

The Challenge Before Us

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What is meant by multimorbidity and complex care? Simply put, these terms refer to people with multiple health issues who require personalized healthcare and attention to social resources over time. Personalized healthcare is about addressing physical and mental health issues. Social resources are elements that make life worth living and help people deal with their illness and disability – elements such as meaningful relationships and valued social roles; caregiving and social support; and housing and the financial resources needed to manage life with serious and chronic health issues. The “complexity” revolves around managing multiple issues with limited predictability about the results.

Likely, the biggest challenge is to align needs of patients and families with care provision and with policy. How do we update health systems in Canada and worldwide to provide high-quality care that respects people, improves health outcomes and quality of life, and staunches the trajectory into illness and disability? Alignment is what this special issue on multimorbidity and complex care is about.

A multiplicity of factors have conspired to give this theme currency:

- Population aging and a decrease in mortality at every life stage
- Difficulty experienced by patients, families and care providers with healthcare “systems” not structured to provide what is needed. In many cases, there may not be a “system.”
- The knowledge by governments that very few patients use the bulk of healthcare: about 10% of the population accounts for about 60% of healthcare, usually individuals with multiple health issues requiring complex, long-term care.

In many ways, the issues are not new. Despite some excellent examples of chronic disease management programs, we have policies and payment systems that treat illness and disability as single conditions in both acute care and rehabilitation. Rehabilitation, for instance, has often been structured around discrete elements of functional improvement, despite the presence of multiple physical and psychosocial conditions.

On a personal note, my mother, who is 91, was recently a patient in a reputable rehabilitation hospital after hip replacement. She suffers from dementia (short-term memory loss). The nursing staff was not adequately trained to deal with cognitive decline, and, as a result, my mother had a very disappointing care experience. Beyond training, the staff seemed overworked and distracted from providing respectful, quality care by other tasks.

Multimorbidity and complex care overlap with care models in geriatrics and integrated care but not all individuals are older. There is also a substantial population of young and midlife populations with multiple health issues that may require years of care and support: and, beyond individual actions there are “upstream” strategies that could prevent and delay disease. Mercer et al. (2012) showed that multimorbidity appears much earlier in populations with social disadvantage, who often do not reach old age.

Where Should We Invest to Improve the Situation?

Many approaches have been tried and are currently being tested, but the evidence of effectiveness is mixed. A recent updated Cochrane Review by Smith and colleagues (2016) on the effectiveness of a large range of primary care interventions, including coordinated care, using a broad list of indicators from cost, healthcare use, health behaviour, health professional behaviours and cost, revealed little improvement. The authors suggest that work on mental health and specific functional areas showed promise. Despite these findings, patient-centred, coordinated

and integrated healthcare and social care is seen by many as the major thrust to improve outcomes. Over the next five years, the evidence will increase markedly over what we have to work with now, given the increase in funding for this work in Canada, the UK, the US, etc. In addition, new methods such as pragmatic trials where the intervention is adapted throughout the trial, as well as mixed methods, will evolve to capture what works, with whom and under what conditions.

The variability in the population challenges gold-standard approaches to evidence such as randomized control trials (RCTs) to accurately assess outcomes. This issue is likely more salient than we think it is, even in single illnesses. Where does an individual fall on the curve of RCTs? Applying evidence from population data to individuals is a tricky business.

So, the challenges before us include rethinking care delivery and policy, embedding opportunities for innovation at every level, and working together globally to share approaches to prevention, care, research, and funding.

What You Will Find in this Special Issue

Over the past 8–10 years, researchers and providers have been working on definitions, frameworks, models of care, understanding issues and trying out improvements. There is a lot to share now, and there is much more in preparation as scientists, funding agencies and governments, and patients and families make this work a key priority.

In this special issue, we profile a collection of work in multimorbidity and complex care. Each of the 12 papers provide important understandings about the problems of multimorbidity and complex care, and they posit new thinking and approaches to address these problems. Some of the papers are more essay-like on system changes and others are based on specific research. But you will see that all the papers have something important to say about the issue and ways forward. Most papers use care models that combine healthcare and social care/conditions, and patient-centred care. They are “roughly” organized into four sections.

