QUALITATIVE RESEARCH

Self-management Support: A New Approach Still Anchored in an Old Model of Health Care

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ABSTRACT

Background: Studies show the great potential for self-management to improve health outcomes, yet it is carried out in a limited way by patients and providers. This study investigated the provider perspective of existing self-management support resources in a region of 1.2 million people. Participants included physicians, nurses, nurse practitioners, educators, and program managers.

Methods: Qualitative study using semi-structured, one-on-one interviews. An iterative immersion/crystallization process identified key themes and new questions and was built on a grounded theory approach. Triangulation was used to validate findings by comparing with data from a related provider workshop and presenting significant findings in follow-up interviews with select individuals.

Results: There was a lack of understanding about self-management. Existing programs lacked an evidence-based approach and were often entrenched in a single disease-focus model of care, despite a majority of patients served having multiple chronic conditions. A new approach to self-management support was desired, although often anchored in an old model of revolving doors for patients. Self-management was described as burdensome for patients and providers alike. There was disbelief about program effectiveness and frustration about lack of sustainability.

Interpretation: Understanding the perspectives of providers engaged in self-management support is a critical first step in developing regional strategies for such support programs. A better understanding of the comprehensive and long-term nature of self-management support is needed. System reform promoting integration of services is essential to enable providers to offer patient-centred self-management support.

Key words: Self-management; SMS; chronic disease; co-morbidities

La traduction du résumé se trouve à la fin de l'article.

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Chronic disease is the most prominent health care problem in Canada.[1] Many initiatives to improve chronic disease care are being implemented and are commonly grounded in the Chronic Care Model (CCM).[2] This model adopts a system-wide approach to managing chronic diseases, identifying patient self-management as a key element. Improving patient self-management of chronic conditions can improve outcomes such as reducing blood pressure and glycemic levels;[1,2] optimizing quality of care; and improving health services use.[3,4] Self-management support (SMS) enables patients to better manage their illnesses; carry out normal roles and activities; and manage the emotional impact of their illnesses in partnership with their health care providers.[5] In Canada, however, as many as 40% of adults with chronic diseases report rarely or never talking with their primary health care provider about specific self-management to improve their health.[6]

There are increasing efforts to understand patients' experiences managing their chronic conditions and accessing resources to support their self-management.[6,7] However, there is a paucity of information on providers' perspectives and experiences. Lack of knowledge about self-management courses among providers may contribute to lower community-based SMS course effectiveness.[8] Identified barriers to providers incorporating SMS in their work include competing time demands during clinical encounters, concerns over sustainability, and perceived lack of cultural relevancy to some patients.[9,10]

As communities seek to improve self-management support resources to promote better health for Canadians living with chronic diseases, it is important to understand the provider perspective on existing self-management support resources to inform policy and planning. Thus, we undertook a qualitative study focused on providers of self-management support programs in a large health region in Eastern Ontario, Canada.

METHODS

The study was conducted in 2007-08 in the Champlain health region, encompassing 1.2 million people, including the city of Ottawa and rural communities. The region is culturally, socio-economically and linguistically diverse, including a significant Francophone, immigrant and Aboriginal population. This region is representative of the rest of Canada and has chronic disease burdens, health outcomes and practices comparable to the rest of the province of Ontario and Canada.[6] A mixed purposeful sampling method was used, including maximum variation sampling criteria

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Table 1. Participant Characteristics

	Participant Characteristics (n=38)	
Role	%	n
Physician	11	4
Nurse Practitioner	5	2
Registered Nurse	36	14
Program Manager	34	13
Nurse Educator	8	3
Health Care Consultant	5	2
Location		
Rural	39	15
Urban	61	23
Program orientation		
Disease-specific	66	25
Across disease	34	13
Gender		
Male	11	4
Female	89	34

to include participants from all health regions and different types of programs, and snowball sampling.[11] This approach relied on initial contacts identified by the regional health service planning, integration and funding organization and Advisory Board that comprised stakeholders including patients, providers and non-governmental organizations. Additionally, participants were identified through a strategy of networking with local health care providers, professional organizations, community groups, and a workshop. Individuals were invited to participate in the scan by telephone or e-mail.

