

Designing Integrated Approaches to Support People with Multimorbidity: Key Messages from Systematic Reviews, Health System Leaders and Citizens

Concevoir des approches intégrées pour aider les personnes souffrant de multimorbidité : messages clés de revues systématiques, de dirigeants de systèmes de santé et de citoyens



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Abstract

Background: Living with multiple chronic conditions (multimorbidity) – and facing complex, uncoordinated and fragmented care – is part of the daily life of a growing number of Canadians.

Methods: We undertook: a knowledge synthesis; a “gap analysis” of existing systematic reviews; an issue brief that synthesized the available evidence about the problem, three options for addressing it and implementation considerations; a stakeholder dialogue involving key health-system leaders; and a citizen panel.

Results: We identified several recommendations for actions that can be taken, including: developing evidence-based guidance that providers can use to help achieve goals set by patients; embracing approaches to supporting self-management; supporting greater communication and collaboration across healthcare providers as well as between healthcare providers and patients; and investing more efforts in health promotion and disease prevention.

Conclusions: Our results point to the need for health system decision-makers to support bottom-up, person-centred approaches to developing models of care that are tailored for people with multimorbidity and support a research agenda to address the identified priorities.

Résumé

Contexte : Vivre avec des maladies chroniques multiples (multimorbidité), et faire face à des soins complexes, non coordonnés et fragmentés, fait partie du quotidien d’un nombre croissant de Canadiens.

Méthodes : Nous avons entrepris : une synthèse des connaissances; une « analyse de l’écart » des revues systématiques actuelles; une synthèse des données probantes disponibles concernant le problème, trois options pour l’évaluer et mettre en place les correctifs; un débat entre les personnes intéressées, impliquant les dirigeants du système de santé; et un panel de citoyens.

Résultats : Nous avons cerné plusieurs recommandations concernant les mesures à prendre, notamment : élaborer des directives fondées sur des données probantes que les intervenants peuvent utiliser pour aider les patients à atteindre leurs objectifs; adopter des approches favorisant l’autogestion; encourager de meilleures communications et collaborations parmi les intervenants de la santé, ainsi qu’entre les intervenants et les patients; investir davantage d’efforts dans la promotion de la santé et la prévention des maladies.

Conclusions : Nos résultats soulèvent la nécessité pour les dirigeants du système de santé d’encourager des approches « du bas vers le haut », centrées sur la personne, afin de développer des modèles de soins qui sont adaptés aux personnes souffrant de multimorbidité, et d’encourager des programmes de recherche qui abordent les priorités identifiées.

Background

Living with multiple chronic conditions (or multimorbidity as defined below) is part of the daily life of a growing number of Canadians. Recent estimates indicate that 12.9% of Canadian adults were living with two or more chronic conditions and that 3.9% were living with three or more chronic conditions (Roberts et al. 2015). Data from Ontario indicate a significant upward trend with the number of Ontarians living with multimorbidity having increased from 17.4% in 2003 to 24.3% in 2009, which is a 40% increase (Pefoyo et al. 2015). Another study found that rates of multimorbidity vary widely across primary care settings (the central point of contact for many with chronic diseases), but similarly indicated that the overall picture is one of high levels of multimorbidity (Stewart et al. 2013). Moreover, multimorbidity disproportionately affects some groups more than others as rates grow steadily with age, and they are higher among the more vulnerable groups in society (e.g., people who are less educated and have lower incomes) (CIHI 2011; Fortin et al. 2006; Health Council of Canada 2007, 2011; Roberts et al. 2015; Stewart et al. 2013). Their objectives and key methodological features are shown in Table 1.

