

Healthcare Quarterly

SPECIAL FOCUS ON
**COMPLEX CARE
AND MULTIMORBIDITY**



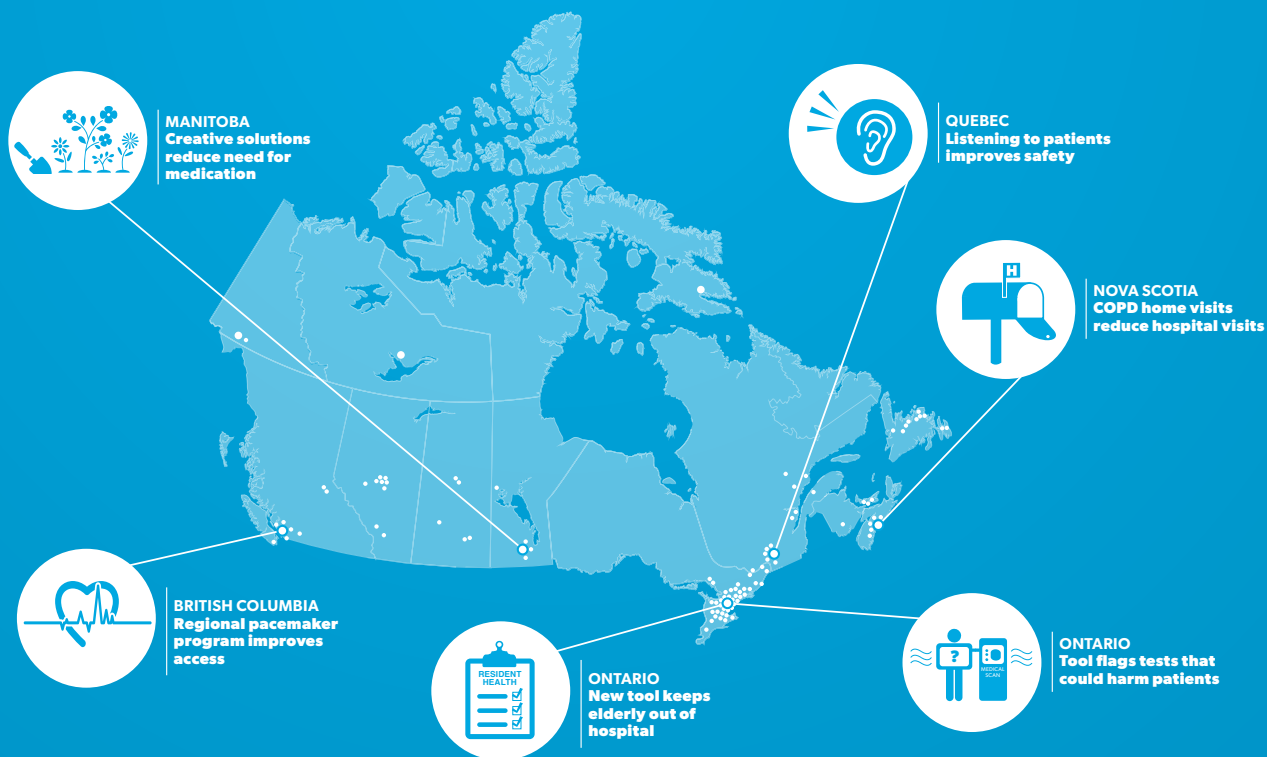
Patient-Centred Care in Complexity and Multimorbidity

Improving Evidence and Measures of Performance

Models of Collaboration

Exemplars of Integration and System Change

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This issue of *Healthcare Quarterly* tackles the challenge of improving care for multimorbid patients. Few health systems across Canada (or elsewhere) are designed to provide integrated, coordinated and high quality care for the complex patients who need it. Indeed, as Nick Goodwin points out in his interview with guest editor Renee Lyons in this issue, the reverse is more often true: the people who would most benefit from such coordinated care – the socially disadvantaged, children, adults with multiple chronic conditions and others – are the least likely to get it (Lyons 2016).

The social, epidemiological and health systems factors creating this conundrum have been recognized for some time. But the health system is like a large cargo ship: fully loaded, it takes a long time to turn, even when those in charge know where they need to be headed. And, unlike that cargo ship, in healthcare there are still arguments about what the new directions should be to create high quality care for multimorbid patients. However, as the articles in this issue illustrate, there is growing agreement on the improvements needed in the roles of those providing care. New and enhanced relationships must be developed between clinicians, others with information and resources, and clients. More flexible and effective coordination is required to weave together a custom array of services necessary for complex patients with varying health and social needs. And, just as critical, the system needs to abandon the enduring silos of care that are reinforced by the governance, regulatory and financial structures that limit the flexibility needed to

create a responsive, effective and efficient health system.

The acerbic American social critic H.L. Mencken (1917) observed that “there is a well-known solution for every human problem – neat, plausible ... and wrong.” None of the essays in this edition falls into that trap. Indeed, there is a clear-eyed recognition of the complexity of these issues and the need to share lessons among the clinicians, researchers, decision-makers, patients, care givers and others addressing these problems.

As guest editor, Renee Lyons has created a rich menu of articles from leading thinkers, who address the challenges of designing care for complex patients and developing the health and community resources that will support that care. Renee’s leadership in this area, both as a thoughtful academic and as an engaged practitioner, is once again demonstrated by her success in assembling this valuable collection. These articles demonstrate that progress is being made in reshaping the mental models and system linkages necessary to answer the challenges of multimorbidity in Canada and elsewhere.

– G. Ross Baker
Editor-In-Chief

References

- Lyons, R. 2016. “In Conversation with Dr Nick Goodwin.” *Healthcare Quarterly* 19(2): 81–85. doi:10.12927/hcq.2016.24704.
- Mencken, H.L. 1917. “The Divine Afflatus” *New York Evening Mail* (16 November 1917).

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Special Focus on Complex Care and Multimorbidity

INTRODUCTION

13 The Challenge Before Us

Renee Lyons

Aligning appropriate care with informed policy is a major challenge in addressing the needs of medically complex patients and their families. Updating 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 is the central focus of this issue.

PATIENT-CENTRED CARE IN COMPLEXITY AND MULTIMORBIDITY

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Kerry Kuluski, Allie Peckham, A. Paul Williams and Ross E.G. Upshur

Person-centred care is a key component of quality in health systems worldwide. This commentary explores the concept of person-centred care and its importance among people who frequently use healthcare, such as those with multimorbidity. It looks specifically at the challenges of providing integrated care in an era of health system re-development and increasing cost constraint.

24 Understanding Clinical Complexity the Hard Way: A Primary Care Journey

Ross E.G. Upshur

In the last decade, the population seen in primary care has shifted, posing substantial challenges for both primary care providers and health systems. The author documents approaches that evolved in an academic family practice environment to address the challenges posed by complex patients typified by multiple concurrent chronic conditions and social determinants challenges.

29 eHealth Advances in Support of People with Complex Care Needs: Case Examples from Canada, Scotland and the US

Carolyn Steele Gray, Stewart Mercer, Ted Palen, Brian McKinstry and Anne Hendry on behalf of The Multi-National eHealth Research Partnership Supporting Complex Chronic Disease and Disability, The eCCDD Network

This article presents three case examples from Ontario (Canada), Scotland and Kaiser Permanente Colorado (United States) to identify how various jurisdictions are using health-related IT technology to address multimorbidity. A SWOT (strengths, weaknesses, opportunities, threats) analysis is presented for each case and a final discussion addresses the future of eHealth for complex care needs.

IMPROVING EVIDENCE AND MEASURES OF PERFORMANCE

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Michelle L.A. Nelson, Agnes Grudniewicz and Sarah Albadry

In Canada, policy makers are working to align services with the Stroke Rehabilitation Best Practice Recommendations (SRBPR) which is complicated given that most strokes occur in the context of other diagnoses. The authors sought to understand clinicians' use of the clinical practice guidelines, and ascertain how much guidance regarding multimorbidity was available in the SRBPR.

44 Performance Measurement for People with Multimorbidity and Complex Health Needs

Walter P. Wodchis

The author reviews approaches to performance measurement in health systems with particular attention to people with multimorbidity and complex health needs, and suggests that performance measurement for this population should be motivated by the Complexity Framework and organized by the Triple Aim. Based on the care needs and appropriate goals for the health system for this population, applicable measures and suggestions for implementing and using performance measurement systems are identified.

49 Realizing the Potential of Rehabilitative Care for People with Complex Health Conditions: The Time Is Now

Charissa Levy, Sue Balogh and Emmi Perkins

The pressures to the healthcare system arising from increasing numbers of medically complex individuals are felt along the entire continuum of care. Rehabilitative care plays a key role in that continuum by providing the process through which individuals are engaged in interventions to address their functional and psychosocial care goals to help them carry on with the business of living.

MODELS OF COLLABORATION

55 It Takes Two to Tango: Researchers and Decision-Makers Collaborating to Implement Practice Changes for Patients with Multimorbidity

Martin Fortin, Martine Couture, Tarek Bouhali, Esther Leclerc and Moira Stewart

An integrated knowledge translation strategy is a key factor in fostering the implementation of practice changes. Building on a 15-year history of projects that include close collaboration between researchers and decision-makers in the Saguenay region of Quebec (Canada), the authors identify several key elements that resulted in practice changes in primary care and improved outcomes for patients with multimorbidity.

60 Building Bridges to Integrate Care (BRIDGES): Incubating Health Service Innovation across the Continuum of Care for Patients with Multiple Chronic Conditions

Onil Bhattacharyya, Michael Schull, Kaveh Shojania, Vicky Stergiopoulos, Gary Naglie, Fiona Webster, Ricardo Brandao, Tamara Mohammed, Jennifer Christian, Gillian Hawker, Lynn Wilson and Wendy Levinson

The Toronto-based Building Bridges to Integrate Care (BRIDGES) collaborative provided resources to refine and test nine new models linking primary, hospital and community care. Given the range of skills required to develop effective interventions, a novel incubator was used to test and spread opportunities for system integration that included operational expertise and support for evaluation and process improvement.

67 A “Simple” Evidence-Based Intervention to Improve Care Transitions for Frail Patients with Complex Health Conditions: Why Didn’t It Work as Expected?

David McNeil, Roger Strasser, Nancy Lightfoot and Raymond Pong

The authors discuss research to evaluate the effectiveness of a care transition intervention involving a hand-off between a hospital-based care transitions nurse and a community-based rapid response nurse. They found that the effectiveness of transitional coordination efforts was thwarted by ineffective communication, which affected the quality of the underlying relationships between the two teams.

EXEMPLARS OF INTEGRATION AND SYSTEM CHANGE

73 Improving Outcomes through Transformational Health and Social Care Integration – The Scottish Experience

Anne Hendry, Alison Taylor, Stewart Mercer and Peter Knight

The Scottish Parliament recently passed legislation on integrating healthcare and social care to improve the quality and outcomes for people with multiple and complex needs across Scotland. This ambitious legislation provides a national framework to accelerate progress in person-centred and integrated care and support.

81 In Conversation with Nick Goodwin

Renee Lyons

Guest editor, Renee Lyons, recently spoke with International Foundation for Integrated Care co-founder and CEO, Nick Goodwin, about examples of excellence in the adoption of integrated care around the world, as well as the challenges that lie ahead in realizing its full potential across health and social care systems.

86 CEO Perspective: A Health System for Patients with Complex Conditions: Reflections from Bridgepoint’s Transformation

Marian Walsh

Bridgepoint has been on a journey for almost 20 years to transform care for the growing population at large and within our healthcare system, with increasingly complex health conditions. Recent recognition of the existence of these patients, through analysis of healthcare utilization and accounts of inadequate care, is a critical development.

COLUMNS

1 From the Editor

6 ICES Report – Epidemiology of Fracture in Adults from Ontario, Canada, with Chronic Kidney Disease: An Examination of Fracture Burden Using Administrative Health Data

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Epidemiology of Fracture in Adults from Ontario, Canada, with Chronic Kidney Disease: An Examination of Fracture Burden Using Administrative Health Data

Kyla L. Naylor, Amit X. Garg, S. Joseph Kim and Gregory A. Knoll

Abstract

Fractures are associated with morbidity and mortality. Individuals with chronic kidney disease (CKD) experience bone mineral metabolism changes, which increases fracture risk. Researchers have quantified the epidemiology of fractures in adults with CKD using administrative health databases from Ontario, Canada, held at the Institute for Clinical Evaluative Sciences. Results demonstrated that many individuals with non-transplant CKD sustain fractures, with the risk increasing as kidney function declines. However, fracture risk in kidney transplant recipients was lower than previously described, which suggests recipients may not be a high-risk fracture group. There is a need to test fracture prevention interventions in the CKD population.

The Issue

The number of chronic kidney disease (CKD) patients in Canada is increasing, with over three million adults living with CKD (Arora et al. 2013; CIHI 2013). There is a concern about poor outcomes associated with CKD, one of which is fractures. Several studies assessing the epidemiology of fracture in CKD have been conducted using administrative databases in the United States. However, these findings may not accurately reflect the Canadian experience, as fracture rates have been shown to vary as much as 15-fold across countries (Kanis et al. 2002). Access to large healthcare databases in Ontario, Canada, provides an opportunity to conduct a comprehensive examination of the epidemiology of fracture in the CKD population.

Multiple factors likely contribute to an increased fracture risk in the CKD population. As kidney function declines, CKD-related mineral and bone disorders may develop (i.e., changes in calcium, phosphorous, vitamin D or parathyroid hormone metabolism), and this can lead to an increased fracture

risk (Kidney Disease Improving Global Outcomes [KDIGO] 2009). Other factors may also increase fracture risk, such as muscle wasting (West et al. 2012) and steroid administration to kidney transplant recipients (Canalis et al. 2007). Despite this increased fracture risk, there remain many unanswered questions about interventions that will safely prevent fractures in the CKD population (KDIGO 2009; Palmer et al. 2009). Moreover, many of the guideline statements for the treatment and evaluation of bone disease in CKD patients are weak or ungraded (KDIGO 2009). An improved understanding of the epidemiology of fracture in the CKD population informs the conduct of well-designed clinical trials and prospective studies.

This report highlights several recent studies conducted at the Institute for Clinical Evaluative Sciences (ICES) by the provincial Kidney, Dialysis and Transplantation team aimed to clarify fracture incidence, improve clinical guidelines, advance prognostication and guide informed consent to help decrease the fracture burden in the CKD population.

Key Findings

Fracture incidence in the non-transplant chronic kidney disease population

Knowing an individual's fracture risk according to kidney function, age and sex is useful to guide sample-size estimates for future fracture prevention trials and for risk stratification. ICES databases were used to determine the three-year cumulative incidence of fracture (defined as a composite of hip, pelvis, forearm or proximal humerus fractures) stratified by age (40–65 and >65 years), sex and kidney function (as measured by an estimated glomerular filtration rate [eGFR] of >60 mL/min/1.73 m², 45–59, 30–44, 15–29 and <15 or chronic dialysis) at cohort entry (2002–2009) (Naylor et al. 2014). As kidney function declined,

fracture risk increased in a graded manner. For example, in women >65 years, the three-year cumulative incidence of fracture across the five eGFR categories was 4.3%, 5.8%, 6.5%, 7.8% and 9.6% over the study follow-up (Figure 1). In other words, 1 in 10 women aged >65 years with an eGFR of <15 mL/min/1.73 m² will experience a fracture over a three-year follow-up. Similar results were found in men (1.6%, 2.0%, 2.7%, 3.8% and 5.0%) (Figure 2). Even individuals with moderate declines in kidney function had a significantly higher fracture risk compared to those with normal kidney function. For example, women aged >65 years with an eGFR of 45–59 mL/min/1.73 m² had a 1.4-times higher fracture risk compared to women with an eGFR of >60 mL/min/1.73 m².

FIGURE 1. Three-year cumulative incidence of fracture in women displayed by kidney function. From: Naylor et al. 2014; reprinted with permission from Elsevier

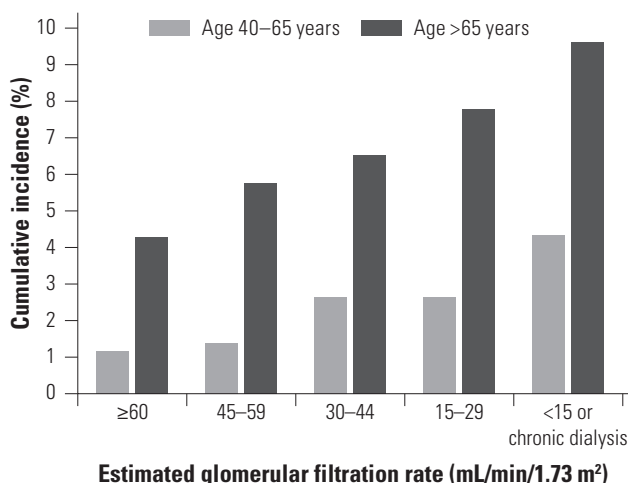
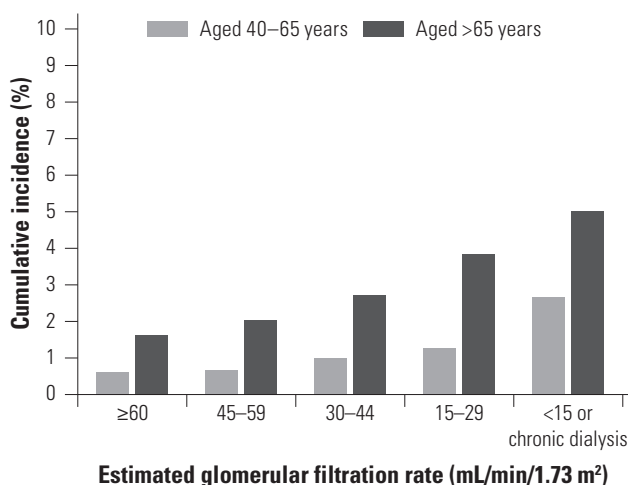


FIGURE 2. Three-year cumulative incidence of fracture in men displayed by kidney function. From: Naylor et al. 2014; reprinted with permission from Elsevier



Falls increase the risk of fracture, and preventing falls is an essential strategy in fracture prevention (Cumming and Klineberg 1994; Papaioannou et al. 2010). ICES databases were used to assess the three-year cumulative incidence of falls resulting in a hospital encounter. Similar to fractures, as kidney function declined, fall risk increased in a graded manner. For example, the three-year cumulative incidence of falls in women aged >65 years across the five eGFR categories was 3.8%, 5.9%, 7.6%, 9.1% and 13.1% (Naylor et al. 2014).

Fracture incidence in kidney transplant recipients

To help quantify fracture risk (defined as a composite of hip, forearm or proximal humerus fractures), kidney transplant recipients who received a transplant in Ontario between 1994 and 2009 were compared with two groups at high risk for fracture (non-dialysis CKD population and a healthy segment of the general population with previous fractures) and one low-risk group (healthy segment of the general population with no previous fracture) matched for age, sex and cohort entry date (Naylor et al. 2016a). Kidney transplant recipients had a significantly higher three-year cumulative incidence of fracture (1.6%) compared with the non-dialysis CKD population (1.1%) and the general population with no previous fracture (0.5%). However, when compared with the general population with a previous fracture (2.3%), recipients had a significantly lower fracture risk. Kidney transplant recipients were not considered a high-risk group for fracture as only 1.7% of them sustained a hip fracture over 10 years (clinical practice guidelines define high-risk as a 10-year risk of hip fracture of ≥3%) (Grossman et al. 2010; National Osteoporosis Foundation 2010).