The first group of papers in the *Patient-Centred Care in Complexity and Multimorbidity* section focuses on patient-centred care. The essay by Kerry Kuluski et al. (2016) leads with some important insights from research on this concept and its operationalization, particularly in Ontario. Ross Upshur (2016) focuses on the challenges of multimorbidity and care need in primary care based on clinical experience and research. Carolyn Steele Gray et al. (2016) speak to the promise of information technology (IT) to improve linkages with patients and families and their care providers.

The *Improving Evidence and Measures of Performance* section addresses evidence and performance. Michelle Nelson et al. (2016) introduce the challenge of using practice guidelines in multimorbidity taking stroke rehabilitation evidence as a case

example. Walter Wodchis (2016) takes on the complex issue of performance measurement in multimorbidity. What goals, definitions and approaches might we consider in gathering data needed to inform providers and users about quality care? Charissa Levy et al. (2016) demonstrate how a systematic approach to rehabilitation is helping to reform basic practices that will enhance care and outcomes for people with complex rehabilitation needs and how simple changes such as direct referral by primary care to rehabilitation hospitals removes the need for acute care hospital stays – saving money and getting the appropriate service more quickly.

The next section, *Models of Collaboration*, provides insight into collaboration to improve care for people with multimorbidity who need complex care. Martin Fortin et al. (2016) examine how a long-term university–government relationship across many joint projects on multimorbidity and complexity has resulted in knowledge and improvements to care. Onil Battacharyya et al. (2016) describe a unique collaborative model involving research and evaluation on multiple projects in complex care with support from an advisory research group on design and methods and ways to share and aggregate cross-project outputs. In contrast, David McNeil et al. (2016) speak about a research study intended to link hospital to home, and the “real-life” challenges amongst health providers in establishing communication and collaboration to improve the transition home.

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The *Exemplars of Integration and System Change* section focuses on innovations to transform healthcare, from direct care management to government policy. Marian Walsh (2016) explains the journey she and Bridgepoint (now part of Sinai Health System) have taken to understand people with multiple health conditions and to build an integrated, high-quality care system, including the development of an award-winning new healthcare facility that specifically focuses on complex rehabilitative care. This is a drastically redefined approach that includes clinical care, comprehensive assessment, complexity clinics, etc. Anne Hendry et al. (2016) explain the work undertaken in Scotland on integrated healthcare and social care for those with multimorbidity needing complex care. The Government of Scotland has initiated bold changes to integrate care and realign funding to be more effective for people with multiple health issues and Canada could learn a great deal from this very exciting bottom-up–top-down policy initiative, as well as the support systems such as polypharmacy management and health record advances. It is a stellar example of the importance

of aligning values, goals and funding within government to support local and regional innovation. Nick Goodwin, head of the International Institute for Integrated Care in Oxford, identifies countries and locales that are global innovators in care reform for people with multiple health issues and provides some wise counsel for Canada on the conditions that foster substantive progress in integrated care (Lyons 2016).

On behalf of Longwoods Publishing, I would like to very sincerely thank all of the contributors for their hard work in preparing papers for this special issue. The enthusiasm to share their perspectives, research and action on this important issue was most welcome. Also, a big thank you is extended to Dianne Foster Kent who was instrumental in seeing this special issue through to publication. And last but not least, thanks to Ross Baker who asked if I could take on the role of guest editor of this special edition as my first “retirement” project. **HQ**

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About the Author

Renee Lyons, PhD, is the founding chair and scientific director emeritus of the Bridgepoint Collaboratory for Research and Innovation at Bridgepoint Active Healthcare in Toronto, ON. She is a professor in the Dalla Lana School of Public Health and Institute for Health Policy, Management and Evaluation at the University of Toronto.

Some Background: My Road Trip into Multimorbidity and Complex Care

I have been researching some side of chronic disease and disability most of my career – from people and social conditions to prevention and health systems improvement. It all began with my experience as a medical social worker. As a social worker, you see it all. Some families start with disadvantage. Others suffer social and financial losses as a result of chronic health conditions. And yet others, regardless of social status, are amazingly resilient and have both personal and social resources in place.