Multimorbidity has been defined as “the co-existence of two or more chronic conditions, where one is not necessarily more central than the others” (Boyd and Fortin 2010). Boyd and Fortin (2010) further indicate that the concept of multimorbidity means that multiple diseases, syndromes and conditions may overlap and potentially interact, as compared to comorbidity where one index disease is the focus in relation to other comorbid conditions. Moreover, the management of multiple chronic conditions can overlap in unique ways for each individual (Boyd and Fortin 2010), thereby making clinical management complex (e.g., due to the need to prescribe and manage several medications). A recent qualitative study conducted in Ontario found that people with multimorbidity face several challenges such as a lack of decision-making support, poor communication and uncoordinated health services (Gill et al. 2014), and others have noted that the care for people with multimorbidity is “fragmented, incomplete, inefficient, and ineffective” (Boyd and Fortin 2010). Also, high-needs users of the health system, many of whom are adults with multimorbidity, account for a disproportionately high share of costs – more than two-thirds in Ontario (Wodchis et al. 2012). Accordingly, there have been growing calls for changes to health systems and clinical decision-making processes to provide the complex and integrated care required by those with multimorbidity (OECD 2011; Tinetti et al. 2012).

To contribute to addressing this pressing health system issue, we undertook a series of projects focused on evidence synthesis and on stakeholder and citizen engagement. Our overall objective was to use these projects to support the actions of those involved in addressing the challenges associated with providing care for people with multimorbidity. In this paper, we provide an overview of the approach we used for each project and the key messages we derived from them.

TABLE 1. Summary of our approach to evidence synthesis and stakeholder and citizen engagement

Project	Objective	Key methodological features
Knowledge synthesis	Synthesize the available research evidence about optimal treatment approaches for people with multimorbidity	<ul style="list-style-type: none"> • Included four types of documents: (1) systematic reviews evaluating the health risks faced by people with multimorbidity and/or programs and models for their treatment; (2) guidelines (or approaches to developing guidelines) outlining approaches for treating people with multimorbidity; (3) effectiveness studies evaluating programs and models for treating people with multimorbidity; and (4) process evaluations of programs and models for treating people with multimorbidity • Conducted database searches,* hand-searched websites of relevant Canadian and international organizations, and asked key informants for literature • Two independent reviewers assessed all literature for inclusion • Extracted the focus and key findings from each document, and appraised the methodological quality of all systematic reviews (using the AMSTAR tool) (Shea et al. 2007)
'Gap analysis'	Identify key knowledge gaps that could be the focus for future research	<ul style="list-style-type: none"> • Updated all of the literature searches (in March 2014) • Developed a 'gap map'[§] by organizing the included reviews and economic evaluations in a matrix by mapping each review according to the level of intervention in the system (at the level of patients or individuals, providers, teams, organizations, sectors or systems) and to outcomes included within the Institute for Healthcare Improvement's Triple Aim Initiative (improving the patient experience of care, improving the health of populations and reducing the per capita cost of care) (Institute for Healthcare Improvement 2014)
Issue and citizen brief	Package the available evidence for stakeholders and citizens	<ul style="list-style-type: none"> • Convened a steering committee and conducted key informant interviews to inform the development of the brief • Updated searches from the knowledge synthesis and synthesized the findings related to the problem, three elements of a potentially comprehensive approach to address the problem, and implementation considerations
Stakeholder dialogue	Identify shared ground, divergences of opinion and possible next steps to address the issue	<ul style="list-style-type: none"> • Convened health system stakeholders (policy makers, managers of health organizations, professional and community leaders, patients/citizens/groups representing them, and researchers) for deliberations to support participants to champion creative efforts to design integrated approaches to support people with multimorbidity • Participants were identified in collaboration with a steering committee and selected based on their ability to: (1) bring unique views, experiences and tacit knowledge to bear on the challenge and learn from the research evidence and from others' views, experiences and tacit knowledge; and (2) champion within their respective constituencies the actions that will address the challenge creatively • Deliberations were facilitated by one of us (JNL) and followed the structure of the issue brief, with a final deliberation focused on next steps that could be taken for different constituencies • Followed the Chatham House Rule (i.e., "the information used during the meeting can be used, but neither the identity nor the affiliation of the speaker(s), nor that of any other participant, may be revealed") (Chatham House 2014) • Conducted a thematic analysis of the deliberations
Citizen panel	Identify the values and preferences that citizens believe should guide next steps	<ul style="list-style-type: none"> • Sought to recruit a panel of 10–14 citizens[¶] in Ontario that was balanced in terms of gender, age, socioeconomic status and lived experience (i.e., balance between those with one chronic disease, with two or more chronic diseases, and those caring for someone with a chronic disease) • Participants were recruited through an organization that maintains a panel of approximately 250,000 Canadians who participate in loyalty programs • The deliberations were facilitated by one of us (FPG) and followed the structure of the citizen brief • Prepared a thematic summary of the deliberations, with specific focus on identifying underlying values and preferences expressed by participants