Similar to the non-transplant CKD population, falls involving a hospital encounter among kidney transplant recipients were common, with a three-year cumulative incidence of 7.9% (Naylor et al. 2016a). Female recipients aged ≥50 years had a particularly high fall risk, with 1 in 10 (11.1%) sustaining a fall in the three years after transplant.

Bone mineral density testing in kidney transplant recipients

In the general population, several measures have been recommended by Osteoporosis Canada to assess bone health. For example, bone mineral density (BMD) tests are widely used to risk-stratify patients and help guide treatment decisions (Papaioannou et al. 2010). However, given the complex pathophysiology of bone disease among kidney transplant recipients, the utility of BMD in this population is controversial (KDIGO 2009). Despite limited evidence supporting the widespread use of BMD among recipients, more than half (58%) of Ontario kidney transplant recipients who received a transplant between 1994 and 2009 had at least one BMD test in the three years after transplant, with approximately 30% having more than two

tests (Naylor et al. 2016b). In total, these tests cost more than \$600,000 (in 2014 Canadian-equivalent dollars). The number of recipients who were administered at least one BMD test significantly increased over time (recipients who transplanted in 1994, 20.9%; in 2009, 66.4%). Recipients were significantly more likely to receive at least one BMD test (58.0%) compared with the general population with no previous fracture (8.5%) and the general population with a previous fracture (13.8%), matching on age, sex and cohort entry date. There was significant variation across the six Ontario transplant centres in the proportion that performed at least one BMD test in the three years post-transplant (from 15.6% to 92.1%), and this variability persisted after controlling for factors likely to influence a clinician's decision to perform a test (e.g., age).

Implications

Many individuals with CKD will fracture and fall. Although fracture risk in kidney transplant recipients was lower than expected, recipients still had a significantly higher fracture risk compared with the healthy general population with no previous fracture. As the Canadian CKD and kidney transplant populations continue to grow with improved survival rates, fractures and their associated morbidity will become an increasing concern. A shift in bone-disease research and resources towards this understudied population could be helpful.

These findings have implications for family physicians. Individuals with mild to moderate declines in kidney function are often primarily managed by family physicians, and kidney transplant recipients are often managed in collaboration with nephrologists. Therefore, family physicians can play an integral role in fracture management in the CKD population.

... fractures and their associated morbidity will become an increasing concern.

While serious falls are common in the CKD population, KDIGO (2009) guidelines for CKD-related mineral and bone disorders only minimally discuss them. However, Osteoporosis Canada guidelines provide an in-depth discussion of falls in the general population as they state their management is an integral part of fracture prevention (Papaioannou et al. 2010). Future CKD guidelines should incorporate a section on falls. Moreover, the efficacy of fall prevention programs in this unique patient population needs to be determined.

Given the burden of fractures in the CKD population, studies that test promising interventions to prevent fracture are needed. According to the KDIGO guidelines, there is insufficient information to guide treatment for fracture prevention one year post-transplant, which may be attributable to clinical trials having inadequate statistical power (KDIGO

2009; Palmer et al. 2009). Moreover, the safety and efficacy of fracture prevention therapies in individuals with an eGFR of <30 mL/min/1.73 m² is uncertain (KDIGO 2013; Lin 1996). Therefore, adequately powered clinical trials are required. Based on three-year cumulative incidence estimates obtained from these ICES studies, thousands of CKD patients would need to be enrolled in clinical trials to ensure sufficient power. This can only be accomplished through a collaboration of multiple centres caring for CKD patients. Prospective studies are also required to determine the utility, timing and cost-effectiveness of BMD testing in kidney transplant recipients.

In summary, using administrative health databases from ICES, the epidemiology of fractures in Ontario CKD patients was quantified. Given the growing burden of CKD, strategies to prevent fractures and falls are needed to improve outcomes in this patient population. **HQ**

References

- Arora, P., P. Vasa, D. Brenner, K. Iglar, P. McFarlane, H. Morrison et al. 2013. "Prevalence Estimates of Chronic Kidney Disease in Canada: Results of a Nationally Representative Survey." *CMAJ* 185(9): E417–23.
- Canadian Institute for Health Information (CIHI). 2013. *Canadian Organ Replacement Register Annual Report: Treatment of End-Stage Organ Failure in Canada, 2003 to 2012*. Ottawa, ON: Author. Retrieved March 16, 2016. <https://secure.cihi.ca/free_products/2014_CORR_Annual_Report_EN.pdf>.
- Canalis, E., G. Mazziotti, A. Giustina and J.P. Bilezikian. 2007. "Glucocorticoid-Induced Osteoporosis: Pathophysiology and Therapy." *Osteoporosis International* 18(10): 1319–28.
- Cumming, R.G. and R.J. Klineberg. 1994. "Fall Frequency and Characteristics and the Risk of Hip Fractures." *Journal of the American Geriatrics Society* 42(7): 774–78.
- Grossman, J.M., R. Gordon, V.K. Ranganath, C. Deal, L. Caplan, W. Chen et al. 2010. "American College of Rheumatology 2010 Recommendations for the Prevention and Treatment of Glucocorticoid-Induced Osteoporosis." *Arthritis Care and Research (Hoboken)* 62(11): 1515–26.
- Kanis, J.A., O. Johnell, C. De Laet, B. Jonsson, A. Oden and A.K. Ogelsby. 2002. "International Variations in Hip Fracture Probabilities: Implications for Risk Assessment." *Journal of Bone and Mineral Research* 17(7): 1237–44.
- Kidney Disease: Improving Global Outcomes (KDIGO) CKD-MBD Work Group. 2009. "KDIGO Clinical Practice Guidelines for the Diagnosis, Evaluation, Prevention, and Treatment of Chronic Kidney Disease–Mineral and Bone Disorder (CKD-MBD)." *Kidney International* 76(Suppl 113): S1–130.
- Kidney Disease: Improving Global Outcomes (KDIGO) Work Group. 2013. "KDIGO 2012 Clinical Practice Guideline for the Evaluation and Management of Chronic Kidney Disease." *Kidney International Supplements* 3(1): 1–150.
- Lin, J.H. 1996. "Bisphosphonates: A Review of Their Pharmacokinetic Properties." *Bone* 18(2): 75–85.

National Osteoporosis Foundation. 2010. *Clinician's Guide to Prevention and Treatment of Osteoporosis*. Washington, DC: Author.

Naylor, K.L., E. McArthur, W.D. Leslie, L.A. Fraser, S.A. Jamal, S.M. Cadarette et al. 2014. "The Three-Year Incidence of Fracture in Chronic Kidney Disease." *Kidney International* 86(4): 810–18.

Naylor, K.L., S.A. Jamal, G. Zou, E. McArthur, N.N. Lam, W.D. Leslie et al. 2016a. "Fracture Incidence in Adult Kidney Transplant Recipients." *Transplantation* 100(1): 167–75.

Naylor, K.L., G.Y. Zou, W.D. Leslie, E. McArthur, N.N. Lam, G.A. Knoll et al. 2016b. "Frequency of Bone Mineral Density Testing in Adult Kidney Transplant Recipients from Ontario, Canada: A Population-Based Cohort Study." *Canadian Journal of Kidney Health and Disease* 3: 2.

Palmer, S.C., D.O. McGregor and G.F. Strippoli. 2009. "Interventions for Preventing Bone Disease in Kidney Transplant Recipients." *Cochrane Database of Systematic Reviews* (3): CD005015.

Papaioannou, A., S. Morin, A.M. Cheung, S. Atkinson, J.P. Brown, S. Feldman et al. 2010. *Clinical Practice Guidelines for the Diagnosis and Management of Osteoporosis in Canada: Background and Technical Report*. Toronto, ON: Osteoporosis Canada. Retrieved March 16, 2016. <http://www.osteoporosis.ca/multimedia/pdf/Osteoporosis_Guidelines_2010_Background_And_Technical_Report.pdf>.

West, S.L., S.A. Jamal and C.E. Lok. 2012. "Tests of Neuromuscular Function are Associated with Fractures in Patients with Chronic Kidney Disease." *Nephrology, Dialysis, Transplantation* 27(6): 2384–88.

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Breakfast with the Chiefs

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Care for Patients with Complex Needs: Canadian Results from the Commonwealth Fund 2015 International Health Policy Survey of Primary Care Physicians

Christina Lawand, Geoff Paltser, Grace Cheung and Alison Ytsma

Abstract

Good primary care is essential for the effective management of patients with chronic conditions in the community and to ensure their care is well coordinated with other parts of the system. The Commonwealth Fund 2015 International Health Policy Survey compares the views and experiences of primary care physicians in 11 countries including Canada. The survey found nearly all (98%) primary care doctors across countries treat patients with complex needs in their practice. However, when examining questions on chronic disease management and coordination of care with other providers, Canadian results are mixed compared to the international average, and show variation at the provincial level. Opportunities likely exist to learn from other countries that have a more systematic approach to primary care delivery.

Introduction

For most people, primary care physicians are the first point of contact with the healthcare system. They provide and coordinate care to manage health problems in the community and help to prevent people from getting sick in the first place. Research shows that effective primary care provides better overall care for patients at a lower cost to the health system. Across Canada, there have been many efforts to improve the delivery of primary care (Beaulieu et al. 2013; Government of Canada 2012).

By providing comparable information on the experiences of primary care physicians in 11 countries, the Commonwealth Fund 2015 International Health Policy Survey of Primary Care Physicians provides an important perspective on how well primary care works in Canada and where improvements still need to be made (Canadian Institute for Health Information 2016; Commonwealth Fund 2015).

Of the many topics covered in the survey, primary care physicians were asked questions about managing complex patients with chronic diseases and coordination of care for these patients across the healthcare system. These questions are highly relevant given that more than 65% of Canadian seniors have multiple chronic conditions such as heart disease, cancer, asthma, diabetes, arthritis and dementia (Public Health Agency of Canada 2010). These individuals are often high users of the health system and face significant challenges to their quality of life. However, many chronic conditions (referred to as ambulatory care sensitive conditions) can be managed in the community through appropriate delivery of primary care, thereby avoiding or delaying costly hospitalizations and further deterioration of health.

Methodology

The Commonwealth Fund 2015 International Health Policy Survey of Primary Care Physicians polled primary care physicians in 11 countries: Australia, Canada, France, Germany, the Netherlands, New Zealand, Norway, Sweden, Switzerland, the United Kingdom and the United States. Data from France were not available at the time this analysis was conducted. In Canada, there were 2,284 respondents and an overall response rate of 31.7%.

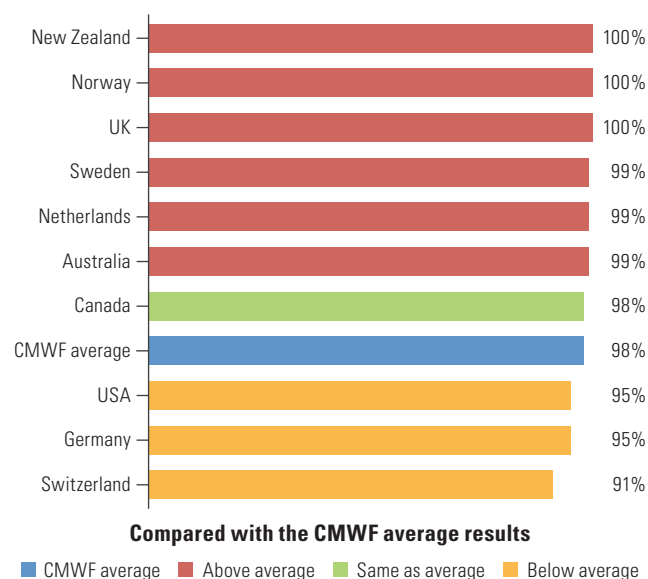
The survey data for Canada were first weighted within each of the 10 provinces by age and gender. Data were, subsequently, weighted by province to reflect Canada's primary care physician distribution. Owing to small sample sizes, detailed provincial and territorial results are not shown for Prince Edward Island, Nunavut, Northwest Territories and Yukon.

Statistical testing was performed to determine whether Canadian and provincial results were significantly different from the international average of 10 countries.

Results

The Commonwealth Fund 2015 International Health Policy Survey of Primary Care Physicians found that 98% of Canadian doctors see patients with multiple chronic conditions. This is on par with the average of all countries surveyed (Figure 1). A similar proportion (96%) of doctors said that their practice is well or somewhat prepared for these patients, slightly below the international average (98%).

FIGURE 1.
Proportion of primary care physicians whose practice often/sometimes sees patients with multiple chronic conditions



Primary care physicians can manage their patient's chronic conditions in a variety of ways. Canadian primary care physicians were asked if their practice uses personnel, such as nurses or case managers, to monitor and manage care for patients with chronic conditions and if their practice gives written instructions about how their patients with chronic conditions can manage their own care at home. Responses varied across provinces, yet results were largely below the international average (Table 1).

Patients with chronic conditions often require specialist care. Canadian primary care physicians are more likely to receive information, such as changes made to medications or care plans, from their patient's specialists than doctors in other countries (Table 2). However, there is room for improvement overall in coordination of care with specialists. As well, Canada ranked below the international average for coordination with other sectors such as home care and social services.

TABLE 1.
Management of patients with chronic conditions, by province

	Proportion of physicians whose practice uses personnel, such as nurses or case managers, to monitor and manage care for patients with chronic conditions that need regular follow-up care (within and outside of practice)	Proportion of physicians whose patients with chronic conditions are routinely/occasionally given written instructions about how to manage their own care at home
BC	53.7%*	83.3% [§]
AB	80.2% [¶]	81.3% [§]
SK	68.5% [§]	79.8%*
MB	53.0%*	80.3% [§]
ON	57.2%*	73.7%*
QC	73.2% [§]	73.9%*
NB	64.2%*	79.9%*
NS	59.4%*	87.2% [§]
NL	53.4%*	78.3%*
Canada	63.7%*	77.2%*
CMWF average	72.7%	87.2%

*Below CMWF average. [§]Same as CMWF average. [¶]Above CMWF average.

TABLE 2.
Extent of coordination between primary care physicians and specialists

When their patient has been seen by a specialist, Canadian primary care physicians always received	Canada	CMWF average
A report back from the specialist with all relevant health information	29%*	23%
Information about changes the specialist made to the patient's medication or care plan	27%*	23%
Information that is timely and available when needed	13%*	9%

*Above CMWF average.

Discussion and Conclusion

Individuals with chronic conditions, particularly those with multiple chronic conditions, are frequent users of the health-care system. The Commonwealth Fund 2015 International Health Policy Survey of Primary Care Physicians shows that almost all Canadian doctors see these patients in their practice.

Proper management of patients with chronic conditions in primary care can help to improve outcomes and increase efficiency. However, most Canadian provinces perform

significantly below the international average with respect to utilizing case managers or other health professionals to manage care for patients with chronic conditions and providing these patients with written instructions on how to manage their care at home. These are only two measures of chronic condition management, and suggest that Canada can learn from other countries that may have a more systematic approach to primary care delivery of services to complex patients and perform above average in these measures.

Coordination of care between different parts of the health and social services system is also critically important for patients with complex needs, yet results for Canada are mixed. Canada performs slightly above the international average when it comes to coordination between primary care physicians and specialists. However, results are low overall for coordination with specialists and show room for improvement. Canada also performs below the international average in measures of primary care coordination with home care and social services, which is important for those with complex needs – though there is significant provincial variation in these measures. **HQ**

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References

- Beaulieu, M.D., J. Haggerty, P. Tousignant, J. Barnsley, W. Hogg, R. Geneau et al. 2013. "Characteristics of Primary Care Practices Associated with High Quality of Care." *CMAJ* 185(12): E590–6.
- Canadian Institute for Health Information (CIHI). 2016. *How Canada Compares: Results from The Commonwealth Fund 2015 International Health Policy Survey of Primary Care Physicians*. Ottawa, ON: Author. Retrieved February 29, 2016.
- The Commonwealth Fund. 2015. *2015 Commonwealth Fund International Survey of Primary Care Physicians in 10 Nations*. New York, NY: The Commonwealth Fund. Retrieved February 29, 2016.
- Government of Canada. 2012. *About Primary Health Care*. Ottawa, ON: Author. Retrieved February 29, 2016.
- Public Health Agency of Canada. 2010. *The Chief Public Health Officer's Report on the State of Public Health in Canada 2010*. Ottawa, ON: Author. Retrieved February 29, 2016.

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The Challenge Before Us

Renee Lyons

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.

The variability in the population challenges gold-standard approaches to evidence such as randomized control trials (RCTs) to accurately assess outcomes.

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**

References

- Bhattacharyya, O., M. Schull, K. Shojania, V. Stergiopoulos, G. Naglie, F. Webster et al. 2016. “Building Bridges to Integrate Care (BRIDGES): Incubating Health Service Innovation across the Continuum of Care for Patients with Multiple Chronic Conditions.” *Healthcare Quarterly* 19(2): 60–66. doi:10.12927/hcq.2016.24701.
- Fortin, M., M. Couture, T. Bouhali, E. Leclerc and M. Stewart. 2016. “It Takes Two to Tango: Researchers and Decision-Makers Collaborating to Implement Practice Changes for Patients with Multimorbidity.” *Healthcare Quarterly* 19(2): 55–59. doi:10.12927/hcq.2016.24700.
- Hendry, A., A. Taylor, S. Mercer and P. Knight. 2016. “Improving Outcomes through Transformational Health and Social Care Integration – The Scottish Experience.” *Healthcare Quarterly* 19(2): 73–79. doi:10.12927/hcq.2016.24703.
- Kuluski, K., A. Peckham, A.P. Williams and R.E.G. Upshur. 2016. “What Gets in the Way of Person-Centred Care for People with Multimorbidity? Lessons from Ontario, Canada.” *Healthcare Quarterly* 19(2): 17–23. doi:10.12927/hcq.2016.24694.
- Levy, C., S. Balogh and E. Perkins. 2016. “Realizing the Potential of Rehabilitative Care for People with Complex Health Conditions: The Time Is Now.” *Healthcare Quarterly* 19(2): 49–54. doi:10.12927/hcq.2016.24699.
- Lyons, R. 2016. “In Conversation with Dr Nick Goodwin.” *Healthcare Quarterly* 19(2): 81–85. doi:10.12927/hcq.2016.24704.
- Mercer, S.W., B. Guthrie, J. Furler, G.C.M. Watt and J.T. Hart. 2012. “Multimorbidity and the Inverse Law in Primary Care.” *BMJ* 344: e4152. doi:10.1136/bmj.e4152.
- McNeil, D., R. Strasser, N. Lightfoot and R. Pong. 2016. “A “Simple” Evidence-Based Intervention to Improve Care Transitions for Frail Patients with Complex Health Conditions: Why Didn’t It Work as Expected?” *Healthcare Quarterly* 19(2): 67–72. doi:10.12927/hcq.2016.24702.
- Nelson, M.L.A., A. Grudniewicz and S. Albadry. 2016. “Applying Clinical Practice Guidelines to the Complex Patient: Insights for Practice and Policy from Stroke Rehabilitation.” *Healthcare Quarterly* 19(2): 38–43. doi:10.12927/hcq.2016.24697.
- Smith, S.M., E. Wallace, T. O’Dowd and M. Fortin. 2016. “Interventions for Improving Outcomes in Patients with Multimorbidity in Primary Care and Community Settings.” *Cochrane Database of Systematic Reviews* (3). Art. No.: CD006560. doi:10.1002/14651858.CD006560.pub3.
- Steele Gray, C., S. Mercer, T. Palen, B. McKinstry, A. Hendry et al. 2016. “eHealth Advances in Support of People with Complex Care Needs: Case Examples from Canada, Scotland and the United States.” *Healthcare Quarterly* 19(2): 29–37. doi:10.12927/hcq.2016.24696.
- Upshur, R.E.G. 2016. “Understanding Clinical Complexity the Hard Way: A Primary Care Journey.” *Healthcare Quarterly* 19(2): 24–28. doi:10.12927/hcq.2016.24695.
- Walsh, M. 2016. “CEO Perspective: A Health System for Patients with Complex Conditions: Reflections from Bridgepoint’s Transformation.” *Healthcare Quarterly* 19(2): 86–90. doi:10.12927/hcq.2016.24705.
- Wodchis, W.P. 2016. “Performance Measurement for People with Multimorbidity and Complex Health Needs.” *Healthcare Quarterly* 19(2): 44–48. doi:10.12927/hcq.2016.24698.