Understanding the experience of illness and disability can lead you down two relatively parallel and often disconnected paths – to fix the health system or to staunch the trajectory into health issues. My research at Dalhousie University and at the Atlantic Health Promotion Research Centre travelled both paths: population health and health promotion research, as well as health systems and policy research, and chronic conditions. These projects were built as team efforts: the teams comprised researchers, health providers and agencies. A pet project was about what it would take to improve care for people in rural communities who had suffered a stroke.

In 2009, I accepted a new research chair in complex chronic disease at Bridgepoint Health (now part of Sinai Health System) and the Faculty of Medicine (University of Toronto) with little idea about what I was getting into. However, who could refuse a generous opportunity to launch a new research program, and this, very importantly, was at a healthcare site whose CEO and team were thirsty for knowledge on how to be the best care provider in Canada to this population! These gifts would be the envy of any applied health scientist.

In 2010, several of us came together under the leadership of Alex Jadad and the support of the government of Spain to write an e-book: *When People Live with Multiple Health Conditions*. When I look back to that book, I can see that most of the chapters were very speculative about the coming tsunami of older adults and that we needed to do something. It raised more questions than provided answers.

Looking back over the 60plus projects we undertook within the Bridgepoint Collaboratory for Research and Innovation (now part of the Lunenfeld–Tannenbaum Research Institute, Sinai Health System) from 2009 to 2014, the project that laid the foundation for all that followed was “The Bridgepoint Study.” Led by young scientists Kerry Kuluski and Celeste Alvaro (Kuluski et al. 2013), our team designed and carried out a very comprehensive study to understand our hospital (complex rehabilitative care) population: Who were they? What was needed to improve care?

Despite the natural urge to change things, we took the time to understand the patient population and the issues they were dealing with. This study was neither randomized, nor was it a representative sample of multimorbidity and complexity in the community. It was about 116 inpatients in the hospital for complex rehabilitative care. However, we piloted and used very systematic and in-depth quantitative and qualitative methods with the idea of including patients with multiple health issues.

We found the following:

1. Every case was different in terms of the combination of health and psychosocial issues, and the trajectory into multimorbidity.
2. Many patients experienced preventable loss in health and social resources as they moved from one health issue to multiple health and social problems – if only they had received help from integrated social and health services earlier!
3. Personalized care was a nice ideology, but it was often in conflict with the prevailing policy and funding environment – e.g., how doctors are paid and hospitals reimbursed, and the disconnects across health and social care.
4. We lacked adequate assessment and care planning approaches, and we needed teamwork, coordinated care and improved integration with community services. The anxiety of patients about returning home without adequate supports was very high.
5. There were older adults but also young and midlife adults looking forward to 20, 30 or 40 years of life with major illness and disability and no coordinated, long-term support. Those clinics typically ended with children’s services.
6. Patients were on too many medications that were not being adequately managed.

7. Mental health issues abounded – anxiety, depression, addictions, along with personality disorders and more. There was almost a 50% incidence of depression.
8. There were IT interoperability problems, let alone systems having the capacity to chart multiple health issues or critical items like the reason for prescribing medications.
9. There were major unaddressed problems experienced by families dealing with a seriously ill family member.

Our team created a complexity framework (Schaink et al. 2012) to conceptualize the elements that need to be considered in clinical care and policy. From there, we looked at many issues such as the potential of using pharmacogenetics in prescribing, new approaches to facility design (Alvaro and Atkinson 2013 and personalizing mobility aids, mental health (Gibson et al. 2015), understanding the younger populations of people with complex health conditions, etc. (<http://www.bridgepointhealth.ca>)

This work would not have been possible without the dedication of the Bridgepoint Collaboratory’s talented post-doctoral fellows and young scientists; collaborations with researchers, health providers and the government in Toronto and elsewhere; and the commitment of Bridgepoint to advancing care for this population. It gives me great pleasure to be able to profile the work of several of those young scientists and their teams in this special edition. Also, the focus on complexity advanced by scientists such as Walter Wodchis at the University of Toronto, Institute for Health Policy, Management and Evaluation, Dalla Lana School of Public Health has helped to develop this issue as a major focus in Toronto and Ontario. Countries such as Spain, Scotland (UK) and the US have been major leaders, and their desire to collaborate for the benefit of all has been excellent.

– Renee Lyons
Guest Editor

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