*We conducted a related articles search of PubMed in June 2012 using each of the 10 studies included in a recent systematic review (Smith et al. 2012) and a hand search of the excluded references in the review. The PubMed search was limited to articles published in 2011 or later (the year the search was last conducted in the review). We also searched Medline in September 2012 using the 'co-morbidity' MeSH term (as the focus of the document) and limiting the search to the last 10 years (2002 to 24 September 2012).

§We used the approach developed by the International Initiative for Impact Evaluation (International Initiative for Impact Evaluation 2014).

¶We excluded employees of healthcare organizations or healthcare professionals, elected officials, and individuals working for market research, advertising, public media or public relations firms.

Methods

Each of the five projects used distinct methods, which we describe in detail in each of the full reports that are published elsewhere (Gauvin et al. 2013, 2014a, 2014b; Wilson and Lavis 2013, 2014; Wilson et al. 2013). We provide an overview of the projects, their objectives and key methodological features in Table 1.

Results

Findings from the evidence syntheses

KNOWLEDGE SYNTHESIS

For the knowledge synthesis, we identified six systematic reviews, eight randomized controlled trials, eight qualitative studies, four cross-sectional studies, six overviews of the applicability of existing guidelines to multimorbidity (each found few or no guidelines addressing treatment for multimorbidity), five guidelines that provide implications or recommendations for treatment (but none that focused exclusively on multimorbidity) and two consensus documents and 10 papers that we classified as “supplementary literature” (document/descriptive analyses, non-systematic reviews and discussion papers/comments/editorials) that provided examples of sets of principles that had been developed for the creation of multimorbidity guidelines.

Key findings from systematic reviews relate to: (1) consequences of and risk and protective factors for multimorbidity; (2) programs and models for treating people with multimorbidity; and (3) guidelines for treating people with multimorbidity. The most commonly identified consequences of multimorbidity include functional impairment and disability, poor quality of life, increased risk of early death (although findings are inconsistent), high health-care utilization, high out-of-pocket costs and the significant burden placed on patients and their families (France et al. 2012; Marengoni et al. 2011). In terms of risk factors, long-term care residents are at high risk for mental–physical multimorbidity (van den Brink et al. 2012). Certain combinations of chronic conditions (e.g., chronic respiratory disease, congestive heart failure and diabetes) present a greater risk for physical decline than other combinations; however, there is inconsistent evidence of the impact of patients’ income, sex, age and ethnicity on multimorbidity (France et al. 2012). A large social network has been found to be a protective factor for the consequences of multimorbidity (Marengoni et al. 2011).

For multimorbidity programs and models, we found three systematic reviews, which found that:

- patient-oriented interventions that focus on specific risk factors or impairments (e.g., functional ability or medication management) and are linked with relevant providers have been found to be more effective than interventions with a general focus (Smith et al. 2012);

- organizational interventions such as integrated treatment programs coordinated by care managers or individualized medication care plans have been found to improve prescribing, medication use and adherence (Smith et al. 2012);
- the effectiveness of comprehensive care programs that are built around the Chronic Care Model is inconsistent across studies, but the effects are either comparable to or better than standard care (de Bruin et al. 2012); and
- inappropriate medication use has been found to be reduced by computerized decision support and pharmaceutical care interventions (Patterson et al. 2012).