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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

References

- Alvaro, C. and C. Atkinson. 2013. “Design for Health and Psychosocial Well-Being: Assessing the Impact of Healthcare Facility Design on the Lives of People Living with Complex Conditions.” *World Health Design* 6(3): 60–67.
- Dorfman, R., Z. Khayat, T. Sieminowski, B. Golden and R. Lyons. 2013. “Application of Personalized Medicine to Chronic Disease: A Feasibility Assessment.” *Clinical and Translational Medicine* 2: 16.
- Gibson, A., K. Kuluski and R.F. Lyons. 2015. “Complex Health Conditions and Mental Health Training: How Prepared Is the Front-Line Service Provider?” *Healthcare Management Forum* 28(1): 16–23.
- Kuluski, K., S. Hoang, A.K. Schaink, C. Alvaro, R. Lyons, R. Tobias and C.M. Bensimon. 2013. “The Care Delivery Experience of Hospitalized Patients with Complex Chronic Disease.” *Health Expectations* 16(4): e111–23. doi:10.1111/hex.12085.
- Schaink, A.K., K. Kuluski, R.F. Lyons, M. Fortin, A.R. Jadad, R. Upshur and W.P. Wodchis. 2012. “A Scoping Review and Thematic Classification of Patient Complexity: Offering a Unifying Framework.” *Journal of Comorbidity* 2(1): 1–9.

What Gets in the Way of Person-Centred Care for People with Multimorbidity? Lessons from Ontario, Canada

Kerry Kuluski, Allie Peckham, A. Paul Williams and Ross E.G. Upshur

Abstract

Person-centred care is becoming a key component of quality in health systems worldwide. Although the term can mean different things, it typically entails paying attention to the needs and background of health system users, involving them in decisions that affect their health, assessing their care goals and implementing a coordinated plan of care that aligns with their unique circumstances. The importance of practising a person-centred approach in care delivery dominates policy and research rhetoric worldwide, yet competing goals set by policy planners to save money, eliminate waste and sustain the healthcare system challenge the implementation of such an approach. In this commentary, we begin by exploring the concept of person-centred care and its importance among people who frequently use healthcare, such as those with multimorbidity. We then provide a brief overview of the evolution of Ontario's healthcare system and its emphasis on achieving cost savings. In doing so, we illustrate the implications for health system users, particularly people with multimorbidity, their carers and formal care providers. Finally, we reflect on examples of innovations that are striving to deliver person-centred care, despite a constrained healthcare environment. While a step in the right direction, we conclude that these "one-off" strategies are unsustainable in the absence of supporting policy levers.

Patient (or Person)-Centred Care – What Is It?

While patients need medical things (treatments and medicines), persons need social things (ability to partake in activities of importance to them, supportive networks, a sense of belonging and purpose and respectful encounters with others). The tendency to use the term *patient-centred* instead of *person-centred* signifies a fundamental disconnect between healthcare and social care, even though the two are required to achieve overall health. Although limited, the practice of patient-centred care is still an improvement over provider-centred care – a paternalistic relationship where patients take what providers give them.

The concept patient-centred care has roots in many disciplines, including family medicine. The Department of Family Medicine at the University of Western Ontario designed a framework for patient-centred care over 30 years ago in an effort to guide physician–patient consultations. It defined patient-centred care as encompassing six interacting components: exploring the disease and the illness experience; understanding the whole person; finding common ground; incorporating prevention and health promotion; enhancing the patient doctor relationship; and being realistic (Stewart et al. 1995). This definition highlights that such an approach extends beyond the sum and severity of physical ailment(s) presented upon assessment.

Patient-centred care (or what we prefer to call person-centred care) entails more than a physician–patient visit, it is a way of being, a practice that values the person and their support networks (including family and the extended network of friends, neighbours, partners, etc.) and considers their needs within the broader context in which they work and live. The Health Innovation Network in London England (London HINS 2015) defined person-centred care as: “not just about giving people whatever they want or providing information. It is about considering people’s desires, values, family situations, social circumstances and lifestyles; seeing the person as an individual, and working together to develop appropriate solutions.” (p. 1).

A need for (or expectation of) person-centred care is fuelled by demands for timely access to care, greater access to information via the internet and, in some cases, a yearning among consumers to play a key role in decision making. Person-centred care is also a reaction against reductionism perceived in evidence-based medicine and other forms of predominantly biomedical models. Person-centred approaches are particularly crucial for people with multimorbidity, not just because they happen to use more healthcare (Rosella et al. 2014) but because of the high disease burden, uncertainty in their care trajectory, the many treatment decisions they face and the constant weighing of risks and benefits which warrants the identification and revisiting of goals of care (Berntsen et al. 2015; Bower 2014; Upshur and Tracy 2008). As noted in a recent editorial in the *New England Journal of Medicine*, in a clinical context, weighing the pros and cons with patients and exploring their personal priorities is not always easy to achieve and may work against natural tendencies to either tell patients what to do when there is strong evidence for a particular solution or put the onus on patients to decide when there is a lack of clear evidence (Fried, 2016). Clearly, understanding the social aspects of a person (their priorities and goals beyond their medical needs) may help guide this complex decision-making process. A family physician who participated in one of our recent studies stated, “We do too many investigations without standing back and asking [the person], ‘What do you want?’” (Gill et al. 2014).

Multimorbidity is “socially patterned,” occurring at a much earlier age among people who experience financial strain (Moffat and Mercer 2015) and tends to coincide with mental health needs (Barnett et al. 2012). Unique combinations of conditions and social determinants (which differentially affect people with multimorbidity) preclude simple reduction to guidelines (Upshur and Tracy 2013). A burgeoning literature on multimorbidity illustrates a lack of clinical guidelines to support patient care (Barnett et al. 2012; Upshur and Tracy 2013; Osborn et al. 2015; Sinnott et al. 2013), little attention to goal setting (Upshur 2010), a lack of care coordination, insufficient follow-up and overall poor care experiences when compared with those with single or no chronic conditions

(Pefoyo et al. 2015; Burgers et al. 2010). Providers commonly feel unsupported and unprepared to manage the needs of people with multimorbidity and their carers (Osborn et al. 2015; Sinnott et al. 2013). Patients and families may defer to providers, particularly primary care physicians, to provide guidance or solutions to their complex medical issues, when in fact there may be no clear trajectory forward. Needless to say, person-centred care, particularly in the context of a growing population of people with multimorbidity, is difficult to achieve. Nevertheless, if person-centred care is such a great idea, what gets in the way of implementing this type of approach?

Clearly, understanding the social aspects of a person (their priorities and goals beyond their medical needs) may help guide this complex decision-making process.

Healthcare Reform in Ontario and Barriers to the Implementation of Person-Centred Care

The difficulty in achieving person-centred care is, in part, a product of the acute-episodic healthcare system in which these patient–provider interactions are embedded. Our healthcare system, hardwired in an acute “one disease at a time” model, makes it particularly difficult to be person-centred for the growing number of people aging with multimorbidity (Pefoyo et al. 2015; Upshur and Tracy 2008; Upshur 2010).

Canada’s healthcare “system” is historically oriented to deliver acute and episodic care. Medicare (Canada’s publicly funded insurance model for hospital and physician care) became institutionalized in the 1950s and 1960s and remains firmly embedded despite attempts to broaden its scope and better align services to the needs of people who are living longer with multiple health and social care needs. The original intention of Tommy Douglas, the founder of Medicare followed by Justice Emmett Hall just over a decade later, was to build a health system in two phases. The first phase culminated into Medicare, Canada’s 13 interconnected healthcare “systems” which provide “medically necessary” hospital and physician care, based on uniform terms and conditions for all insured Canadians. In the second phase they were to “implement public policies for keeping people well, not just patching them up once they get sick” (Raphael 2009). While the second phase failed to materialize into a robust institutional structure, there was never a shortage of evidence on the importance of prevention and upstream factors that influence health, notably the social determinants of health. The 1970s saw a wave of documents, including Canada’s Lalonde Report (Lalonde 1974) which drew attention to a variety of factors that influence health (the majority of which lie outside the healthcare system) as well as a call for greater citizen engagement in the healthcare system. In the decades leading up to and following

this time frame, a wave of empirical literature connected the social determinants of health to health outcomes (Bosma et al. 1997; Fitzpatrick et al. 2015; Marmot et al. 1991; Marmot 1993; Mikkonen and Raphael 2010; Raphael et al. 2008; Raphael 2009; Stringhini et al. 2012). Accounting for the social determinants of health through healthcare assessments and delivery arguably aligns with a person-centred approach but seldom occurs.

Particular structures (aka: levers) create barriers to movement beyond biomedical and single-disease frameworks. Examples include: fee-for-service models of reimbursement for physicians (although primary care physicians are increasingly moving toward blended payments), length of stay targets in hospitals incentivizing expedient discharges back to the community (with few resources to respond), wait-time targets for specific conditions (knee, hips, heart, etc.) and hospital funding models that set length of stay targets for single diseases and ailments (Palmer et al. 2014). Such incentives place the focus on disease and body parts as opposed to on people who are part of broader social and geographical contexts. These broader contexts are critical, given that one's ability to manage health and engage in broader society, including the workplace, depends on the level of integration and support within these broader realms. Indeed, 75% of the factors that influence health lie outside the healthcare system (The Standing Senate Committee on Social Affairs 2002), but a reactive approach characterized by treating/curing/fixing using a biomedical lens continues to have a strong foothold in healthcare. Although we are starting to steer the ship away from this highly reactive model by way of blended payment schemes for physicians, greater emphasis on team-based care, investments in primary healthcare models (e.g., including nurse-led clinics, allied health and community-based care) with a focus on prevention, there remains a historical array of institutional factors (e.g., policies and associated incentives) which limit the extent to which person centeredness can feasibly occur.

The imperative to discharge patients “sicker and quicker” became a matter of survival for a fiscally constrained hospital climate.

When the patient-centred framework was introduced in Family Medicine, Ontario moved (in a policy sense) in the opposite direction. The Health Services Restructuring Commission (HSRC) was appointed in 1996 by the Harris Conservative government and was given a 4 year mandate to (1) make decisions on how to restructure Ontario's public hospitals and (2) make recommendations to the Minister of Health on how to reform other parts of the healthcare system (Sinclair et al. 2005). What culminated was the closure of 43 hospitals (a combination of public, private and psychiatric

facilities), the removal of 10,000 hospital beds, medical school admission caps and downsizing of many nursing positions to part-time/seasonal contract positions (Ingelhart 2000). The imperative to discharge patients “sicker and quicker” became a matter of survival for a fiscally constrained hospital climate.

The Community Care Access Centres, Ontario's main organizer of professional home care services, did not receive budget increases commensurate with the influx of people who were being discharged and were subsequently forced to strategically realign their priorities to meet the needs of mostly post-acute patients. Accompanying legislation precluded the CCACs from operating with a deficit and limited eligibility for lighter care (e.g., homemaking) to those who had heavier care needs. These policy changes shifted the home care sector into primarily a “post-acute” operation, aimed at those who were more medically complex. At the same time, recommendations made by the HSRC, to build and/or restore 20,000 long-term care facility “places” (interpreted by the Ontario government as beds), were implemented (Coyte et al. 2002). This policy decision represented a misalignment between the needs of the system (the growth of long-term care beds, mostly in the for-profit sector) and the needs of people who largely preferred to age in their homes (Williams et al. 2016).

The 2006 Aging at Home Strategy was a promising 1.1-billion-dollar initiative dispersed to each of the 14 Local Health Integration Networks (aka: regional health authorities) to create and sustain programs that aimed to keep people in their homes as long as possible and prevent or delay long-term care (LTC) and hospital use. However, in 2009, a proportion of “aging at home” funds were re-directed to acute-care hospitals to address alternate level care (ALC) patients—individuals who were occupying an acute-care bed but no longer required acute care. From that end, “aging at home” morphed into “not aging in hospital,” a more reactive measure of home support, mirroring the post-acute home care foci of the earlier policy reforms in the 1990s.

A program of research on the *Balance of Care* conducted in Ontario by Williams et al. (Kuluski et al. 2012; Williams et al. 2009a, 2009b) shed light on the potential unintended consequences of this policy decision. Williams et al. examined the characteristics of individuals wait-listed for facility-based LTC in nine jurisdictions across Ontario and worked with panels of health and social care providers to build community care packages. This exercise offered a sense of the proportion of people who were “destined” for LTC who could potentially age at home safely with a community care package at a similar or lower public cost than LTC. The researchers found that between one-quarter and one-half of people on the wait-list (depending on the region) could potentially remain in their communities with a home care package at a similar or lower cost than LTC. Ironically, much of what was required in the

care package was lighter care (e.g., medication help, meal assistance, transportation, housekeeping and respite for caregivers), services that were much harder to get following the Harris (conservative) reforms and notably absent from provincially funded care packages at the time of study. It is important to note that even the liberal reforms (“aging at home” which morphed into addressing hospital issues) did not restore these service needs. Care providers who participated in the expert panels for this research stated that there was a fundamental disconnect between what they were mandated to do (i.e., what services were available) and what home care clients actually needed (Williams et al. 2016).

The disconnect between what people need and what is provided in home care packages was illustrated by a care provider in our study of the experiences of people with multimorbidity, their carers and care providers (Gill et al. 2014):

“...once they need [home care], they don't seem to get as much as they really need. They'll come in for an hour a week and help you with a bath. And if you don't need help with a bath, they don't come in...They may need help with the food shopping. They may need help with food prep. That stuff is hard to get support for.”

These findings were recently echoed by the Ontario Expert Group on Home and Community Care (2015), who stated that care continues to be driven by the needs of the system and not its users (including unpaid family carers and broader support networks). As noted in the sections that follow, home care reform sits within a broader quality improvement agenda in Ontario.

Healthcare quality improvement, with patient-centeredness as a core aspect, was front and centre in Ontario's 2012 *Action Plan for Health Care* (Ministry of Health and Long-term Care 2012). Described as “obsessively patient-centred,” the Action Plan outlined a commitment to improve access to care, integrate services and provide care “in the right place at the right time.” The latest policy document *Patients First* (Ministry of Health and Long-Term Care 2015), released in 2015, outlines a commitment to involve people and their families in care planning, invest in the community care sector and to improve access to end-of-life care (among other things). In early June 2016, the Ministry of Health and Long-term Care (2016) proposed the *Patients First Act*, new legislation that would presumably help move these initiatives forward. These policy documents/plans emerged from a broader provincial commitment to improve quality in the healthcare system (mirroring a global effort). Foundational to this was the creation of Health Quality Ontario, a government-funded agency formed after the passage of Ontario's Excellent Care for All Act (ECFAA) in 2010. Under ECFAA, annual quality improvement plans and public reporting of key quality indicators are required for hospitals and, most recently, home care

organizations, primary care and LTC facilities. These sectors are held accountable in measuring and meeting pre-specified targets (minimizing exposure to infectious disease, lowering rates of ALC, etc.). Although patient experience is one domain of quality that is measured, unpacking this can be challenging in time-constrained environments. For instance, there may be a tendency to adopt indicators that are easier to measure such as “tick the box” patient satisfaction surveys that assume satisfaction is synonymous with experience, painting an inaccurate or misleading picture of the adoption of person-centred care.

... care continues to be driven by the needs of the system and not its users ...

A relatively recent approach to embed a “low rules” strategy to integrate care for Ontario's growing number of people with complex health and social needs is Health Links. In contrast to previous “top down” efforts to reform care, the strategy voluntarily brings together health and social care service providers who work in close geographic proximity to develop and implement integrated, person-centred strategies for their heaviest health-care users (Evans et al. 2014). While it is too early to determine the effect of such a strategy on the ability to execute a person-centred strategy in care delivery, it has been rated positively by care providers and managers (though not without its challenges) as an approach providing a foundation to better coordinate services for patients with complex care needs and their families. Geographically based coordinated services are also the intention of *Community Based Hubs*, which were endorsed by the Ministry of Health and Long-Term Care in its 2014 Mandate Letter (Ministry of Health and Long-Term Care 2014). Community Based Hubs entail cross-ministerial (i.e., health, education, municipal affairs and housing) developments of geographically based, ground up initiatives to support the health and well-being of citizens. Community Based Hubs share some commonalities with Health Links. The key difference is that Health Links are intended to focus on the top/high cost users of health resources (Evans et al. 2014), while hub models seem to take a life-course approach by leveraging the capacity of communities to keep people healthier over the long-term and not just pick them up once already quite complex. As these models continue to emerge, it is important that they do not become exemplary “silos” like other components of health services.

Alongside community-based reforms, hospital-funding reforms are underway in Ontario. Referred to as Activity Based Funding (ABF), a predetermined fee is provided to hospitals for each episode of care and client type, but client type is typically categorized by disease/reason for current health visit (e.g., pneumonia, hip fracture and child birth) with little attention to multimorbidity, mental health and social needs. A recent systematic review on the implications of ABF in 10 countries

found that the introduction of this funding model was associated with a 24% increase in discharge from hospitals to post-acute services (including home care) (Palmer et al. 2014).

Quicker hospital discharges can be looked at in a positive light, given that prolonged hospitalization can be associated with unnecessary exposure to infectious disease, other adverse events and emergency service back-logs (Sutherland and Crump 2013). On the other hand, if the discharge happens too quickly without the necessary supports in the community, hospital readmissions may be the result. Further to that, a 24% increase in discharge to post-acute care cannot be successful if this sector is not adequately resourced to meet the increasing influx of people. If history repeats itself in Ontario, ABF may have perverse consequences for providers, people and their support networks.

Given that episodes of care typically expand beyond the hospital, Ontario is now experimenting with integrated funding models (i.e., bundled care) which include hospital care and the window of time (e.g., 30 days) following discharge. While this incentivizes a more integrated approach, it is not clear if services will be aligned with the needs of healthcare system users and their support networks. A study that is currently underway to assess the user experience of integrated funding in Ontario provides an important opportunity to draw on the user experience to provide insight into gaps and future directions of this model, including how it can connect to ongoing supportive care beyond the time frame of the bundled payment.

... there is also considerable effort across the province to develop and test models of care that are more person-centred.

Person-Centred Care: A Matter of Personal Will in Constrained Healthcare Environments?

In a healthcare system heavily constrained by lack of resources and time, it seems that person-centred care becomes the “luck of the draw” or (as articulated by a person with multimorbidity), “a lottery [in terms of] who you get” (Kuluski et al. 2013). It seems that it comes down to personal will and concerted effort by care providers to overcome the barriers to deliver person-centred care. For instance, in a recent study conducted by the lead author (KK) and her team on the care delivery experience of people with multimorbidity (Kuluski et al. 2013), many people recognized that providers worked in a busy environment with few resources, but that it came at the expense of personal dignity:

“They are understaffed here ... I really think they are great nurses. I do. But because they have such a high patient load, generally I wish some of my needs had been met a bit faster. And the very basic one is toileting.”