Semi-structured interviews were conducted by the same interviewer, experienced in conducting qualitative interviews. An interview template was created using the RE-AIM health behaviour intervention evaluation framework.[12-14] The interview template was reviewed by the Advisory Board for comprehensiveness, and relevance to the project goal and to regional context. It consisted of 34 questions, such as "How many patients does your program serve?" and "Are you aware of any patient barriers to using your program?" Interviews lasted 30 to 45 minutes and continued until both broad representations from various communities of care and theme saturation were reached.

Self-management support (SMS) and self-management were defined by the literature[7] and used throughout the project. Self-management support is "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." Self-management "relates to the tasks that an individual must undertake to live well with one or more chronic conditions. These tasks include gaining confidence to deal with medical management, role management and emotional management".[8]

Responses to interview questions were gathered as field notes and written on the interview template verbatim; summaries were prepared for each interview. An iterative immersion/crystallization process[9] was used to identify key themes and new questions and was built on a grounded-theory approach. This allowed ongoing data analysis and identification and exploration of unanticipated research questions. Each interview template and summary was reviewed independently by at least two team members. Each member highlighted key themes, which the entire team then analyzed to compare and identify consistent themes, disconfirming statements or themes, and areas needing additional information for clarification. Significant findings were presented for validation in follow-up interviews with select individuals. Additionally, a summary of interview themes was presented to 145 providers at a self-management support skill-building workshop hosted by the research team. Workshop participants were invited to provide written feedback on these themes during small-group sessions. Workshop participants were also invited to share perspectives on presented themes in both post-session evaluation sheets and through e-mail after the workshop. All responses were summarized and used to validate findings where there was strong agreement, or add research questions where there were new themes. Finally, findings were presented to the project Advisory Board to challenge interpretations and seek validation. The study was approved by the local research ethics board.

Table 2. Types of Programs Represented

	Types of Programs Represented (n=42)
Hospital programs	6
Family health team	4
Non-profit health association	6
Community health centres	6
Provincially funded programs (diabetes, stroke, lung health, CCACs)	10

RESULTS

Thirty-eight participants involved in self-management support were recruited from all six regions in the health authority and included a mix of rural and urban centres, disease-specific and general health organizations, as well as a range of health professionals (Table 1). Half of the participants came from primary care practices while the other half came from non-profit disease organizations such as the Arthritis Society, Community Care Access Centres or provincial disease-specific programs (Table 2).

Lack of common understanding of Self-management Support (SMS)

Most interviewees requested a definition of SMS and then shared relevant aspects of their programs. One program manager commented, "*We have no specific self-management program, although we have self-management-related packages for diabetes and a checklist for managing symptoms*." Only six participants offered a comprehensive self-management program, which included all elements in the project definition.

Many participants interchanged patient education with SMS, and most programs primarily offered patient education. Most commonly lacking SMS elements were action planning, problem solving, skill-building, and motivation, as well as longer-term follow-up and support – often attributed to insufficient funding. "*Unfortunately, there is no maintenance program, but we would like one because 75% of patients do not maintain after the program ends,*" said a registered nurse.

Several recurrent themes emerged, particularly about the added challenge of co-morbidities, poor integration of existing resources, and common barriers to providing, or patients accessing, SMS resources (Table 3).

Co-morbidity

Co-morbidities provided a bigger challenge: "*Coordinating care, depression and social isolation is a big factor. Inertia sets in and with co-morbidities there are a lot of referrals and very few specialists and then transportation is an issue with multiple appointments,*" said one registered nurse.

Table 3. Major Access Barrier Themes: Co-morbidity and Program Integration

	%	n
Total Respondents	100	38
Co-morbidity		
50% of their patients had multiple co-morbidities	47	18
Felt ill-equipped to deal with the co-morbidities and unable to address conditions that fell outside the scope of their training	29	11
Refer co-morbid patients to programs for other conditions	66	25
Perception of Program Integration		
Lack of Resources/Sustainability	42	16
Providers stated that	52	21
• better integration of existing programs was needed,		
• they had a limited knowledge of neighbouring programs,		
• they worked in isolation from other programs		
Were unaware of any other specific self-management support programs at all.	34	13
Identified a need for more self-management support resources to fill in the gaps for missing programs or to better connect the ones that existed.	95	36

Another program manager explained, "*The system is not needs-oriented but system-oriented. Services need to be based on needs of the individual.*"

Additionally, co-morbidities limited the provider's ability to advise the patient. Another registered nurse commented, "*We are not sure about the exercise component [for patients], and we have to ask the doctor. Mostly we have a lot of arthritis too, which is usually another co-morbidity. Often they'll have both and not be able to exercise.*"

Poor program integration

Twenty-one providers (52%) stated that better integration of existing programs was needed because they had a limited knowledge of and worked in isolation from neighbouring programs: "*More integration and more information on existing programs [is needed], in order for health care providers to be able to educate on these resources,*" remarked a registered nurse.