Promising interventions evaluated in primary studies that we identified include nurse-led interventions (Ishani et al. 2011; Williams et al. 2012), pharmacist-led shared medical appointments (Taveira et al. 2011), guided care teams (Boult et al. 2011; Boyd et al. 2007) and patient-centred, team-based collaborative care management (Katon et al. 2012; Lin et al. 2012; McGregor et al. 2011; Von et al. 2011).

Finally, we found several overviews focused on the applicability of existing guidelines to multimorbidity, examples of guidelines that included recommendations related to multimorbidity and principles that have been suggested for the creation of multimorbidity guidelines. The overviews of the applicability of existing guidelines to multimorbidity found inconsistent attention paid to multimorbidity. The overviews also found that many guidelines identify considerations about comorbidity (but not multimorbidity) and considered it in treatment, and some provided information about the burden of treatment on the patient, but none actually specified preferred actions for patients with more than one concurrent condition (Boyd et al. 2005; Fortin et al. 2011; Hughes et al. 2012; Lugtenberg et al. 2011; Mutasingwa et al. 2011; Vitry and Zhang 2008).

While not focused on managing multimorbidity, several guidelines that we identified either included recommendations related to multimorbidity or undertook a development process that may be informative for efforts to develop a multimorbidity guideline. Examples of this include ensuring consistency with guidelines for the major risk factors for the disease focused on in the guideline and providing advice about what to prescribe based on possible physical comorbidities and co-prescribing scenarios (NICE 2009, 2012).

The most frequently cited principles/recommendations (see the knowledge synthesis for the full list of 15 principles/recommendations) that have been suggested for the creation of multimorbidity guidelines are to:

- include information on the most common multimorbidity disease clusters along with the main chronic condition (Boyd et al. 2005; Fabbri et al. 2012; US Department of Health and Human Services 2010);
- develop a patient-centred approach to guideline development (Boyd et al. 2012a; Eddy et al. 2011; Lugtenberg et al. 2011; Mutasingwa et al. 2011; Tinetti et al. 2004; US Department of Health and Human Services 2010; van Weel and Schellevis 2006);

- cross-reference guidelines with each other (Guthrie et al. 2012; Hughes et al. 2012);
- use patient-friendly language (Boyd et al. 2005, 2012b; Cox et al. 2011; Fabbri et al. 2012; Guthrie et al. 2012; Hughes et al. 2012; Mutasingwa et al. 2011; Tinetti et al. 2004);
- consider the feasibility of implementation (Boyd et al. 2012a; Fabbri et al. 2012); and
- include older adults and patients with comorbid conditions in randomized trials and include the results in the development of guidelines (Boyd et al. 2005, 2012a; Lugtenberg et al. 2011; Tinetti et al. 2004; US Department of Health and Human Services 2010; van Weel and Schellevis 2006).

GAP ANALYSIS

We included 26 systematic reviews (six high-quality, 17 medium-quality and three low-quality) and four economic evaluations in the “gap analysis” (the full matrix is available in the original report). Many of the systematic reviews address several intervention levels and/or types of outcomes but most address interventions at the level of providers or teams and disease-focused outcomes. Moreover, while three reviews addressed prevention/upstream interventions, all exclusively addressed disease-focused outcomes and none addressed any of the other seven outcomes relevant to the three outcome domains (improving the patient experience of care, improving the health of populations and reducing the per capita cost of care) included in the Triple Aim Initiative. Further, almost half of the reviews ($n = 12$) did not include a study that was conducted in Canada, and those that did contained very few, pointing to a lack of Canada-specific evidence available about interventions for people with complex-care needs. In addition, four broad priority areas for future research emerged from our “gap analysis” (and from key informant interviews that we conducted to inform the analysis): (1) identifying complex-care patients and paying particular attention to those with the most complex needs; (2) taking a balanced approach to evaluating interventions and ensuring coverage of program-, system- and societal-level interventions; (3) adopting a patient-centred approach to measuring outcomes; and (4) developing guidance for patients/individuals and for providers.