Others in this same study outlined the characteristics of providers who delivered care that was consistent with a person-centred approach compared with those who did not:

“A good listener. They actually listen to what you’re saying. Non-judgmental. They actually are there to help you. Whereas some of them, they’re just here for the buck [...] It’s hard to describe it but there’s no rapport, and a bit of a chip on the shoulder.”

“So professionally she follows up on any changes that are happening with me... she’s in a role that provides care and caring, which are 2 different things, she actively cares. She is caring. And I believe that that is the minimum standard of operation for somebody in healthcare.”

In addition to the day-to-day examples of providers who go above and beyond to deliver person-centred care, there is also considerable effort across the province to develop and test models of care that are more person-centred. For example, Toronto Central CCAC’s Integrated Client Care Program (Goldhar et al. 2014) targets people with complex care needs and their families and assigns them a “quarterback” (care coordinator) to help bridge the gap between various services and providers. Patients and families are involved in co-designing a care plan, goals of care are assessed and an emergency transfer package comprising medicines and pertinent patient information is put together. Each patient is assigned to a single pharmacy, emergency department and hospital, thereby fostering a more integrated experience.

Likewise, Seniors Managing Independent Living Easily (SMILE) program offered out of South East LHIN begins by asking what is most important to clients and their caregivers. Drawing on a modest budget SMILE improves access not only to formal providers but also to non-traditional providers such as neighbours, as a means to lever local capacity and expand beyond the traditional basket of services (Williams et al. 2016).

These are only two of the many “stand alone” examples in Ontario that include principles that align with a person-centred approach. In addition to recognizing the work of these efforts, it is critical to acknowledge that the sustainability of these programs, including their ability to “scale up” and “spread,” will continue to be threatened by a policy climate that favours cost-cutting, acute-episodic care, provider-centred approaches and quick fixes.

Conclusions

Person-centred care is a key component of quality in healthcare systems but difficult to achieve in practice. Using Ontario as a case example, we illustrate competing foci on cost containment and cost shifting from hospital to the community and the ongoing tensions between a heavily institutionalised Medicare

model (which incentivizes treatment of diseases and body parts over whole person care) and a push toward more innovative approaches that respond to both the health and social needs of people and their support networks. Although innovations that support a person-centred model of care delivery exist, these appear to be the exception and not the rule. As Ontario moves ahead with various reforms in the hospital (e.g., ABF) and community sectors (integrated funding, Health Links and Community Health Hubs) paying attention to the ways in which a person-centred focus can be implemented and supported by key policy levers (e.g., funding and accountability frameworks) will be critical to making this mode of practice the rule and not the exception; otherwise well-intentioned policy goals and strategies may continue to morph into reactive, episodic-based care. **HQ**

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References

Barnett, K., S.W. Mercer, M. Norbury, G. Watt, S. Wyke and B. Guthrie. 2012. "Epidemiology of Multimorbidity and Implications for Health Care, Research, and Medical Education: A Cross-Sectional Study." *The Lancet* 380(9836): 37–43.

Berntsen, G.K., D. Gammon, A. Steinsbekk, A. Salamonsen, N. Foss, C. Ruland et al. 2015. "How Do We Deal with Multiple Goals for Care Within an Individual Patient Trajectory? A Document Content Analysis of Health Service Research Papers On Goals For Care." *BMJ Open* 5(12): e009403.

Bosma, H., M.G. Marmot, H. Hemingway, A.C., Nicholson, E., Brunner and S.A. Stansfeld. 1997. "Low Job Control and Risk of Coronary Heart Disease in Whitehall II (Prospective Cohort) Study." *BMJ* 314(7080): 558–65.

Bower, P. 2014. "Better Management of Multimorbidity: A Critical Look at the Ariadne Principles." *BMC Medical* 12: 222.

Burgers, J.S., G.E. Voerman, R. Grol, M.J. Faber and E.C. Schneider. 2010. "Quality and coordination of care for patients with multiple conditions: results from an international survey of patient experience." *Evaluation & The Health Professions* 33(3): 343–64.

Coyte, P., A. Laporte, P. Baranek and W. Croson. 2002. *Forecasting Facility and In-home Long-Term Care for the Elderly in Ontario: The Impact of Improving Health and Changing Preferences*. Toronto, ON: University of Toronto.

Evans, J.M., A. Grudniewicz, W.P. Wodchis and G.R. Baker. 2014. "Leading the Implementation of Health Links in Ontario." *Healthcare Papers* 14(2): 21–25.

Expert Group on Home & Community Care. 2015. *Bringing Care Home*. Retrieved June 15, 2016. <http://health.gov.on.ca/en/public/programs/ccac/docs/hcc_report.pdf>.

Fitzpatrick, T., L.C. Rosella, A. Calzavara, J. Petch, A.D. Pinto, H. Manson et al. 2015. "Looking Beyond Income and Education: Socioeconomic Status Gradients among Future High-Cost Users of Health Care." *American Journal of Preventive Medicine* 49(2): 161–71.

Fried, T.R. 2016. "Shared Decision Making—Finding the Sweet Spot." *New England Journal of Medicine* 374(2): 104–06.

Gill, A., K. Kuluski, L. Jaakkimainen, G. Naganathan, R. Upshur and W.P. Wodchis. 2014. "Where Do We Go from Here?" Health System Frustrations Expressed by Patients with Multimorbidity, Their Caregivers and Family Physicians." *Healthcare Policy* 19(4): 73–89.

Goldhar, J., S. Daub, I. Dhalla, P. Ellison, D. Purbhoo and S.K. Sinha. 2014. "Integrated Client Care for Frail Older Adults in the Community: Preliminary Report on a System-Wide Approach." *Healthcare Quarterly* 17(3): 61–69.

Ingelhart, J. 2000. "Revisiting the Canadian Health Care System." *New England Journal of Medicine* 342(26): 2007–12.

Kuluski, K., A.P. Williams, W. Berta and A. Laporte. 2012. "Home Care or Long-Term Care? Setting the Balance of Care in Urban and Rural Northwestern Ontario, Canada." *Health & Social Care in the Community* 20(4): 438–48.

Kuluski, K., S.N. Hoang, A.K. Schaink, C. Alvaro, R.F. Lyons, R. Tobias et al. 2013. "The Care Delivery Experience of Hospitalized Patients with Complex Chronic Disease." *Health Expectations* 16(4): e111–23.

Lalonde, M. 1974. *A New Perspective on the Health of Canadians: A Working Document*. Ottawa, ON: Government of Canada.

London HINS. ND. *What Is Person Centred Care and Why Is It Important?* Retrieved April 14, 2016. <www.hin-southlondon.org/system/ckeditor_assets/attachments/41/what_is_person-centred_care_and_why_is_it_important.pdf>

Marmot, M. 1993. "Epidemiological Approach to the Explanation of Social Differentiation in Mortality: The Whitehall Studies." *Sozial-und Preventivmedizin* 38(5): 271–79.

Marmot, M.G., G.D. Smith, S. Stansfeld, C. Patel, F. North, J. Head et al. 1991. "Health Inequalities among British Civil Servants: The Whitehall II Study." *Lancet* 337(8754): 1387–93.

Mikkonen, J. and D. Raphael. 2010. *Social Determinants of Health: The Canadian Facts*. Toronto, ON: York University School of Health Policy and Management.

Ministry of Health and Long-Term Care. 2012. *Ontario's Action Plan for Health Care*. Toronto, ON: Government of Ontario. Retrieved June 15, 2016. <http://www.health.gov.on.ca/en/ms/ecfa/healthy_change/docs/rep_healthychange.pdf>.

Ministry of Health and Long-Term Care. 2014. *2014 Mandate letter: Health and Long-Term Care. Premier's instructions to the Minister on priorities for the year 2014*. Toronto, ON: Government of Ontario. Retrieved June 15, 2016. <<http://www.ontario.ca/page/2014-mandate-letter-health-and-long-term-care>>.

Ministry of Health and Long-Term Care. 2015. *Patients First: Action Plan for Health Care*. Toronto, ON: Government of Ontario. Retrieved June 15, 2016. <http://www.health.gov.on.ca/en/ms/ecfa/healthy_change/>.

Ministry of Health and Long-Term Care. 2016. *Ontario Introduces Legislation to Further Improve Patient Access and Experience*. Toronto, ON: Government of Ontario. Retrieved June 15, 2016. <<https://news.ontario.ca/mohltc/en/2016/06/ontario-introduces-legislation-to-further-improve-patient-access-and-experience.html>>.

Moffat, K. and S.W. Mercer. 2015. "Challenges of Managing People with Multimorbidity in Today's Healthcare Systems." *BMC Family Practice* 16(1): 129.

Osborn, R., D. Moulds, E.C. Schneider, M.M. Doty, D. Squires and D.O. Sarnak. 2015. "Primary Care Physicians in Ten Countries Report Challenges Caring For Patients with Complex Health Needs." *Health Affairs* 34(12): 2104–12.

- Palmer, K.S., T. Agoritsas, D. Martin, T. Scott, S.M. Mulla, A.P. Miller et al. 2014. "Activity-Based Funding of Hospitals and Its Impact on Mortality, Readmission, Discharge Destination, Severity of Illness, and Volume of Care: A Systematic Review and Meta-Analysis." *PLoS ONE* 9(10): e109975.
- Pefoyo, A.J.K., S.E. Bronskill, A. Gruneir, A. Calzavara, K. Thavorn, Y. Petrosyan et al. 2015. "The Increasing Burden and Complexity of Multimorbidity." *BMC Public Health* 15(1): 415.
- Raphael, D. 2009. *Social Determinants of Health: Canadian Perspectives*. Toronto, ON: Canadian Scholars' Press.
- Raphael, D., A. Curry-Stevens and T. Bryant. 2008. "Barriers to Addressing the Social Determinants of Health: Insights from the Canadian Experience." *Health Policy* 88(2/3): 222–35.
- Rosella, L.C., T. Fitzpatrick, W.P. Wodchis, A. Calzavara, H. Manson and V. Goel. 2014. "High-Cost Health Care Users in Ontario, Canada: Demographic, Socio-Economic, and Health Status Characteristics." *BMC Health Services Research* 14: 532.
- Sinclair, D.G., M. Rochon and P. Leatt. 2005. *Riding the Third Rail: The Story of Ontario's Health Services Restructuring Commission, 1996–2000*. Toronto, ON: Institute for Research in Public Policy.
- Sinnott, C., S. Mc Hugh, J. Browne and C. Bradley. 2013. "GPs' Perspectives on the Management of Patients with Multimorbidity: Systematic Review and Synthesis of Qualitative Research." *BMJ Open* 3(9): e003610.
- Stewart, M., B.B. Brown, W.W. Weston, I.R. McWhinney, C.L. McWilliam and T.R. Freeman. 1995. In M. Stewart, B.B. Brown and T.R. Freeman TR, eds. *Patient-Centered Medicine: Transforming the Clinical Method*. First ed. Oxford, UK: Sage Publications.
- Stringhini, S., L. Berkman, A. Dugravot, J.E. Ferrie, M. Marmot, M. Kivimaki et al. 2012. "Socioeconomic Status, Structural and Functional Measures of Social Support and Mortality: The British Whitehall II Cohort Study, 1985–2009." *American Journal of Epidemiology* 175(12): 1275–83.
- Sutherland, J.M. and R.T. Crump. 2013. "Alternative Level of Care: Canada's Hospital Beds, the Evidence and Options." *Health Policy* 9(1):26–34.
- The Standing Senate Committee on Social Affairs. 2002. *Healthy Public Policy: Health Beyond Health Care. The Health of Canadians – The Federal Role Final Report Part 6: Health Promotion and Disease Prevention Volume Six: Recommendations for Reform*. Ottawa, ON: Parliament of Canada.
- Upshur, R.E. 2010. "Can Family Physicians Practise Good Medicine Without Following Clinical Practice Guidelines? Yes." *Canadian Family Physician* 56(6): 518–20, 522–24; discussion e207–08.
- Upshur, R.E. and C.S. Tracy. 2008. "Chronicity and Complexity: Is What's Good for the Diseases Always Good for the Patients?" *Canadian Family Physician* 54(12):1655–58.
- Upshur, R.E. and C.S. Tracy. 2013. "Is Evidence-Based Medicine Overrated in Family Medicine?: Yes." *Canadian Family Physician* 59(11): 1160–61.
- Williams, A.P., D. Challis, R. Deber, J. Watkins, K. Kuluski, J.M. Lum et al. 2009a. "Balancing Institutional and Community-Based Care: Why Some Older Persons Can Age Successfully at Home While Others Require Residential Long-Term Care." *Healthcare Quarterly* 12(2): 95–105.
- Williams, A.P., J.M. Lum, R. Deber, R. Montgomery, K. Kuluski, A. Peckham et al. 2009b. "Aging at Home: Integrating Community-Based Care for Older Persons." *Healthcare Papers* 10(1): 8–21.
- Williams, A.P., J. Lum, F. Morton-Chang, K. Kuluski, A. Peckham, N. Warrick et al. 2016. *Integrating Long-Term Care in a Community-Based Continuum: Why We Need to Shift the Policy Discourse from "Beds" to "Places"*. Montréal, QC: Institute of Research on Public Policy (IRPP).

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Understanding Clinical Complexity the Hard Way: A Primary Care Journey

Ross E.G. Upshur

Abstract

Ten years ago, complexity was not a term often used in primary care. In the last decade, however, the population seen in primary care has shifted, posing substantial challenges for both primary care providers and health systems. In this essay, I will document the approaches that evolved in an academic family practice environment to address the challenges posed by complex patients typified by multiple concurrent chronic conditions and social determinants challenges. I will describe the research that led to the creation, implementation and evaluation of an inter-professional model of care and associated outcomes. I will describe how this work subsequently led to the evolution of clinical models and research projects designed to reframe the discourse around complexity as well as move forward on elaborating new policy, clinical and service delivery innovations. I will conclude with some thoughts about what I see as the major challenges in the short and immediate term for research and practice, drawing on 15 years of practice and research experience with complex populations.

Introduction: The Emergence of Complexity

Complexity in medical care was not discussed when I went to medical school. Indeed, the notion of complexity science was evolving in disparate research fields remote from medicine. It is only recently that the notion of complexity has emerged in analysis of both patients and the delivery of healthcare.

It is important to distinguish the concepts of complexity in healthcare from that of complexity science. Complexity science has numerous applications in a variety of fields including physics, economics, meteorology and ecology. Complexity science studies the dynamic, incompletely predictable and often chaotic behaviour of open systems.

In this essay, I focus on complexity as it relates to the understanding of patients and what makes a patient complex. Specifically, I focus on the assessment and management of complex patients in a primary care context. I draw from both clinical experience and research conducted by our team over the past decade that has focused on complex patients.

What Do We Mean by Patient Complexity?

It can be argued that the emergence of complexity in patients is primarily the result of the following driving forces:

1. Demographic transition;
2. Improved therapeutic interventions; and
3. Advent of clinical practice guidelines.

It is now well recognized that the Canadian population is aging rapidly and that the greatest gains in longevity are for those who have reached the age of 80. It has been noted for some time that in high-income countries, the population mortality curve has become progressively rectangular. This means that the mean age of death has occurred at a progressively older age over the past half century. However, the increase in longevity has not been associated with a reduction in morbidity. In fact, the demographic transition has been associated with a growth in individuals living with multiple concurrent chronic conditions or multimorbidity. For example, Denton and Spencer (2010) show that in Canada, the number of people with no chronic conditions decreases over the life course and the co-occurrence of chronic diseases increases with age. This is often referred to as multimorbidity. It is clear now that multimorbidity is the most prevalent form of chronic disease and highly prevalent in primary care in Canada (Tinetti et al. 2010; Fortin et al. 2005).

The idea that multimorbidity is the rule and not the exception for both population and individual health has not yet fully been integrated into health system planning and health professions education. It represents, in my mind, the pre-eminent challenge of health systems planning and health professions education in the early twenty-first century.

Improved therapy, particularly for cardiovascular conditions such as hypertension, ischemic heart disease and congestive heart failure, as well as effective therapies for cancer, have also contributed to patient complexity. Simply put, lives “saved” from fatal outcomes earlier in the life course permit the accumulation of additional morbidities through time. Ironically, better management of these diseases has prolonged life to the extent that more conditions that are chronic are acquired due to life extension. Mortality has decreased in every age category and morbidity has increased in every age category over the past half century.

Another simultaneous occurrence is the emergence and growth of clinical practice guidelines (CPGs). CPGs were virtually non-existent when I graduated from medical school in the 1980s. Under the influence of evidence-based medicine and concerns for knowledge translation, CPGs rapidly grew in the 1990s through 2000s. Weisz et al. (2007) provide a fascinating historical account that documents the impressive growth in the production of CPGs over the past 30 years. Over time, guidelines have become less opinion driven and more systematic with greater reliance on randomized controlled trials and systematic reviews. As well, the number of organizations producing CPGs has grown, and only recently has some consensus on how best to format CPGs emerged. Currently, primary care clinicians must contend with potentially thousands of CPGs. Few of these are relevant in the context of complexity (Mutasingwa et al. 2011).

The implications of the above forces became clinically relevant to me in the early 2000s. When I first started practice, as a rural family physician, in the mid-1980s, there were only a few patients in a clinic day that could be counted as having multimorbidities, and the majority of them were seniors. However, 15 years later, it was clear to me, now in an academic family practice, that my patient population had fundamentally altered in significant ways. Patients were older and typically had a higher burden of chronic disease than I had previously encountered, but such was the case for younger cohorts as well.

Part of this change was likely explained by our practice being sited in an academic tertiary care centre as well as located in an area of Toronto with a high proportion of seniors. Rather than regarding this context as a bias, it was clear that it was a microcosm of the future of primary care. If primary care were to play its proper role as the point of first contact for all patient problems and the locus of continuity of care, then it was imperative that there be the requisite management tools and care approaches to provide appropriate care for complex patients.

However, it was equally evident that primary care was not prepared for this challenge. Typical office visits in primary care are short and often do not permit attention to more than one problem at a time. This approach to care delivery in primary care sets up a situation of mutual frustration. Patients feel rushed and clinicians feel stressed. A cascade of poor quality care occurs where issues are only partially addressed.

What the Literature Says About the Challenges Posed by Complex Patients

The difficulties of managing patients with multimorbidity in primary care are numerous. The range of challenges faced by clinicians is largely because models and methods of care for this population have not evolved with the demographic transition. In essence, there is a mismatch between the needs of the patient population and how services are currently offered or funded. This mismatch is reflected in studies, indicating that primary care physicians find patients with multimorbidity “too complex and too time consuming” (Ekdahl et al. 2012).

Sinnott et al. (2013) conducted a systematic review of primary care providers’ experiences of providing care to patients with multimorbidity. Four key findings emerged:

1. disorganisation and fragmentation of healthcare;
2. the inadequacy of guidelines and evidence-based medicine;
3. challenges in delivering patient-centred care;
4. barriers to shared decision-making.

They also made note of clinician’s sense of isolation in decision-making for patients with multimorbidity. This isolation is a risk factor for burnout and moral distress.