Thirteen providers (34%) were not aware of any other specific self-management support programs at all. Another nurse said, "*I didn't even know we had self-management programs.*" Regional silos as well as disease-specific silos limited the scope of activity and the community reach of programs. "*We accept referrals from fifteen physicians. This is an issue, as we can't accept anybody else,*" said a nurse educator. Thirty-six respondents (95%) identified a need for more SMS resources to fill in the gaps for missing programs (e.g., stroke, mental health) or to better connect existing ones. "*We need better integration; programs won't exist without referrals. System building is needed. And better linkages in the system to avoid silos,*" said a program manager.

Patient and provider barriers

Transportation, cost and cultural barriers were frequently cited as patient barriers to existing programs by both rural and urban participants (see Table 3). "*Winter weather is a problem for seniors. There are many more no-shows on snowy days. They are not comfortable because of mobility,*" said a nurse educator.

Cost and financial issues were mentioned by 17 providers (48%). Lost wages, parking and transportation costs, meals away from home, and child care expenses easily amounted to a "*one-hundred-dollar day*" per patient. Further, as a provider pointed out, in many rural areas "[is] *takes a tank [of gas] to get a tank.*"

Cultural issues were mentioned by 9 providers (24%); education and low health literacy levels were cited by 11 (29%) as barriers.

Self-management too great a burden

Five providers (13%) stated that self-management was a significant undertaking for patients and required a major commitment many patients were unable to give. A nurse/manager stated, "[*The program is*] *a huge commitment. Two days a week for three months.*" Three providers noted that the burden of self-management was not equally shared. A family physician commented that "*some people are more capable [of self-management], such as upper class, more economically well-off with only one disease. The onus on them is much different from the working poor and marginally housed with three chronic conditions.*"

Further, participants identified the need for innovative approaches to making SMS available to everyone. One clinic manager said:

> *"Strategies to self-manage on a low-income are different from self-management on a high income. These kinds of things make it more difficult, if you can't pay your rent. There is a general level of stress when you live on a low-income. It is difficult to self-manage your own well-being when your energy is spent elsewhere."*

Another clinical manager said:

> *"Particularly for people who are new to Canada, there are barriers to the environment, so what you were able to do and eat in your home country to be healthy don't translate to this country. So that is a context issue, where so many things that were natural and supported by your health in one environment, don't translate to another."*

Finally, 42% commented on the negative effect of unsustainable funding models on their ability to plan and improve.

INTERPRETATION

This study aspired to understand providers' perspectives in working with SMS programs. Many of our findings were surprising and highlight the importance of engaging providers in health policy and program planning.

Limitations

The participants in this scan may not be representative of all the region's providers. It is unclear whether there is a difference between the providers interviewed and those who declined to participate or were not invited. The low participation of physicians leaves a key element unexplored. The scan did not reflect the actual reach of programs and effect on patients, as many programs were unable to provide these data. Finally, the scan was the first step towards a regional strategy for self-management support. The results thus reflect the experience of participants prior to a widespread effort to improve providers' skills and knowledge, and improve access to SMS programs.

SMS limitations

Despite strong interest and a wide range of programs, many providers purportedly engaged in SMS do not have a common understanding of what SMS entails. Many of the programs offering patient SMS are only delivering parts of the recommended approach, most commonly education. However, patient education alone is often less effective than comprehensive interventions addressing education, behaviour and psychological components.[4,15,16] The elements most often lacking in these SMS programs were action planning, problem solving, skill-building and motivational counselling. These crucial elements are particularly important in assisting to overcome literacy and cultural barriers to patient self-management.[10] These elements may also demand longer-term relationships.