ISSUE BRIEF AND CITIZEN BRIEF

The issue brief drew on the same systematic reviews that we identified in the knowledge synthesis and supplemented them with additional local evidence about the problem and systematic reviews related to specific components of the three elements of a potentially comprehensive approach to address the problem. The three elements broadly related to: (1) developing integrated models of care that improve the patient experience, improve health and keep per capita costs manageable; (2) enabling primary care, community care and other providers to identify and use guidelines (or care pathways) that meet the needs of people living with multimorbidity; and (3) enabling primary care, community care and other providers to efficiently support self-management by patients with multimorbidity. In addition to the systematic reviews included in the knowledge synthesis that focused on elements 1 and 2,

we identified additional reviews that found improvements in physical and mental health outcomes for patient education and family interventions designed to help patients with multimorbidity use self-management resources, and for information and communication technology, home-based support and a range of interventions aimed at supporting appropriate medicine use by consumers.

Findings from Citizen and Stakeholder Engagement

Stakeholder dialogue

The stakeholder dialogue brought together 21 participants, which included three policy makers, nine managers (a number of which are involved with Health Links in Ontario), three providers, five researchers and one from a disease-based society. Participants agreed with the framing of the problem in the issue brief, but raised three several additional considerations. First, many identified a lack of clarity about the target population of integrated approaches (e.g., is the target: people with or at-risk for multimorbidity, low-income people with multimorbidity, complex and vulnerable patients and/or high-needs patients in relation to both healthcare and the full spectrum of the social determinants of health?). Building on this, the second consideration raised was the need to determine what the goal is for addressing the “problem” of multimorbidity (e.g., is it a goal in itself, a mechanism for strengthening primary care more generally or a way of improving the patient journey for those with and without multimorbidity?). Finally, many emphasized that the full trajectory or journey for a patient (not just those living with multimorbidity) is not always the focus of care, which was seen as a missed opportunity for prevention and providing person-centred care.

In deliberating about the elements of a potentially comprehensive approach to address the problem, participants agreed that the status quo is not an option and identified three areas of focus in relation to the elements, which include:

1. focusing on person-centred care, identifying how to scale up successful approaches and building the capacity of health professionals that would be involved in new models of care;
2. developing an optimal approach for producing care guidelines or guidance for people with multimorbidity that is person-centred and focuses on identifying patients’, caregivers’ and families’ goals; and
3. developing tools and resources for self-management through partnerships between providers and citizen groups that include proactive approaches and use social media/technology to reach more people.

Towards implementing these approaches, participants emphasized the need for collaborating within teams and across silos, engaging patients, caregivers and families, funding approaches that support models of care for people with multimorbidity and making better use of technology (e.g., electronic medical records and computerized clinical decision support). Moreover, participants identified several next steps that they thought should be taken. These

included “staying the course” and not prematurely abandoning current support for bottom-up, person-centred approaches to developing models of care; develop evidence-based guidance that providers can use to help achieve goals set by patients; embracing approaches to supporting self-management that are innovative and prioritize collaboration; and developing a research agenda to address the many unanswered questions in this domain.

Citizen panel

The citizen panel brought together an ethnoculturally and socioeconomically diverse group of 11 citizens. Based on their lived experience, panel participants identified several factors they saw as driving the challenge, which included an ageing population with increasingly complex care needs, fragmentation of care, the psychosocial and economic burden on informal/family caregivers, lack of informational support and lack of focus on health promotion and disease prevention to curb the burden of chronic health conditions. When asked to deliberate about the elements of an approach to address the problem, participants identified six values that they viewed as being important to underpin future actions, which include:

1. patient- and caregiver-centredness (care and support must be attuned to the complex needs of people with multiple chronic health conditions, as well as the needs of their informal/family caregivers);
2. access (to reliable and timely information, as well as to coordination support);
3. collaboration (to mobilize all those who can provide needed support and services beyond what is provided by the health system);
4. solidarity (to ensure we do not leave the most vulnerable to fend for themselves);
5. empowerment (to equip people to engage in conversations with healthcare providers and manage their own care); and
6. trust (between patients and providers).