Similarly Fried et al. (2011) in a study of primary care physicians’ experiences of caring for older patients with multimorbidity identified the following five themes:

1. concerns about patients’ ability to adhere to complex medical regimens such as lack of social supports and concerns regarding adherence;
2. variability in beliefs regarding the harms and benefits of guideline-directed care in terms of uncertainty regarding the applicability of evidence and lack of calibration of outcomes to patients’ life worlds;
3. variability in approaches to balancing trade-offs between harms and benefits, such as difficulties in setting treatment priorities and the inability to quantify benefits and harms;
4. difficulties in involvement of patients in the decision-making process in terms of difficulty in aligning treatment goals or in conflicting goals; and
5. barriers to clinicians’ preferred approaches to decision-making, particularly related to insufficient time and remuneration and managing unrealistic expectations.

These findings should be taken very seriously, and policy makers and planners would do well to embark immediately on substantial reforms of service delivery and training. The situation is pressing because the demographic changes indicate a large cohort of older adults in keeping with the aging of the baby boom generation. There is every reason to believe their patterns of morbidity will match those measured in recent cohorts of older adults from the Depression and World War II generations.

Quite simply, a complex patient is one whose needs exceed the temporal and informational capacity of any single provider at a particular point in time.

The Need for a Complexity Framework

Multimorbidity is but one component of patient complexity. Schaink et al. (2012) identified additional factors that contribute to complexity. These include patterns of healthcare utilization such as high utilization, psychosocial factors such as mental health addictions and impairments of cognition, and challenges in the social determinants of health such as income, housing and food security. Many of these elements point out the current deficiencies with the way in which health and social services interact. Complex patients often have several interacting factors at play that thwart simple solutions based in medical approaches, e.g., reliance on a network of supports from family and other formal and informal caregivers.

A complexity framework should not only provide guidance in terms of explaining the nature of complexity but also be directive in helping to conceptualize the variety of care needs anticipated when seeking to provide care. Unfortunately, most clinicians and other service providers come equipped with skills that will only partially address these many needs and are often at a loss when it comes to figuring out the most appropriate manner with which to address multiple needs.

Time and Information Complexity

In my view, the essence of complexity relates to two fundamental factors: time and information. Quite simply, a complex patient is one whose needs exceed the temporal and informational capacity of any single provider at a particular point in time. Complex patients have a lot going on simultaneously. This was something I recognized in my clinical work. Patients would come with long lists of issues related to symptoms, diseases, prescriptions, the views of their specialists and things they had heard from friends and families or those they had seen on television or read on the internet pertaining to their health. The sheer volume of concerns to process in a clinical encounter far exceeded the time available for discussion. Addressing one issue at a time over a series of visits is not an optimal process,

as there exists no easy way to assign priority to a particular concern and there is a high probability of one seemingly resolved condition becoming unstable in the interim.

Time is probably the most valuable of scarce resources in healthcare. Anyone with passing familiarity with modern healthcare will attest to the pervasive sense of time pressure felt by all who participate in healthcare. Patients and family members experience time stress as a sense of being rushed and express their frustration at the inability for their concerns to be adequately considered. Clinicians feel moral distress and suffer from feelings of dissatisfaction about being unable to do their jobs properly. A lack of time may be a complaint for many people, but it is particularly the case for complex patients. There is a reason behind why complex patients provoke avoidant behaviour from clinicians. Few clinicians will admit to mastery, and, as a consequence, optimal care is seldom delivered.

Richard Horton, editor of the *Lancet* recognized the importance of creating time-enriched environments to make complex decisions. He wrote:

However, what is the one variable – one that we have too easily given up on – that would allow these influences to be judged more carefully for the individual patient? The answer is time. Time would allow for the range of available data to be considered, and then arguments to be constructed, analysed, reviewed, refined, and finally agreed on. The approach we are currently endorsing – accepting that we must inevitably lose the fight for time, revealed by providing ever-narrower synoptic summaries or ‘bottom-lines’ of increasingly complex evidence – does not address the more fundamental point – namely, the need to provide a temporal space to interpret that information. (Horton 1999: 3162)

Complex patients remind us that we must be vigilant in advocating for time in order to provide appropriate high-quality care. Patients accumulate chronic diseases over a life course. I would often remind medical trainees working with me that it takes a patient a long time to become complex and it will take them a long time to understand all the dimensions of their complexity. However, most healthcare professionals have not received any training with respect to the management of complex patients. This is something requiring urgent attention.

Are There Any Promising Approaches?

It was clear that current approaches were sub-optimal. With a colleague, Shawn Tracy, I argued that a new philosophy of care was required to address complexity, one that would fundamentally alter our clinical and educational approaches (Upshur and Tracy 2008). It entailed reconceptualising the

manner in which we understand patient needs. Rather than the traditional medical approach to diagnosis and therapy based on the traditional model of seeking and reversing singular causes with the hope of cure, a model that was based in dialogue and deliberation was required.

Another dimension of complex patients is that there is often a lack of strong evidence regarding treatment and management decisions. Optimal decision-making requires acknowledgement that there is a high degree of uncertainty regarding appropriate management and prognosis associated with complex patients. If we wish to be truly patient-centred, uncertainty needs to be acknowledged. It is often the case, as a study by Kuluski and colleagues demonstrates, that patients, their caregivers and clinicians do not often share the same treatment goals (Kuluski et al. 2013). Aligning treatment goals is important to successful care planning, but often patients and families are unclear themselves about care goals or defer to healthcare professionals who are similarly confused and may devolve to acting on clinical imperatives, which may drive utilization needlessly. Investing in goal setting and goal alignment with complex patients is a time-consuming process, but a necessary step to ensure that services and needs are matched. It is also in keeping with the spirit of “patient-centred care.”

The Overarching Importance of Team-Based Approaches

Recognizing these challenges, with colleagues at Sunnybrook, we created an interprofessional team-based approach to managing complex patients. Our initial model focused on older adults with multimorbidity and limitations of an activity of daily living. We designed and implemented the program in an academic family medicine environment. We have subsequently refined the model, tested it in other practices, conducted a multisite pragmatic controlled trial and adapted the model to a transition-to-home from a complex continuing-care rehabilitation setting.

We have named it the IMPACT model (Interprofessional Model of Practice for Aging and Complex Treatments) (Tracy et al. 2013). The IMPACT practice model comprises family physicians, a community nurse, a pharmacist, a physiotherapist, an occupational therapist, a dietitian and a community social worker. In addition, the model is designed to accommodate trainees from each of the various disciplines. The model was expanded in an IMPACT+ model to include specialist physicians such as those from internal medicine, psychiatry and geriatrics. One defining feature of the model is that the assessment is carried out over a period of hours, with a caregiver and all members of the team present. The virtue of concurrent assessment, compared with the sequential assessment typically conducted, is that it permits clinicians to discuss differences of opinions amongst themselves. It is often not acknowledged that the same patient being evaluated by multiple healthcare

providers often receives subtly or overtly different accounts of what is wrong with them and what the optimal solution to the problem should be. The team discussions also permit healthcare professionals to express their concerns and uncertainties about the patient and the evidence that the care plan will work. The model also serves as a one-stop shop, permitting the identification of all relevant patient, provider and caregiver concerns.

Our research has shown that effective teams can be created, that healthcare providers enjoy working in this environment as it is a rich learning environment and the time afforded permits thorough reflection on the patient’s problems. Patients and caregivers feel they have been given sufficient time to be heard.

I am convinced after over a decade studying this model that team-based interprofessional models are required for complex patients. There is much debate on whether this is a cost-effective model, whether it reduces utilization, particularly hospitalizations and emergency room visits. But utilization measures may not be the best measures of effect, particularly for complex patients with significant chronic disease burdens. Even with the investment of time such as in IMPACT, they will become unstable in the future.

However, the IMPACT model does help to address several of the issues identified in the literature cited above. It provides more time for all to articulate and clarify treatment goals. It helps to simplify complex treatment regimens to focus only on those issues that matter to patients and caregivers. It spares families and caregivers numerous visits for additional assessments. It provides a clinical context to acknowledge uncertainty and share the burden of decision-making. It permits the possibility for the necessary social and community services to be identified and contacted as a coordinated care plan emerges from the assessment. If for no other reason than to permit healthcare providers and caregivers to continue their struggle to provide care for people with highly demanding health and social needs, it seems more than worthwhile to me. It remains for future research to determine the optimal mix of healthcare professionals, the duration of the visit and how best to finance such models.

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Concluding Thoughts

The title of this essay refers to understanding complexity the hard way. Most of the barriers and concerns noted by primary care providers are things I have experienced in my clinical work with this population. Both clinical care and research in this area are difficult but profoundly rewarding. We are still a very long way from a health system that is optimally calibrated to manage the growing population of complex patients. We need new measures

and management tools. A pressing need is to understand what we mean by outcomes in the context of complexity (Upshur et al. 2014). There are many signals that the broader policy and provider world is aware of these challenges, even though the focus has been disproportionately on high cost users. We need to be equally, if not more committed to quality and appropriateness of care. Innovation and research are required to address these issues. Encouraging signals such as Choosing Wisely (Leon-Carlyle et al. 2015), Minimally Disruptive Medicine (May et al. 2009), Deprescribing (Thompson and Farrell 2013) and system innovations such as Health Links in Ontario indicate the perception that there is a need to simplify and counter the belief that more assessments and more interventions will achieve meaningful clinical and patient-centred goals. My maxim: the best plan for a medically complex patient is the simplest plan to achieve and maintain the explicitly stated and agreed upon goals between patients, their caregivers and their healthcare providers. This is a tall order and much needs to be done quickly to achieve this goal including appropriate funding streams to support the work. Given the advent of the largest cohort of older adults we are likely to ever see, failure here would call into question the very meaning and purpose of a publicly funded health system. **HQ**

References

- Denton, F.T. and B.G. Spencer. 2010. "Chronic Health Conditions: Changing Prevalence in an Aging Population and Some Implications for the Delivery of Healthcare Services." *Canadian Journal on Aging* 29(1): 11–21.
- Ekdahl, A.W., I. Hellström, L. Andersson and M. Friedrichsen. 2012. "Too Complex and Time-Consuming to Fit in! Physicians' Experiences of Elderly Patients and Their Participation in Medical Decision Making: A Grounded Theory Study." *BMJ Open* 2(3): e001063.
- Fortin, M., G. Bravo, C. Hudon, A. Vanasse and L. Lapointe. 2005. "Prevalence of Multimorbidity among Adults Seen in Family Practice." *Annals of Family Medicine* 3(3): 223–28.
- Fried, T.R., M.E. Tinetti and L. Iannone. 2011. "Primary Care Clinicians' Experiences with Treatment Decision Making for Older Persons with Multiple Conditions." *American Medical Association's Journal of Internal Medicine* 171(1): 75–80.
- Horton, R. 2000. "Common Sense and Figures: The Rhetoric of Validity in Medicine (Bradford Hill Memorial Lecture 1999)." *Statistics in Medicine* 19(23): 3149–64.
- Kuluski, K., A. Gill, G. Naganathan, R. Upshur, R.L. Jaakkimainen and W.P. Wodchis. 2013. "A Qualitative Descriptive Study on the Alignment of Care Goals between Older Persons with Multimorbidities, their Family Physicians and Informal Caregivers." *BMC Family Practice* 14: 133.
- Leon-Carlyle, M., R. Srivastava and W. Levinson. "Choosing Wisely Canada: Integrating Stewardship in Medical Education." *Academic Medicine* 90(11): 1430.
- May, C., V.M. Montori and F.S. Mair. 2009. "We Need Minimally Disruptive Medicine." *BMJ* 11: 339.
- Mutasingwa, D., H. Ge and R.E.G. Upshur. 2011. "How Applicable Are Clinical Practice Guidelines to Elderly with Co-Morbidities?" *Canadian Family Physician* 57(7): e25362.
- Schaink, A., K. Kuluski, R. Lyons, M. Fortin, A. Jadad and R. Upshur. 2012. "A Scoping Review and Thematic Classification of Patient Complexity: Offering a Unifying Framework." *Journal of Comorbidity* 2(1): 1–9.
- Sinnott, C., S. Mc Hugh, J. Browne and C. Bradley. 2013. "GPs' Perspectives on the Management of Patients with Multimorbidity: Systematic Review and Synthesis of Qualitative Research." *BMJ Open* 3(9): e003610.
- Tinetti, M.E., T.R. Fried and C.M. Boyd. "Designing Health Care for the Most Common Chronic Condition--Multimorbidity." *JAMA* 307(23): 24934.
- Tracy, C.S., S.H. Bell, L.A. Nickell, J. Charles and R.E. Upshur. "The IMPACT Clinic: Innovative Model of Interprofessional Primary Care for Elderly Patients with Complex Health Care Needs." *Canadian Family Physician* 59(3): e148–55.
- Thompson, W. and B. Farrell. 2013. "Deprescribing: What Is It and What Does the Evidence Tell Us?" *The Canadian Journal of Hospital Pharmacy* 66(3): 2012.
- Upshur, R.E. and S. Tracy. 2008. "Chronicity and Complexity: Is What's Good for the Diseases Always Good for the Patients?" *Canadian Family Physician* 54(12): 1655–58.
- Upshur, R., K. Kuluski and C.S. Tracy. 2014. "Rethinking Health Outcomes in the Era of Multiple Concurrent Chronic Conditions." *Healthy Debate*. Retrieved July 7, 2016. <<http://healthydebate.ca/opinions/rethinking-health-outcomes-in-the-era-of-multiple-concurrent-chronic-conditions>>.
- Weisz, G., A. Cambrosio, P. Keating, L. Knaapen, T. Schlich and V.J. Tournay. 2007. "The Emergence of Clinical Practice Guidelines." *Milbank Quarterly* 85(4): 691–727.

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eHealth Advances in Support of People with Complex Care Needs: Case Examples from Canada, Scotland and the US

Carolyn Steele Gray, Stewart Mercer, Ted Palen, Brian McKinstry and Anne Hendry on behalf of The Multi-National eHealth Research Partnership Supporting Complex Chronic Disease and Disability, The eCCDD Network

Abstract

Information technology (IT) in healthcare, also referred to as eHealth technologies, may offer a promising solution to the provision of better care and support for people who have multiple conditions and complex care needs, and their caregivers. eHealth technologies can include electronic medical records, telemonitoring systems and web-based portals, and mobile health (mHealth) technologies that enable information sharing between providers, patients, clients and their families. IT often acts as an enabler of improved care delivery, rather than being an intervention per se. But how are different countries seeking to leverage adoption of these technologies to support people who have chronic conditions and complex care needs? This article presents three case examples from Ontario (Canada), Scotland and Kaiser Permanente Colorado (United States) to identify how these jurisdictions are currently using technology to address multimorbidity. A SWOT (strengths, weaknesses, opportunities, threats) analysis is presented for each case and a final discussion addresses the future of eHealth for complex care needs. The case reports presented in this manuscript mark the foundational work of the Multi-National eHealth Research Partnership Supporting Complex Chronic Disease and Disability (the eCCDD Network); a CIHR-funded project intended to support the international development and uptake of eHealth tools for people with complex care needs.

Introduction

Information technology use in healthcare, or eHealth, has become increasingly prominent since the late 1980s. A frequently cited definition of eHealth (Oh 2005) identifies it as “an emerging field in the intersection of medical informatics, public health, and business, referring to health services and information delivered or enhanced through the Internet and related technologies” (Eysenbach 2001: e20). eHealth technologies may include the following: software systems like electronic medical/health records (EMRs/EHRs); clinical decision-support tools; health information websites; web-based portals for patients, clients and providers; health education programs; and telecare and mobile health (mHealth) technologies used to enable delivery of healthcare and social-care services and support in individuals’ homes (Boonstra and van Offenbeek 2010; Kreps and Neuhauser 2010).

There are a number of areas where eHealth technologies could support the healthcare needs of people living with complex chronic disease and disability (CCDD). People with CCDD can be characterized as having multiple chronic conditions (multimorbidity) as well as social/contextual challenges that make management of their health difficult (Barnett 2012; Schaink et al. 2012). A study of community-dwelling individuals with CCDD revealed that they require improved person-centred bi-directional information sharing between

patients and their primary care and other care providers (such as specialists and allied health professionals), as well as bi-directional information sharing between different professionals and care providers to improve their care delivery (Steele Gray et al. 2014). EMRs and EHRs, telemonitoring and web-based applications and resources may address these needs through improving coordination, continuity and access to services and information for both patients and providers (Barakat 2013; Becker 2014; Burton et al. 2004; IHI 2003; Lester 2011; McLean and Sheikh 2009; Pagliari et al. 2007; Seto et al. 2012).

While there is significant potential to use eHealth to improve care planning and delivery, it is not clear how different countries are leveraging these technologies to support people with chronic conditions and complex care needs. This article presents a SWOT analysis (strengths, weaknesses, opportunities, threats) of three case examples from Ontario (Canada), Scotland and Kaiser Permanente Colorado (KPCO, US) with regard to adopting eHealth technologies to support people with CCDD. The case reports presented mark the foundational work of the Multi-National eHealth Research Partnership Supporting Complex Chronic Disease and Disability (the eCCDD Network), which aims to foster the international development and uptake of eHealth tools for people with complex care needs.

The information presented is based on site visits by the lead author to Scotland and Colorado, as well as the knowledge and input of those in the collaboration who work in the area of eHealth/IT and multimorbidity and complex care needs in each of the three jurisdictions.

In Ontario, 79% of total health-system costs are used by only 10% of the population ... many of these “high-cost users” tend to be those with multiple chronic conditions...

Ontario Overview

Canadian provinces receive federal funding to cover medically necessary hospital and physician services for citizens, as stipulated under the Canada Health Act, 1985 (Canadian Parliament 1985). Provinces have the option to invest more than this minimum requirement to fund other services like rehabilitative care, residential care, home and community care services and medications. This approach results in variation around who pays for what services across Canada (Marchildon 2013). Overall, about 70% of total healthcare expenditure comes from public sources (CIHI 2015).

In Ontario, the Ministry of Health and Long-Term Care (MOHLTC) funds healthcare services through an insurance

model. Funding for services flows through 14 regional bodies called Local Health Integration Networks to healthcare organizations to deliver services to Ontario citizens, with the exception of physicians who are paid primarily through a fee-for-service basis directly from the MOHLTC. In Ontario, 79% of total health-system costs are used by only 10% of the population (Commission on the Reform of Ontario’s Public Services 2012); many of these “high-cost users” tend to be those with multiple chronic conditions and complex care needs living in the community (Rosella et al. 2014).

Ontario SWOT analysis

Strengths

Government support for EHRs, information sharing and telehealth: There are three main government agencies that support eHealth adoption in Ontario: (1) eHealth Ontario, established in 2008 to enable the adoption of EHRs in Ontario; (2) Ontario Telemedicine Network, which develops and supports telemedicine solutions including remote patient monitoring, virtual visits and videoconferencing for multidisciplinary teams (Ontario Telemedicine Network 2015); and (3) Canada Health Infoway, a federally funded agency established in 2001 to co-fund eHealth projects with provinces and territories (Canada Health Infoway 2015). These agencies additionally support several programs to improve patient information sharing across provider teams and organizations (eHealth Ontario 2015). Of particular note is the EHR Connectivity Strategy lead by eHealth Ontario intended to support a provincially integrated EHR system (eHealth Ontario 2016a), which includes the connecting GTA program, to create an information hub that houses EHR data from acute and community care sectors (eHealth Ontario, 2016b).

Foundational legislation and regulations and supportive policies: The Personal Health Information Protection Act, 2004 (Ontario Legislature 2004), along with the Privacy and Data Protection Policy, 2014 (eHealth Ontario 2014), offers important measures to support data security and privacy. In 2010, the MOHLTC expanded subsidies for purchasing and implementing EMRs to all physicians. This initiative helped to increase the saturation of EMR use in the Province from 44% in 2009 to 65% in 2012 (Hutchison and Glazer 2013).