Co-morbidities

Traditionally, health care has been organized around the convenience of providers rather than patients,[11,17] leading to a silo mentality that places protection of professional territory and responsibilities over the development of patient-centred care.[12] The repeated concern with regard to caring for patients with co-morbidities may in part reflect the difficulties caused by a system based on disease-specific care. The persistence of this disease focus is surprising in self-management: these programs are supposed to reflect a new approach to patient-centred care. Patients presenting with co-morbidities are the norm, not the exception.[18,19] Fifty-five percent of Canadians ages 60 to 79 and 64% of those 80 or older have two or more significant chronic diseases,[20] a number consistent with reports from other countries.[20,21] Rather than increase resources within disease-specific programs, better connecting SMS programs with a unified approach across diseases will address common risk factors and facilitate patients' needs at fewer points of care. Innovative changes to disseminating funding are needed to encourage collaborative care among providers and establish an expectation that providers build programs centred on patient needs rather than system convenience.

Isolation

The fact that providers felt they had little knowledge of complementary programs and, worse, felt unable to facilitate patients' access to programs through direct referrals, also supports the need for greater system changes – in particular, integration. A discussion about what true integration means and ways to enhance community buy-in – such as financial incentives and innovative funding approaches – is greatly needed[13] to begin better supporting self-management in Canada.[14] Integration was recently defined as "[bringing] together services, providers, and organizations from across the continuum to work together jointly so that their services are complementary to one another, are coordinated with each other, and are a seamless unified system, with continuity for the client."[14,22]

These findings are consistent with reports from the UK where the Expert Patient Program, which trained allied health members of primary care teams to provide SMS, was broadly implemented.[8] This program was modeled after the successful Stanford program, yet failed to achieve similar effectiveness. This highlights an integration and access-to-care problem that requires both system redesign as well as provider education to build knowledge and skills in health system access and resources.

Similarly, addressing the major patient barriers to receiving SMS, shared across rural and urban populations – such as transportation issues, cost associated with leaving work or travel, and cultural or language barriers – may require creative approaches to offering care outside of traditional medical bases and bringing it into the communities. While it makes sense for patient safety and cost for people to travel to a hospital centre for complex medical treatments or imaging, ongoing SMS needs to be delivered where people live and manage their chronic conditions, as well as where they seek medical care.

Health system reform requires understanding the perspectives of the providers working within it. Improving health care providers' skills in SMS must be done in concert with changes to the system in which they deliver care.

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RÉSUMÉ

Contexte : Des études démontrent l'immense potentiel de l'autogestion des soins pour améliorer les résultats de santé. Pourtant, les patients et les fournisseurs de soins utilisent cette approche de façon limitée. La présente étude s'est penchée sur la perspective du fournisseur de soins quant aux ressources d'appui actuelles en matière d'autogestion dans une région de 1,2 million d'habitants. Les participants englobaient des médecins, du personnel infirmier, des infirmières praticiennes, des pédagogues, et des gestionnaires de programmes.

Méthode : Étude qualitative faisant appel à des entrevues semi-structurées et individuelles. Grâce à un processus itératif d'immersion/de cristallisation, fondé sur une approche théorique reposant sur les faits, de nouvelles questions et des sujets-clés ont été identifiés. Nous avons procédé par triangulation pour valider les résultats en établissant des comparaisons avec des données provenant d'un atelier connexe et en présentant les conclusions importantes tirées dans le cadre d'entrevues de suivi avec quelques personnes désignées.

Résultats : On comprend mal ce qu'est l'autogestion des soins. Les programmes actuels n'ont pas une approche fondée sur les preuves et sont souvent limités à un modèle de soins axé sur une seule maladie et cela, même si, en majorité, les patients ciblés sont atteints de plusieurs conditions chroniques. Une nouvelle approche d'appui à l'autogestion est souhaitée, même si l'autogestion est enracinée dans le vieux phénomène de la « porte tournante » pour les patients. Le programme d'autogestion des soins est jugé coûteux tant pour les patients que pour les fournisseurs, et suscite du scepticisme quant à son efficacité et de la frustration face à son manque de viabilité.

Interprétation : Une première étape fondamentale consiste à bien cerner la perspective des fournisseurs qui soutiennent l'autogestion afin d'élaborer des stratégies régionales relatives aux programmes d'appui. Une meilleure connaissance de la nature polyvalente et à long terme de l'appui à l'autogestion est nécessaire. Une réforme du système qui encourage l'intégration des services est indispensable pour permettre aux fournisseurs d'offrir un soutien en autogestion axé sur le patient.

Mots clés : autogestion; soutien de l'autogestion; maladie chronique; comorbidités

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