Panel participants also generally agreed about the need to focus efforts on the key components of the Chronic Care Model (Wagner et al. 1996) as a viable approach to improve how care is organized and delivered, but identified three priorities for its use. First, participants emphasized the need to adapt the model to people with multimorbidity, who often suffer from mental health problems and addictions, or from Alzheimer’s and other dementias, as they may be unable to self-manage or make informed decisions. Second, many identified the need to offer tools, resources and coaching for informal/family caregivers who must navigate the complex legal system to provide care and support for someone with multimorbidity who is unable to self-manage or make informed decisions. Finally, participants strongly emphasized the need to implement long-awaited electronic health records and other e-health initiatives that could provide informational support and coordination support to people with multimorbidity and their informal/family caregivers.

Discussion

Key findings across projects

While much of the evidence is mixed and inconclusive or lacking (e.g., in the case of guidelines), several key messages emerged from the literature we identified: (1) the main consequences of multimorbidity (functional impairment, poor quality of life, high healthcare utilization, high out-of-pocket costs and increased burden on the patient for their care); (2) interventions that are more targeted (e.g., integrated treatment programs coordinated by care managers) are more effective than those with a broader or more generic approach (e.g., case management or changes in care delivery); (3) “complex and multifaceted pharmaceutical care” can reduce inappropriate medication use and adverse drug events; and (4) recommendations exist for developing multimorbidity-specific guidelines. Our findings also suggest strong alignment between stakeholders’ priorities and citizens’ values and preferences, which point to several actions that can be taken, including: (1) developing evidence-based guidance that providers can use to help achieve goals set by patients; (2) embracing approaches to supporting self-management; (3) supporting greater communication and collaboration across healthcare providers as well as between healthcare providers and patients; and (4) investing more efforts in health promotion and prevention.

Strengths and limitations

The primary strength of our approach is the power of combining the best available research evidence from systematic reviews with tacit knowledge and real-world views and experiences of those involved in or affected by the issue to derive a more holistic understanding of it and to identify actions that can be taken by health system decision-makers to address it. The main limitation of our approach is that the stakeholder dialogue and citizen panel were convened with participants from Ontario (although the stakeholder dialogue had one participant from Quebec and another from the US). This could mean that the key themes identified in each are not representative of those from other provinces in Canada.

Implications for research

While we identified many systematic reviews that were at least somewhat relevant to multimorbidity, there was consensus among the stakeholder dialogue participants that there is a need to develop a clearly articulated research agenda. Such an agenda could be shaped around the four priorities that emerged from our mapping of the literature and key informant interviews, which included identifying complex-care patients; taking a balanced approach to evaluating a range of program-, system- and societal-level interventions; measuring patient-relevant outcomes; and developing evidence-based guidance that can be used by health providers to help achieve the goals set by people with multimorbidity and their families and caregivers. A logical first step would therefore be to engage in a priority-setting process to build on these areas and identify more specific research priorities that need to be addressed in the short, medium and long term, and the gap analysis, as well as themes from

the stakeholder dialogue and citizen panel, can provide important insight into setting future research priorities.

Implications for policy

Our findings provide several insights that can be used by health system decision-makers in Canada, who are grappling with how to design integrated approaches to support people with multimorbidity. The most fundamental actionable message from our findings is the need to move forward with efforts to support bottom-up, person-centred approaches to developing models of care. Critical to this is thinking beyond our historical focus on physicians and hospitals to develop integrated approaches for providing the range of supports that people with multimorbidity require, regardless of who provides them or where they are provided. In particular, this will likely require considering reforms, such as Ontario is now doing through its proposal to strengthen patient-centred care through bundled payments (Government of Ontario 2015) that would allow provincial and territorial health systems to provide accessible, comprehensive, coordinated and continuing care to people with multimorbidity across home and community, primary and acute care. Moreover, efforts to this end will need to consider a number of additional factors, including how best to identify those at risk for multimorbidity (particularly in vulnerable and hard-to-reach populations), monitor and evaluate models of care using meaningful indicators of success, scaling up successful approaches and building the capacity of providers to effectively provide care within these models.

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