Third sector innovation hubs, incubators and accelerators: A number of innovation hubs and incubators support the development of new eHealth and mHealth solutions for a variety of chronic-disease populations. Many of these hubs operate on a not-for-profit basis and are fully or partially supported through government funding, with many housed within academic hospitals or universities. Innovators from these settings can also reach out to Ontario Centres of Excellence (funded by the Ontario government) to help market, scale and spread innovations (Ontario Centres of Excellence 2015).

Weaknesses

While adoption of EMRs by physicians continues to grow, the existing operations do not adequately support disease management and registries and systems are plagued by interoperability challenges (Hutchison and Glazer 2013: p. 700). A lack of federal or provincial guidance with regard to an eHealth strategy or national infrastructure (Rozenblum et al. 2011) has left Ontario with dozens of legacy EMR systems with “no viable way of assembling a comprehensive and accurate healthcare view of any one patient anywhere in the province” (Powers 2011: p.e30).

Beyond interoperability challenges, other weaknesses in the system include the following:

- eHealth technologies are often insufficiently focused on user needs (Ontario Medical Association 2015)
- Most technologies focus on single-disease populations, with few meeting the needs of “high users” (Becker 2014) like people with CCDD.
- There are few instances of links between healthcare and social-care organizations, making it difficult to wrap a full range of services and supports around individuals who need them.

... the existing operations do not adequately support disease management ...

Opportunities

Since 2013, the MOHLTC has been seeking to address the needs of the “high user” population through improved integration of hospital, primary care and home and community care services via Health Links (Ontario Ministry of Health and Long-Term Care 2015). There is an opportunity for the Ontario government to provide guidance to Health Links, with regard to adopting new technologies that can support people with CCDD. One notable example is a pilot project being run by a branch of the MOHLTC testing the adoption of an electronic Coordinated Care Plan (Huron Perth Health Link 2014).

While Ontario’s eHealth funding with minimal top-down strategy has led to significant system fragmentation, it has also resulted in a wealth of new innovations in the eHealth and mHealth space; a notable unintended consequence of systems with limited top-down government strategies (Webster 2012). Innovation hubs and incubators, as well as clinicians and hospitals, are constantly creating new technologies, many of which may improve information sharing and person-centredness in the health system, thus addressing identified needs of people with CCDD. There are also research-based initiatives that seek to integrate patient information. For example, the University of Toronto Practice-Based Research Network (UTOPIAN) seeks to integrate primary-care data across Ontario for research purposes, which could help to improve

care delivery for people with CCDD (Family & Community Medicine 2016).

Threats

There are a number of potential threats to adopting new technologies for CCDD in the Ontario context:

- Increased fragmentation could occur due to the large number of new eHealth and mHealth solutions being developed in parallel rather than in collaboration.
- There may be insufficient human resources, in particular, Health Informatics and Health Information Management professionals needed to support implementation of eHealth technologies (Atkinson 2009).
- Ongoing support for eHealth initiatives in Ontario needs to demonstrate clear value for money to gain support (Murphy 2010). However, evidence of eHealth impact on health outcomes and cost effectiveness are often mixed (Black 2011).
- Ontario is still largely a provider-centric system.
- Although there is legislation in place to ensure privacy and security of patient information, the introduction of new technologies poses new challenges that must be addressed (Canada Health Infoway 2014).

Scotland

Overview

The National Health Service in Scotland (NHS Scotland) delivers healthcare services free at the point of care to all Scottish residents. NHS Scotland is divided into 14 local health boards responsible for planning and delivery of services and a number of national boards for support functions (training, procurement, health improvement, quality improvement and information and intelligence). Services are paid for through general taxation, as in the rest of the UK, and most providers are employed directly by the NHS, although most general practitioners act as independent contractors, as do some other providers such as dentists, community pharmacists and opticians (National Health Service Scotland 2015a). Many practitioners and specialists offer both NHS-funded and private services.

A notable challenge facing Scotland’s public services is the growing number of seniors and individuals with multimorbidity in the population (Barnett et al. 2012; National Health Service Scotland 2015b). Scottish citizens experience some of the worst health inequalities in Europe. There are huge discrepancies in life expectancy within and across cities, with socioeconomic deprivation being a key driver of inequality (Audit Scotland 2012). The overlap of high health needs and social complexity is similar to the needs of people with CCDD (Schaink et al. 2012). Public bodies in Scotland are now looking toward new solutions to improve outcomes for these individuals and reduce health inequity.

Scotland SWOT analysis

Strengths

Policy shifts to support healthcare and social-care integration: The Public Bodies (Joint Working) Scotland Act (2014) requires the integration of adult healthcare and social-care services in Scotland, providing the groundwork from which to build a truly integrated system to support the needs of individuals with CCDD. All integration arrangements are to be in place by April 2016, including integration schemes, boards, budgets, indicators and governance structures.

EMR interoperability: There is a degree of interoperability between general practitioner (GP) and hospital systems, particularly in respect of laboratory results, letters between hospital and GP practice, and emergency-care summaries. Anticipatory Care Plans for people with complex needs can also be electronically shared by GPs for use by Out of Hours teams, emergency services and Emergency Departments. NHS Scotland is currently increasing the interoperability between systems by developing governance and standards for linking healthcare and social-care information and methods to integrate primary- and secondary-care information via portal systems.

Innovation centres, funding and improvement support: The Digital Health Institute (2015), Telescot (2015), and the Scottish Centre for Telehealth and Telecare (2015) have been leading the development, adoption and the evidence base for the use of new technologies in healthcare settings. Additionally, in 2014, the Scottish Government introduced a Technology-Enabled Care (Scottish Government 2015; Joint Improvement Team 2015) program supported by £10 million funding per annum for three years to support health and care partnerships scale up use of technology and to develop capability and support knowledge exchange across partnerships.

Strong person-centred third sector and research: There is a strong third sector in Scotland to advocate for and help enable person-centred healthcare and social-care delivery. Many third sector healthcare and social-care organizations are represented by the Health and Social Care Alliance (ALLIANCE; 2015), which engages with local and national bodies to influence service delivery, leads a number of programs that support self-management and gives individuals and their caregivers a strong voice in the design and delivery of their health and social care. In addition, Scotland has steadily developed academic capacity in primary-care research over the last decade or so supported by the Scottish Government, particularly through the collaborative work of the Scottish School of Primary Care. This support includes a national program of research on multimorbidity (Scottish School of Primary Care 2015), which produces evidence to improve care for persons with CCDD, as well as other major programs spanning eHealth, Quality and Safety and expertise in complex interventions and health-service evaluation.

Weaknesses

There are a number of challenges with regard to information sharing and communication in the Scottish health system that could make adopting eHealth technologies to support people with CCDD challenging:

- The phased roll out of the clinical portal means many GPs cannot yet access information directly from hospital EMRs, so clinicians generally still rely on paper-based systems to exchange information about patients moving between primary and secondary care.
- Emerging new and mobile technologies cannot easily connect to existing EMR systems.
- Healthcare and social-care have completely different electronic record systems.
- GPs, primary- and community-care teams and hospital staff are often unaware of the community services and non-NHS resources in their neighbourhoods.
- There are very few instances of effective co-location of healthcare and social-care services.

There is a strong third sector in Scotland to advocate for and help enable person-centred healthcare and social-care delivery.

Opportunities

Across Scotland, supported by the Integrated Care Fund (£100 million per annum for three years) and the Primary Care Transformation Fund (£320 million over 3 years), many projects are in early implementation phase and offer opportunities for improved communication and person-centred integrated care for people with CCDD.

- New models of integrated primary care: involves co-location of multiprofessional teams of GPs, nurses, pharmacists, social workers and allied health professionals embedded in GP practices and community hubs and enabled by telehealthcare networks.
- The House of Care – a model of collaborative primary care that is intended to enable individuals to identify their priorities and goals in collaboration with care providers.
- The Links Worker program – places Community Links Practitioners within primary care teams in very deprived areas (Deep End practices) to support improved connections to community resources for patients and their families and caregivers.
- A Local Information System for Scotland (ALISS) – provides an online portal to create connections to community supports, and Living it UP, an online self-management platform, are two examples of national technology-enabled care programs (Joint Improvement Team 2015).

Threats

A number of system-level threats exist which may limit implementation of eHealth solutions which support people with CCDD:

- General access and sustainability issues, notably a growing shortage of GPs and other members of the community workforce.
- A traditionally provider-centric system that exacerbates tensions between practitioner and personalized goals.
- A hesitance to disinvestment in acute care to build capacity in primary and community settings.

KPCO has been on the forefront of health IT (HIT) for several decades, beginning development of its first EHR in the early 1990s.

Kaiser Permanente Colorado

Overview

KPCO is a not-for-profit, integrated healthcare delivery system, operating in Colorado, US. For over 45 years, this organization has provided comprehensive health services to members in Denver, Boulder, Southern Colorado and Northern Colorado. Currently KPCO has over 626,000 members, 28 medical offices and 7,000 staff and physicians (with nearly 1,000 physicians from multiple medical specialties and subspecialties) (Kaiser Permanente 2015).

With new Federal legislation in the United States, namely the Patient Protection and Affordable Care Act, 2010 (US Government 2010), KPCO has been experiencing an influx of people with multimorbidity and complex care needs. KPCO is seeking new innovative ways to deliver care for individuals with CCDD and has sought to use its sophisticated IT systems in tandem with new care-delivery models to improve care for these patients.

KPCO SWOT analysis

Strengths

KPCO has been on the forefront of health IT (HIT) for several decades, beginning development of its first EHR in the early 1990s. KPCO's experience in developing and using EHR, ancillary HIT functions, and clinical databases has enabled KPCO to learn how to dovetail these systems within clinical care. Through these learning experiences, KPCO has developed and enabled HIT tools and workflows to improve care-delivery processes and care coordination, enable risk stratification processes and foster patient engagement. KPCO clinical performance-benchmark metrics are at or near the top in the country. There has additionally been heavy investment and 20 years of development in IT from the Kaiser Permanente parent company.

KPCO has four main strengths in relation to delivering care to patients with CCDD:

1. *Integration through co-location and technology:* Integration across multiple health sectors is facilitated through co-location of services and through an integrated EHR and an EHR-tethered patient and provider portal system. All KPCO providers can access EHR patient data to get near instant diagnostic images and quick lab results. The EHR includes a system for adding medication orders, allowing prescriptions to be routed electronically to KPCO-linked pharmacies and messaging systems, so physicians and allied health professionals at KPCO can easily discuss patient care.
2. *Technology enabled patient-provider communication:* Providers and patients are able to communicate easily via the patient portal that is linked to the EHR. The MyHealthManager system pulls data from the EHR to patients' personal health records so they can view lab results, medications and care plans. The system also supports online appointment setting, medication refill requests and patient-provider communication (via secure email). A mobile app is available for download, allowing patient access to the portal through their mobile devices.
3. *EHR-enabled chronic-care management:* KPCO uses "Health Track Registries" to manage people with chronic illnesses, including asthma, COPD, diabetes and mental illness. Chronic care nurse managers (care coordinators) use EHR data to identify individuals at high risk of emergency department or hospital visits and identify gaps in care. The managers engage in patient outreach to reduce risk through improving medication and care plan adherence or helping to improve self-management skills. The care coordinators also field emails from patients regarding their chronic illness.
4. *Centralized oversight and governance:* The centralized oversight and governance model at KPCO helps to avoid a number of barriers to adopting new technology, such as providing medical insurance coverage for providers to cover new models of care. Furthermore, all medical care providers are salaried at KPCO, which allows for a centralized incentive system. The incentive system also actively explores new care-delivery models to achieve Triple Aim objectives (Berwick et al. 2008). The EHR system alerts and decision-support tools also allow for better oversight of the delivery of care to ensure adherence to best practices.

Weaknesses

The KPCO IT system lacks a robust mechanism to capture patient-reported data to proactively meet needs while reducing unnecessary use of the system, which is viewed as particularly important to manage patients with CCDD. While KPCO

has been trying to adopt these capabilities, four IT system weaknesses currently stand in the way:

1. Determining what information would be best to include in the EHR system to avoid data overload on the providers is an ongoing challenge.
2. There is a lack of clarity around how best to package and visualize data to be useful to both providers and patients.
3. Inadequate infrastructure within the EHR system to house patient-reported data and the inability of the systems in place to generate automatic feedback reports to providers to support more efficient delivery of care are resulting in manual workflows to coordinate data sources.
4. Legacy IT systems and interfaces with other healthcare organizations and providers continue to act as obstacles. For instance, KPCO experiences challenges in gaining access to hospital data from contract facilities not on KPCO's IT platform.

Opportunities

The influx of people with CCDD with a number of health and social needs is an opportunity for KPCO to further improve on its already impressive system of care. KPCO is experimenting with new, innovative delivery models, including the following:

- The Health Risk Assessment tool used to quickly identify high-needs patients and tailor programs and services to these individuals (Cross 2004).
- The Special Needs Population team, a new branch of the "Health Track Registries," which uses data from the Health Risk Assessment to develop annual care plans for people with multimorbidity and social complexity.
- The Primary Care Plus model for senior care comprises an interdisciplinary care team, including a registered nurse, community specialist, primary care physician, and geriatrician who come together to develop a care plan for patients, which includes a set of goals. KPCO is also piloting Green Teams, which are integrated primary care models that include multiple providers in a single unit.

Additionally, KPCO is making progress in creating better channels for data flow from contracted healthcare partners. KPCO is currently interfacing several products that exchange health information into its systems, which will provide access to hospital data from other healthcare systems. Opportunities exist to improve the timeliness and accuracy of incorporating these data streams into KPCO HIT systems. Ready access to healthcare-partner information will improve the ability to track the transition of Kaiser patients between care facilities.

Threats

There are five notable organizational level challenges which are threats to moving forward in adopting eHealth technologies to support people with CCDD:

- The system currently supports single-disease management. KPCO currently struggles to identify who manages people with multimorbidity and to develop multidisciplinary care teams to improve integrated care and reduce burden on primary care physicians.
- Patient engagement is an ongoing problem, particularly for care coordinators who are having a difficult time getting patients to become active members of their care team.
- There is uncertainty in how to address social and financial problems that exacerbate health issues and lead to poor health outcomes and higher service use.
- While KPCO is a not-for-profit organization, there is still the need to make a business case for any and all new technology that gets adopted.
- Even with improved health information exchange capabilities, poor interoperability standards may lead to inaccurate data transmission. Additionally, high implementation costs may delay adoption of information transmission processes.

The Future of eHealth for People with Complex Care Needs

When we look across these three cases, there are a number of notable similarities highlighted in Table 1.

In all cases, government and organizational interest in addressing the needs of people with CCDD and building eHealth technologies is promising. However, to mitigate threats and overcome the identified weaknesses in each jurisdiction, we offer the following recommendations.

Recommendation #1: Ensure interoperability between multiple types of systems and data sources

Person-centred care approaches are crucial to address the needs of people with CCDD (Upshur and Weinreb 2008; Sinnott et al. 2013). eHealth technologies can help to enable person-centred care and support by allowing information to be shared between providers and users of services across care systems (King et al. 2012; Winkelman and Choo 2003). The information to be collected could include person-centred data collected through mobile apps and telemonitoring devices; however, most integration efforts in the three cases focus mainly on interoperability between healthcare EMR systems. Integrating data from multiple sources across multiple sectors can improve person-centred care; however, while integration of person-reported outcome data is an important element of person-centred care, it is not sufficient to support person-centred care delivery on its own (Miller et al. 2014).

TABLE 1.
Cross-Case SWOT

Strengths	Weaknesses
<ul style="list-style-type: none"> • Government or organizational commitment and investment in technology • Some supported system interoperability (or movement in this direction) • New innovations and system capabilities being implemented • Growing awareness of the challenge of complexity and requirement for person-centred solutions 	<ul style="list-style-type: none"> • Full interoperability across health sectors and connecting health and social-care not yet realized • Lack of integration between non-EMR/EHR systems like mobile apps and other person-centred data sources • Fragmentation within health systems and/or between health and social-care services (with Scotland way ahead given new legislation)
Opportunities	Threats
<ul style="list-style-type: none"> • Government and/or organization focus on addressing needs of people with CCDD across all sectors with implementation of new models of care and support which can be enabled through eHealth technologies 	<ul style="list-style-type: none"> • Access to sustainable resources (funding and human resources) is tenuous in all sectors • All systems remain provider-centric, which can limit adoption of person-centred technologies • Need to make a business case and demonstrate value for money • Need to ensure privacy and security with adoption of new technologies

Recommendation #2: Identify how eHealth technologies can be used to enhance or support innovative models of care through user-involvement in development and implementation

The numerous innovative models of care delivery in early implementation stages in each of the three jurisdictions are impressive, and many of these models may be enhanced through adoption of eHealth technologies. However, implementing new eHealth solutions can be challenging and requires strong stakeholder involvement (Mair et al. 2012), in particular identifying “implementation leaders” to support the process (Damschroder et al. 2009). Equally important will be designing these technologies to meet user needs by adopting user-centred or co-design methods (Devi et al. 2012), which may be particularly important for people with CCDD (Steele Gray et al. 2016). Ensuring people and their caregivers are part of the design process marks a shift towards more person-centric systems.

Recommendation #3: Ensure implementation strategies include economic evaluations and sustainability plans

A key issue is the need to make a business case for the use of eHealth technologies as a means to support government and public buy-in and to secure investment. Most implementation frameworks suggest the inclusion of robust monitoring and evaluation (Damschroder et al. 2009; Lemaire 2011; Mair et al. 2012; van Gemert-Pijnen et al. 2011) and increasingly economic impact statements in favour of adoption of new technologies (Digital Health Institute Scotland 2015; Ontario Health Innovation Council 2014). Building these considerations into plans for implementing new or existing technologies can help support sustained uptake and scale and spread of tools to support people with CCDD.

