pourraient peser sur les résultats de l'autogestion des soins; un tel cadre pourrait aussi appuyer le renforcement des capacités d'évaluation.

Mots clés : autosoins; soutien à l'autogestion des soins; maladie chronique; évaluation de programme