Recommendation #4: Adopt national-level eHealth strategies

The World Health Organization has argued that in order to realize the full benefits of IT solutions for healthcare, national-level strategies and integrated actions are required (World Health Organization 2012). Interoperability of eHealth information is an important enabler of coordinated care. National-level strategies may drive a shared vision and perhaps enable coordinated action to achieve long-term goals. In this way, a national-level strategy could enable system-level transformation, which is required in order to meet the needs of persons with CCDD. This communal thrust may also occur through vendors with shared goals and economic incentives. It is still unclear if national strategies, private enterprise or a combination is needed to spur efficient development of interoperable eHealth information tools needed to achieve coordinated care for CCDD patients. **HQ**

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References

- Atkinson, M. 2009. *eHealth in Canada. Current Trends and Future Challenges* (p. 44). Ottawa, ON: Information and Communications Technology Council.
- Audit Scotland. 2012. *Health Inequalities in Scotland*. Edinburgh, Scotland: Author.
- Barakat, A., R.D. Woolrych, A. Sixsmith, W.D. Kearns and H.S.M. Kort, 2013. "eHealth Technology Competencies for Health Professionals Working in Home Care to Support Older Adults to Age in Place: Outcomes of a Two-Day Collaborative Workshop." *Journal of Medical Internet Research* 2(2): e10.
- Barnett, K., S.W. Mercer, M. Norbury, G. Watt, S. Wyke and B. Guthrie 2012. "Epidemiology of Multimorbidity and Implications for Health Care, Research, and Medical Education: A Cross-Sectional Study." *Lancet* 380(9836): 37–43.
- Becker, S., T. Miron-Shatz, N. Schumacher, J. Krocza, C. Diamantidis and U.V. Albrecht, 2014. "mHealth 2.0: Experiences, Possibilities, and Perspectives." *JMIR mHealth and uHealth* 2(2): e24.
- Berwick, D.M., T.W. Nolan, and J. Whittington 2008. "The Triple Aim: Care, Health and Cost." *Health Affairs* 27(3): 759–69.
- Black, A.D., J. Car, C. Pagliari, C. Anandan, K. Cresswell, T. Bokun, B. McKinstry et al. 2011. "The Impact of eHealth on the Quality and Safety of Health Care: A Systematic Overview." *PLoS Medicine* 8(1): e1000387.
- Boonstra, A. and A.G. van Offenbeek. 2010. "Towards Consistent Modes of E-Health Implementation: Structural Analysis of a Telecare Programme's Limited Success." *Information Systems Journal* 20: 537–61.
- Burton, L.C., G. Andersen and I.W. Kues. 2004. "Using Electronic Health Records to Help Coordinate Care." *Millbank Quarterly* 82(3): 457–81.
- Canada Health Infoway. 2014. *Privacy and Security Requirements Considerations for Digital Health Solutions*. Version 2.0. Retrieved April 21, 2016. <www.infoway-inforoute.ca/index.php/en/component/edocman/resources/technical-documents/architecture/2154-privacy-and-security-requirements-and-considerations-for-digital-health-solutions?Itemid=101>.
- Canada Health Infoway. 2015. *About Canada Health Infoway*. Retrieved November 16, 2015. <www.infoway-inforoute.ca/en/about-us>.
- Canada Parliament. 1985, Canada Health Act, R.S.C. c.6, s.1, in c. C-6, C. Parliament, Editor: Justice Laws Web Site.
- Canadian Institute for Health Information (CIHI). 2015. *National Health Expenditure Trends, 1975 to 2015*. Toronto, ON: Author.
- Commission on the Reform of Ontario's Public Services. 2012. *Public Services for Ontarians: A Path to Sustainability and Excellence*. Toronto, ON: Queen's Printer for Ontario.
- Cross, M.A. 2004. "More Plans Discover Value of Health Risk Assessments." Retrieved April 21, 2016. <www.managedcaremag.com/archives/2004/10/more-plans-discover-value-health-risk-assessments>.
- Damschroder, L.J., D.C. Aron, R.E. Keith, S.R. Kirsh, J.A. Alexander and J.C. Lowery. 2009. "Fostering Implementation of Health Services Research Findings into Practice: A Consolidated Framework for Advancing Implementation Science." *Implement Science* 4: 50–65.
- Devi, K.R., A.M. Sen, and K. Hemachandran 2012. "A Working Framework for the User-Centered Design Approach and a Survey of the Available Methods." *International Journal of Scientific and Research Publications* 2(4): 1–8.
- Digital Health Institute Scotland. 2015. *About the Digital Health Institute*. Retrieved November 23, 2015. <<https://dhi-scotland.com>>.
- eHealth Ontario. 2014. *Privacy and Data Protection Policy, version 6.3*, E. Toronto, ON: Chief Privacy Officer.
- eHealth Ontario. 2016a. *EHR Connectivity Strategy*. Retrieved April 21, 2016. <www.ehealthontario.on.ca/en/ehr-connectivity-strategy>.
- eHealth Ontario. 2015. *Initiatives*. Retrieved November 23, 2015. <www.ehealthontario.on.ca/en/initiatives/>
- eHealth Ontario. 2016b. *Connecting Ontario*. Retrieved April 21, 2016. <www.ehealthontario.on.ca/en/regional-partners/view/cgta>.
- Eysenbach, G. 2001. "What Is e-Health?" *Journal of Medical Internet Research* 3(2): E20.
- Family & Community Medicine. 2016. *UTOPIAN*. Toronto, ON: University of Toronto. Retrieved April 21, 2016. <www.dfc.utoronto.ca/research/UTOPIAN.htm>.
- Institute of Medicine. 2003. *Key Capabilities of an Electronic Health Record System: Letter Report* (p. 35). Washington, DC: The National Academy Press.
- Health and Social Care ALLIANCE Scotland. 2015. *Who We Are*. Retrieved November 23, 2015. <www.alliance-scotland.org.uk/who-we-are/>
- Huron Perth Health Link. 2014. *Huron Perth Health Link Winter 2014 Update*. Toronto, ON: Ontario Ministry of Health and Long-term Care.
- Hutchison, B. and R. Glazier. 2013. "Ontario's Primary Care Reforms Have Transformed the Local Care Landscape, but a Plan Is Needed for Ongoing Improvement." *Health Affairs* 32(4): 695–703.
- Joint Improvement Team. 2015. *TEC Programme: Overview of Year One Activity*. Retrieved April 21, 2016. <www.jitscotland.org.uk/resource/tec-programme-overview-of-year-one-activity>.
- Kaiser Permanente. 2015. *Kaiser Permanente Colorado*. Retrieved November 23, 2015. <<http://share.kaiserpermanente.org/article/kaiser-permanente-colorado/>>.
- King, G., C. O'Donnell, D. Boddy, F. Smith, D. Heaney and F.S. Mair 2012. "Boundaries and E-Health Implementation in Health and Social Care." *BMC Medical Informatics & Decision Making* 12: 100.
- Kreps, G.L. and L. Neuhauser. 2010. "New Directions in eHealth Communication: Opportunities and Challenges." *Patient Education and Counseling* 78(3): 329–36.
- Lemaire, J. 2011. "Scaling Up Mobile Health: Elements Necessary for the Successful Scale Up of mHealth in Developing Countries." Retrieved April 21, 2016. <www.k4health.org/sites/default/files/ADA_mHealth%20White%20Paper.pdf>.
- Lester, R.T., M. van der Kop, D. Taylor, K. Alasaly, J. Coleman and F. Marra. 2011. "M-health: Connecting Patients to Improve Population and Public Health." *BC Medical Journal* 53(5): 218–19.
- Mair, F.S., C. May, C. O'Donnell, T. Finch, F. Sullivan and E. Murray. 2012. "Factors That Promote or Inhibit the Implementation of e-Health Systems: An Explanatory Systematic Review." *Bulletin of the World Health Organization* 90(5): 357–64.
- Marchildon, G.P. 2013. *Canada: Health System Review. Health Systems in Transition*. Toronto, ON: University of Toronto Press.
- McLean, S. and A. Sheikh. 2009. "Does Telehealthcare Offer a Patient-Centred Way Forward for the Community-Based Management of Long-Term Respiratory Disease?" *Primary Care Respiratory Journal* 18(3):125–26.
- Miller, D., C. Steele-Gray, K. Kuluski and C. Cott. 2014. "Patient-Centered Care and Patient-Reported Measures: Let's Look Before We Leap." *Patient* 8(4): 293–99.

- Murphy, F. 2010. "Ontario's eHealth Strategy and Implications in Primary Care: Does the Strategy Have the Necessary Components to Succeed?" Retrieved April 21, 2016. <<http://dtp.lib.athabascau.ca/action/viewdtrdesc.php?cpk=798&id=40833>>.
- National Health Service Scotland. 2015a. *NHS Scotland – How It Works*. Retrieved November 23, 2015. <www.ournhsscotland.com/our-nhs/nhsscotland-how-it-works>.
- National Health Service Scotland. 2015b. *The Challenges*. Retrieved November 23, 2015. <www.ournhsscotland.com/our-nhs/challenges>.
- Oh, H., C. Rizzo, M. Enkin and A. Jadad. 2005. "What Is eHealth (3): A Systematic Review of Published Definitions." *Journal of Medical Internet Research* 7(1): e1.
- Ontario Centres of Excellence. 2015. *What We Do*. Retrieved November 16, 2015. <www.oce-ontario.org/about-us>.
- Ontario Health Innovation Council. 2014. *The Catalyst Towards an Ontario Health Innovation Strategy. A Report to the Government of Ontario*. Toronto, ON: Author.
- Ontario Legislature. 2004. Personal Health Information Protection Act, 2004, S.O. 2004, c.3, in Sched. A. (Ed.). Ontario, Canada: Ontario Legislature.
- Ontario Medical Association. 2013. *Priorities for Building an Integrated and Accessible Primary Care System in Ontario*. Toronto, ON: Author.
- Ontario Ministry of Health and Long-Term Care. 2015. *Transforming Ontario's Health Care System. Community Health Links Provide Coordinated, Efficient and Effective Care to Patients with Complex Needs*. Retrieved November 16, 2015. <www.health.gov.on.ca/en/pro/programs/transformation/community.aspx>.
- Ontario Telemedicine Network. 2015. *About Us*. Retrieved November 16, 2015. <<https://otn.ca/en/about-us>>.
- Pagliari, C., D. Detmer and P. Singleton. 2007. "Potential of Electronic Personal Health Records." *BMJ* 335(7615): 330–33.
- Patient Protection and Affordable Care Act, in 18001. 2010. p. 906.
- Powers, P. 2011. "Ontario's e-Health Journey – Assessing the Path Forward – Part One." *Electronic Healthcare* 10(1): 29–35.
- Scottish Parliament. 2014. Public Bodies (Joint Working) (Scotland) Act (asp 9). The National Archives. Retrieved June 20, 2016. <<http://www.legislation.gov.uk/asp/2014/9/contents/enacted>>.
- Rosella, L.C., T. Fitzpatrick, W.P. Wodchis, A. Calzavara, H. Manson and V. Goel. 2014. "High-Cost Health Care Users in Ontario, Canada: Demographic, Socio-Economic, and Health Status Characteristics." *BMC Health Services Research* 14: 532.
- Rozenblum, R., Y. Jang, E. Zimlichman, C. Salzberg, M. Tamblyn, D. Buckeridge et al. 2011. "A Qualitative Study of Canada's Experience with the Implementation of Electronic Health Information Technology." *CMAJ* 183(5): e281–88.
- Schaink, A.K., K. Kuluski, R.F. Lyons, M. Fortin, A.R. Jadad, R. Upshur et al. 2012. "A Scoping Review and Thematic Classification of Patient Complexity: Offering a Unifying Framework." *Journal of Comorbidity* 2(1): 1–9.
- Scottish Centre for Telehealth & Telecare. 2015. *About*. Retrieved November 23, 2015. <<http://sctt.org.uk/about>>.
- Scottish Government. 2015. *Technology Enabled Care*. Retrieved November 23, 2015. <<http://news.scotland.gov.uk/News/Technology-enabled-care-11fe.aspx>>.
- Scottish School of Primary Care. 2015. *Research Programmes*. Retrieved November 23, 2015. <www.sspc.ac.uk/current-research/programmes>.
- Seto, E., K.J. Leonard, J.A. Cafazzo, J. Barnsley, C. Masino and H.J. Ross. 2012. "Mobile Phone-Based Telemonitoring for Heart Failure Management: A Randomized Controlled Trial." *Journal of Medical Internet Research* 14(1).
- Sinnott, C., S. Mc Hugh, J. Browne and C. Bradley. 2013. "GPs' Perspectives on the Management of Patients with Multimorbidity: Systematic Review and Synthesis of Qualitative Research." *BMJ Open* 3(9): e003610.
- Steele Gray, C., D. Miller, K. Kuluski and C. Cott. 2014. "Typing eHealth Tools to Patient Needs: Exploring the Use of eHealth for Community-Dwelling Patients with Complex Chronic Disease and Disability." *JMIR Research Protocols* 3(4): e67.
- Steele Gray, C., A.I. Khan, K. Kuluski, I. McKillop, S. Sharpe, A.S. Bierman et al. 2016. "Improving Patient Experience and Healthcare Quality in Primary Care for Patients with Complex Chronic Disease: Adopting Qualitative Methods into a User-Centred Design Approach to Develop the Electronic Patient Reported Outcomes (ePRO) Tool." *Journal of Medical Informatics Research Protocols* 5(1): e28. doi: 10.2196/resprot.5204.
- Telescot. 2015. *What Is Telescot?* Retrieved November 23, 2015. <www.telescot.org/about-us.html>.
- Upshur, C. and L. Weinreb. 2008. "A Survey of Primary Care Provider Attitudes and Behaviors Regarding Treatment of Adult Depression: What Changes after a Collaborative Care Intervention?" *Primary Care Companion to The Journal of Clinical Psychiatry* 10(3): 182–86.
- van Gemert-Pijnen, J., N. Nijland, M. van Limburg, H.C. Ossebaard, S.M. Kelders, G. Eysenbach and E.R. Seydel. 2011. "A Holistic Framework to Improve the Uptake and Impact of eHealth Technologies." *Journal of Medical Internet Research* 13(4): e111.
- Webster, P.C. 2012. "The Extinction of an e-Health Strategy." *CMAJ* 184(10): E527–28.
- Winkelman, W.J. and D.W. Choo. 2003. "Provider-Sponsored Virtual Communities for Chronic Patients: Improving Health Outcomes through Organizational Patient-Centred Knowledge Management." *Health Expectations* 6(4): 352–58.
- World Health Organization. 2012. *National eHealth Strategy Toolkit Overview*. Retrieved April 21, 2016. <www.who.int/ehealth/publications/overview.pdf>.

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Applying Clinical Practice Guidelines to the Complex Patient: Insights for Practice and Policy from Stroke Rehabilitation

Michelle L.A. Nelson, Agnes Grudniewicz and Sarah Albadry

Abstract

In Canada, policy makers are working to align services with the Stroke Rehabilitation Best Practice Recommendations (SRBPR). Complicating the application of clinical practice guidelines (CPGs) is the fact that most strokes occur in the context of other diagnoses. We sought to understand clinicians' use of the CPGs and ascertain how much guidance regarding multimorbidity was available in the SRBPR. Study results indicated that using the recommendations was problematic due to a perceived lack of guidance regarding comorbidities and multimorbidity, and concerns regarding the applicability to "real-life patients." Comorbidities were mentioned in less than half of the recommendations, but no explicit guidance was provided regarding the management of comorbidities. Given the prevalence of multimorbidity in stroke rehabilitation, this clinical context is ideal for development and testing of CPGs that account for multimorbidity and other complexity factors. Results may also suggest limitations to using CPGs in the development of activity-based funding models.

Introduction

Mr. Prince is a 78-year-old man with type 2 diabetes, hypertension, renal insufficiency, osteoarthritis (with bilateral total knee replacements) and generalized anxiety. He has been admitted to an inpatient stroke rehabilitation unit following his stroke. Mr. Prince sustained substantial functional impairments from

his stroke, and the rehabilitation team must develop a treatment plan that meets his needs for functional improvement in the context of his co-occurring diseases.

There are 50,000 new stroke cases each year in Canada, with a combined direct and indirect cost of \$2 billion annually (Lindsay 2014), and considerable challenges to providing high-quality care. In over 80% of cases, a stroke occurs alongside other serious medical diagnoses (Ostwald et al. 2008), and patients like Mr. Prince are the norm rather than the exception in stroke rehabilitation. On average, patients have five comorbid conditions, such as hyperlipidemia, diabetes and hypertension (Fisher et al. 2006; Johansen et al. 2006; Karatepe et al. 2008; Liu et al. 1999). In addition to multiple chronic conditions, patients may also experience psychosocial challenges, often leading to care complexity. While multimorbidity is not a new phenomenon, there is increasing recognition of its impact. Multimorbidity increases rates of complications, leads to longer hospital stays and is negatively correlated with functional outcomes and gains in stroke patients, increasing the cost and decreasing the efficiency of stroke rehabilitation (Fischer et al. 2006; Hackett et al. 2009; Karatepe et al. 2008).

As evidence-informed care is posited to support the provision of high-quality, sustainable, patient-centred care, policy makers and administrators are turning to clinical

practice guidelines (CPGs) to support decision-making and resource allocation (Lindsay et al. 2008). In stroke rehabilitation, organizations across Canada are working to align clinical programs with the Canadian Stroke Rehabilitation Best Practice Recommendations (SRBPR) (Lindsay et al. 2014). These CPGs are built on a synthesis of over 2,400 studies, more than 1,300 of which are randomized control trials (RCTs), to support the adoption of evidence-based practice across the continuum of care (Teasell et al. 2016).

Despite the widespread development of CPGs, multimorbidity remains a recognized barrier to their application in a variety of settings and across conditions (Boyd et al. 2005; Fortin et al. 2011). The high-quality evidence on which most CPGs are founded is largely based on relatively short-term RCTs, which exclude the elderly or those with comorbid conditions (Glynn et al. 2008; Jadad et al. 2011; Kane and Butler 2012). As such, it is challenging to apply CPGs developed for the treatment of single diseases in the care of patients with multiple, often complex, chronic conditions. Evidence for clinical scenarios where patients present with multiple simultaneous problems is very limited (Fortin et al. 2011).

Boyd et al. (2005) and Fortin et al. (2012) examined CPGs for common chronic conditions for relevance to patients with multimorbidity, finding that very few CPGs provided treatment recommendations for patients with two or more conditions. To date, stroke CPGs have not been examined in this manner. We do not know to what extent they provide guidance for patients with multiple health conditions who require complex care. In this two-pronged research study, we examined how stroke rehabilitation clinicians are using evidence in everyday practice, and we appraised the degree to which stroke CPGs provide guidance for the complex patient population.

Study Approach

We undertook a two-phased study. In the first phase (Spring 2013), we conducted focus groups with stroke rehabilitation clinicians to explore how clinicians incorporate evidence into their daily practice while working with complex patients. We followed this phase with a critical appraisal of the SRBPR (Winter 2015) to determine the degree to which stroke rehabilitation CPGs provide specific clinical guidance regarding multimorbidity and other complexity factors.

Phase I: Focus groups

We invited all clinical team members working on two inpatient stroke rehabilitation units at a complex rehabilitation hospital to participate in focus groups as part of a larger study on complexity in stroke rehabilitation. Detailed methods are reported elsewhere (Nelson et al. 2016). Twenty-three occupational therapists, physical therapists, speech language pathologists, nurses and rehabilitation assistants participated

in one of four focus group sessions. Recruitment was iterative and conducted until thematic saturation was reached (no new concepts emerged). The study was approved by the Joint Bridgpoint-West Park-Toronto Central Care Access Centre Research Ethics Board.

Focus group participants were asked to reflect on their use of evidence and, more specifically, the role of the CPGs in their clinical decision-making. Audio recordings were transcribed verbatim. Transcripts were thematically coded using the constant comparative method (Grove 1988), simultaneously with data collection so that topics/issues arising in earlier focus groups could be explored in greater depth in later groups.

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Phase II: Guideline appraisal

Following the first phase of the study, we conducted a critical appraisal of the SRBPR, retrieved from the Canadian Best Practices for Stroke Care website (Lindsay et al. 2014). We drew upon work conducted by Boyd et al. (2005) and Fortin et al. (2011) to assess (1) which recommendations address/mention comorbid conditions, (2) if the recommendation was specific for the comorbidities mentioned, (3) if the recommendation provided treatment/management options pertaining to the comorbidities mentioned and (4) if the recommendation mentioned medication management for the multimorbidity. For the purpose of the study, “comorbidity” included stroke risk factors and other chronic conditions and excluded impairments resulting from the stroke.

As complexity and multimorbidity can be described with numerous terms (e.g. complex chronic conditions, multimorbidity, co-occurring conditions), we also reviewed the recommendations to assess if the guidelines provided direction regarding the modification of treatment based on “patient context.” This additional activity was conducted with the belief that CPGs may allude to accommodating comorbidities under the concept of “patient context,” “patient needs” or “patient-centredness.”

Each recommendation was individually reviewed and charted by two researchers (M.N. and S.A.). All disagreements were resolved by consensus after discussion between reviewers.

Results

Phase I: Focus groups

Focus group participants felt that the application of SRBPR to their practice was problematic for two key reasons: (1) lack of specificity in the recommendations regarding issues of complexity and (2) a perceived lack of applicability of the recommendations to “real-life patients.” We discuss these themes below.

Lack of specific clinical guidance

Participants found “the best practice guidelines fairly vague to begin with” (FG1) and felt that this perception contributed to their low rates of use. This was compounded by the participants’ perception that the recommendations provided limited clinical guidance for patients with multiple co-occurring conditions and other psychosocial issues (i.e., complex patients). Participants felt that instead of providing specific management direction, the recommendations only provided general information regarding treatment options:

“For physiotherapy best practices – they say maximize mobility! But they don’t tell us exactly HOW to do it, they just say do it. It’s so vague that any of these things can fall right into it, for example, it says identify supports, well ok but now what? Where are the best practice guidelines around the supports that are out there and which are the best?” (FG2)

Participants reported lower reliance on the recommendations; rather, most clinical team members depended on their own, and team members’, judgment and clinical decision-making experience:

“The guidelines are vague. They say: ‘this may or not be beneficial. We suggest you do it.’ But I don’t really have time to apply 30 different treatments to every patient, and then it’s up to me and my clinical judgment and my experience. So I am not looking at the best practices – rather I am relying on my own experiences for what I have found personally, clinically relevant.” (FG1)

Participants were uncertain of the applicability of the guidelines to their real-life daily practice.

Low perceived applicability of the recommendations to “real-life patients”

Participants felt that the recommendations focused on patients’ physical outcomes with less emphasis on the medical, social and environmental issues, which often complicate care and present a challenge for clinical team members to address:

“I don’t think that these things [medical, social, and environmental issues] are taken into consideration... so I think best practices seem to focus a lot on physical function and not necessarily on the environment and the broader issues enough.” (FG2)

Participants were uncertain of the applicability of the guidelines to their real-life daily practice. They felt that the guidelines were developed according to evidence from controlled trials in environments that were somewhat unrepresentative of real practice encounters:

“I want to know – I know that there are studies, but who decides what the best practices are? I mean, is it a study in a controlled environment and then it comes to real life, when you have all this [complex issues] to deal with?” (FG1)

When asked if the recommendations match the “real world,” one participant, gesturing to a list of complexity factors, stated:

“They don’t. Is all of that considered? All of the other stuff adds much more complexity and sucks up much more of our time. We have to address those things – these things are so important in getting them home. And that is a person! The real-life social issues – that is the important stuff!” (FG3)

Phase II: Critical guideline appraisal

We reviewed all 26 stroke rehabilitation best practice recommendations and corresponding sub-recommendations. Table 1 outlines the recommendations reviewed and whether each recommendation mentions comorbidities, provides explicit guidance regarding multimorbidity and alludes to a holistic approach to rehabilitation.

Comorbidities and stroke risk factors were mentioned in only 9 of the 26 recommendations. None of these recommendations provided explicit clinical guidance relevant to these comorbidities. The only exception was Recommendation 7.2 – Vascular Cognitive Impairment and Dementia, which addressed screening, assessment and management of vascular cognitive impairment in patients with vascular risk factors such as hypertension and diabetes.

When comorbidities were addressed in a recommendation, it was in a general non-specific manner, with no guidance or direction on how to manage these comorbidities in rehabilitation. There was very limited guidance on how to adjust therapies to suit patients with comorbidities. For example, a recommendation stated:

“Following medical clearance, patients should participate regularly in an aerobic exercise program that accommodates the patient’s co-morbidities and functional limitations to improve gait speed, endurance, stroke risk factor profile, mood, and cognition.”

TABLE 1.
Multimorbidity addressed by stroke rehabilitation recommendations

Recommendation	Mentions comorbidities	Provides explicit guidance for multimorbidity	Alludes to holistic approach
5.1 Initial Stroke Rehabilitation Assessment	No	No	No
Eligibility and Admission Criteria for Stroke Rehabilitation	Yes	No	No
5.2 Stroke Rehabilitation Unit Care	No	No	Yes
5.3 Delivery of Inpatient Stroke Rehabilitation	No	No	No
5.4 Outpatient and Community-Based Stroke Rehabilitation (Including ESD)	No	No	No
5.5.1 Management of the Arm and Hand Following Stroke	No	No	No
5.5.2 Range of Motion and Spasticity in the Shoulder, Arm and Hand	No	No	No
5.5.3 Management of Shoulder Pain Following Stroke	No	No	No
5.6.1 Lower Limb Mobility and Transfer Skills	No	No	No
5.6.2 Lower limb Spasticity Following Stroke	No	No	No
5.6.3 Lower Limb Gait Training Following Stroke	Yes	No	No
5.6.4 Falls Prevention Management	Yes	No	No
5.7 Assessment and Management of Dysphagia and Malnutrition Following Stroke	Yes	No	No
5.8 Rehabilitation of Visual Perceptual Deficits	No	No	No
5.9 Rehabilitation to Improve Central Pain	No	No	Yes
5.10 Rehabilitation to Improve Communication	No	No	No
5.11 Life Roles and Activities	No	No	No
6.1 Supporting Patients, Families And Informal Caregivers Following Stroke	No	No	Yes
6.2 Patient, Family and Informal Caregiver Education	Yes	No	Yes
6.3 Interprofessional Communication	No	No	Yes
6.4 Discharge Planning	No	No	Yes
6.5 Community Reintegration following Stroke	Yes	No	Yes
6.6 Transition of Patients to Long-Term Care following a Stroke	No	No	Yes
6.7 Post-Stroke Fatigue	Yes	No	Yes
7.1 Post-Stroke Depression	Yes	No	No
7.2 Vascular Cognitive Impairment and Dementia	Yes	No	No
8.1 Telestroke Recommendations	No	No	No

Three of the nine recommendations that mention comorbidities also include generic statements encouraging clinicians to adopt a holistic approach. These statements were non-specific and provided limited clinical guidance. An additional six recommendations included generic statements encouraging a holistic approach without mention of comorbidities. One of the recommendations is as follows:

“The care plan should be patient-centered, incorporate the agreed-upon goals and preferences of the patient, family, and healthcare team based on shared decision-making, and be culturally appropriate.”

Seventeen of the recommendations contained no mention of any comorbid conditions. These recommendations were primarily focused on the organizational aspect of patient care and the stroke rehabilitation unit.

Discussion

Stroke rehabilitation clinicians in this study perceived that the best practice recommendations lacked specificity regarding management of comorbidities and psychosocial issues, and were perhaps not applicable to “real-life patients.” Results from our critical appraisal of the recommendations found that only 9 of 26 rehabilitation recommendations mentioned comorbidities or stroke risk factors, none of which provided detailed guidance on how to manage care for these comorbid patients. These results are similar to the work conducted by others (Boyd and Fortin 2010; Fortin et al. 2012; Guthrie et al. 2012; Hughes et al. 2012), who report limited clinical guidance provided for patients with multimorbidity in CPGs in other clinical settings. We built upon this literature by appraising stroke rehabilitation CPGs, a clinical area where the majority of patients experience co-occurring conditions, and we added important insights into the challenges faced by providers in day-to-day practice.

CPGs are widely recognized as “knowledge tools” that support high-quality healthcare services (Davies et al. 2007) by assisting clinicians and patients with healthcare decisions. CPGs can also be used to promote efficient use of resources, reduce inappropriate variation in practice, steer quality-improvement efforts, highlight shortcomings of existing literature and suggest future research. In stroke rehabilitation, services are continually being organized to align with the Canadian SRBPR. In our study, stroke rehabilitation clinicians were concerned that these recommendations, based upon over 1,300 RCTs, do not match the patients seen in daily practice. If RCTs commonly exclude older adults and individuals with comorbidities (Boyd and Fortin 2010; Fortin et al. 2011; Guthrie et al. 2012; Jadad et al. 2011), what type of patient population is this evidence built upon? And can this evidence be generalized to guide the care of our patient, Mr. Prince, the “real life” stroke patient? A deeper understanding of the evidence base for stroke rehabilitation interventions is needed to determine what evidence is relevant to which patients with comorbidities.

Clinicians’ limited reliance on CPGs when working with patients with multimorbidity is supported in the literature (Caughey et al. 2011) and raises an important question in terms of CPGs’ impact on reducing practice variation. If the point of CPGs is to reduce inappropriate practice variation, does the lack of specific clinical guidance for multimorbidity and other complexity factors foster inappropriate variation and perhaps decrease the quality of care? If viewed from the stance that CPGs are meant to assist in the provision of consistent care within a specified clinical situation, but not necessarily expected to define a standard of care (College of Physicians and Surgeons of Ontario 2012), practice variation would not be seen as a deficiency of practice. Perhaps with the high variability of comorbid conditions and psychosocial issues seen in the patient population, working towards uniform treatment is an unreasonable expectation. As noted by Manski

(2011: 3), “different clinicians may reasonably interpret the available evidence in different ways and may reasonably use different decision criteria to choose treatments. Thus, there is no *prima facie* reason to view treatment variation as unwarranted, inappropriate, or unacceptable.” However, clinicians in this study seemed uncomfortable relying solely on their clinical judgement in the absence of specific guidance. There is an opportunity within the stroke rehabilitation recommendations to provide principles for the application of the guidelines to patients with multimorbidity and complexity more broadly.

Stroke rehabilitation, like many other clinical settings, would benefit from the alignment of treatment recommendations for common chronic conditions. For this to happen, we need to expand beyond the disease-specific approach of CPGs and collaborate across boundaries to develop recommendations that are relevant to patients with multimorbidity. As noted by Guthrie et al. (2012), although it is not possible to have good-quality evidence for every combination of chronic conditions, it would be helpful to bring together relevant recommendations for different chronic conditions, highlighting synergies, cautions and contraindications. Stroke rehabilitation is one clinical area that could lead this type of activity, as stroke patients generally present with some common comorbidities – hyperlipidemia, diabetes and hypertension (Gallacher et al. 2013). This paper also suggests that mental health and social determinants of health (factors that affect many complex patient populations, not just stroke patients) need to be seen as these “other” factors that have a strong impact on treatment adherence. Given that the Canadian SRBPR are continuously updated, there is an ongoing opportunity for CPG conveners to collaborate, develop and test mechanisms that would improve and align CPGs for patients with commonly co-occurring conditions.

The study results also raise important questions regarding the use of CPGs in the development of funding models. The implementation of quality-based funding is intended, in part, to motivate healthcare providers to adopt best practices and set quality standards. However, if CPGs fail to account for the clinical reality of multimorbidity, using them to develop fundable care pathways may be met with limited success. As the majority of stroke rehabilitation patients have multiple chronic conditions, funding mechanisms that seek to implement evidence-informed practice for these patients must explicitly account for multimorbidity, social determinants and mental health.

There is a mismatch between the intention of CPGs and the capacity of care providers to meet the needs of a growing and increasingly complex patient population. This research highlights an opportunity to harness the insights of clinicians to inform the development of CPGs that better align with the day-to-day realities of providing care. This knowledge can then be used in shaping healthcare governance structures and funding models to support quality of care and improved health outcomes.

Conclusion

Our study suggests that stroke rehabilitation clinicians may find themselves having to rely extensively on their clinical judgement and experience when making treatment decisions for complex patients. The critical appraisal confirmed that the Canadian SRBPR do not sufficiently reflect the realities of patients in rehabilitation settings. For clinicians creating treatment plans for patients like Mr. Prince, the CPGs provide very limited guidance specific to the management of multimorbidity. These results are not surprising – many studies across disease and clinical contexts have made similar conclusions. Given the prevalence of comorbidity and complexity in stroke rehabilitation, we feel this clinical context is ideal for development and testing of CPGs that account for multimorbidity and other complexity factors. By extension, developing strategies to transcend disease-specific care approaches could support the pursuit of broader system-level solutions to care for patients with multimorbidity. **HQ**

References

- Boyd, C.M. and M. Fortin. 2010. "Future of Multimorbidity Research: How Should Understanding of Multimorbidity Inform Health System Design." *Public Health Reviews* 32(2): 451–74.
- Boyd, C.M., J. Darer, C. Boulton, L.P. Fried, L. Boulton and A.W. Wu. 2005. "Clinical Practice Guidelines and Quality of Care for Older Patients with Multiple Comorbid Diseases: Implications for Pay for Performance." *JAMA* 294(6): 716–24.
- Caughey, G.E. and E.E. Roughead. 2011. "Multimorbidity Research Challenges: Where to Go from Here?" *Journal of Comorbidity* 1(1): 8–10.
- Davies, D.A., J.B. Goldman and V.A. Palda. 2007. *Canadian Medical Association Handbook on Clinical Practice Guidelines*. Canadian Medical Association. Retrieved June 20, 2016. <<https://www.cma.ca/Assets/assets-library/document/en/clinical-resources/CPG%20handbook-e.pdf>>
- Fischer, U., M. Arnold, K. Nedeltchev, R.A. Schoenenberger, L. Kappeler, P. Höllinger et al. 2006. "Impact of Comorbidity on Ischemic Stroke Outcome." *Acta neurologica scandinavica* 113(2): 108–13.
- Fortin, M., E. Contant, C. Savard, C. Hudon, M.E. Poiras and J. Almirall. 2011. "Canadian Guidelines for Clinical Practice: An Analysis of Their Quality and Relevance to the Care of Adults with Comorbidity." *BMC Family Practice* 12(1): 74.
- Gallacher, K.I., G.D. Batty, G. McLean, S.W. Mercer, B. Guthrie, C.R. May et al. 2014. "Stroke, Multimorbidity and Polypharmacy in a Nationally Representative Sample of 1,424,378 Patients in Scotland: Implications for Treatment Burden." *BMC medicine* 12(1): 151.
- Glynn, L.G., B. Buckley, D. Reddan, J. Newell, J. Hinde, S.F. Dinneen et al. 2008. "Multimorbidity and Risk among Patients with Established Cardiovascular Disease: A Cohort Study." *British Journal of General Practice* 58(552): 488–94.
- Grove, R.W. 1988. "An Analysis of the Constant Comparative Method." *International Journal of Qualitative Studies in Education* 1(3): 273–79.
- Guthrie, B., K. Payne, P. Alderson, M.E. McMurdo and S.W. Mercer. 2012. "Adapting Clinical Guidelines to Take Account of Multimorbidity." *BMJ* 345. <<http://dx.doi.org/10.1136/bmj.e6341>>
- Hackett, M.L., N. Glozier, S. Jan and R. Lindley. 2009. "Psychosocial Outcomes in Stroke: the POISE Observational Stroke Study Protocol." *BMC Neurology* 9(1): 24.
- Hughes, L.D., M.E. McMurdo and B. Guthrie. 2013. "Guidelines for People Not for Diseases: The Challenges of Applying UK Clinical Guidelines to People with Multimorbidity." *Age and Ageing* 42(1): 62–69.
- Jadad, A.R., M.J. To, M. Emara and J. Jones. 2011. "Consideration of Multiple Chronic Diseases in Randomized Controlled Trials." *JAMA* 306(24): 2670–72.
- Kane, R.L. and M. Butler. 2012. "Are We Ready for Multimorbidity?" *Aging Health* 8(6): 635–36.
- Karatepe, A.G., R. Gunaydin, T. Kaya and G. Turkmen. 2008. "Comorbidity in Patients after Stroke: Impact on Functional Outcome." *Journal of Rehabilitation Medicine* 40(10): 831–35.
- Lindsay, M.P., G. Gubitz, M. Bayley, M.D. Hill, S. Phillips and E.E. Smith. 2014. *Canadian Stroke Best Practice Recommendations Overview and Methodology*. On behalf of the Canadian Stroke Best Practices Advisory Committee and Writing Groups. Ottawa, ON: Heart and Stroke Foundation, Canada.
- Lindsay, P., M. Bayley, A. McDonald, I.D. Graham, G. Warner and S. Phillips. 2008. "Toward a More Effective Approach to Stroke: Canadian Best Practice Recommendations for Stroke Care." *Canadian Medical Association Journal* 178(11): 1418–25.
- Liu, M., T. Tsuji, K. Tsujiuchi and N. Chino. 1999. "Comorbidities in Stroke Patients as Assessed with a Newly Developed Comorbidity Scale." *American Journal of Physical Medicine and Rehabilitation* 78(5): 416–24.
- Manski, C.F. 2013. "Useful Variation in Clinical Practice under Uncertainty: Diversification and Learning." Retrieved January 20, 2016. <http://faculty.wcas.northwestern.edu/~cfm754/variation_in_clinical_practice.pdf>
- Nelson, M., E. Hanna, S. Hall and M. Calvert. (2016). "What Makes Stroke Rehabilitation Patients Complex? Clinicians Perspectives and the Role of Discharge Pressure." *Journal of Comorbidity* 6(2): 35–41.
- Ostwald, S.K., J. Wasserman and S. Davis. 2006. "Medications, Comorbidities, and Medical Complications in Stroke Survivors: The CARES Study." *Rehabilitation Nursing* 31(1): 10–14.
- Teasell, R.W., M.P. McRae and H.M. Finestone. 2000. "Social Issues in the Rehabilitation of Younger Stroke Patients." *Archives of Physical Medicine and Rehabilitation* 81(2): 205–09.

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Performance Measurement for People with Multimorbidity and Complex Health Needs

Walter P. Wodchis

Abstract

This paper reviews approaches to performance measurement in health systems with particular attention to people with multimorbidity and complex health needs. Performance measurement should be informative and used by multiple stakeholders in order to align performance improvement efforts. System performance measures must allow for macro-system and meso-organization and provider-level reporting, and they should be relevant and important to stakeholders at each level, as well as to patients and all potential care recipients. Measures that assess health outcomes and individuals' experiences with providers, including care planning and coordination of care across providers, are essential to assess value for people with multimorbidity and complex health needs. I suggest that performance measurement for this population should be motivated by the Complexity Framework and organized by the Triple Aim. Based on the care needs and appropriate goals for the health system for this population, applicable measures and suggestions for implementing and using performance measurement systems are identified. Particularly in the case of people with multimorbidity and complex health needs, performance measures must move beyond measures specific to individual encounters to track care for people over time and space. Measures must be rooted in individuals' own needs and goals for care. New systems are required to enable collection and reporting of these measures.

Introduction

Measuring and reporting on the performance of the health system allows patients, carers, providers and health system decision-makers to identify whether the health system is doing what it should and if patient and population health outcomes are optimized. In conjunction with goals or benchmarks, performance measurement also allows stakeholders to be aware of performance gaps and opportunities for improvement. Performance measures that closely reflect the goals established for the health system are necessary to assess progress.

Health system performance measures should serve to measure the value of health produced from the delivery of health and social services. Performance measurement should be informative and used by multiple stakeholders in order to align performance improvement efforts. The assessment of provider effectiveness and quality, constituent resources and associated costs, as well as individuals' experiences and outcomes are all important goals of health system performance.

System performance measures must allow for macro-system and meso-organization and provider-level reporting, and they should be relevant and important to stakeholders at each level, as well as to patients and all potential care recipients. General population health measures of life expectancy, health-related quality of life and well-being that are relevant to the entire population should be included, alongside specific measures for particular populations such as the effective coordination of care among multiple providers for people with complex health needs. Performance measures

should reflect the goals of providers and patients, and resolve differences when these are not aligned (Kuluski et al. 2013).

This monograph begins with an overview of the dominant approaches to performance measurement in health systems across industrialized nations with particular relevance to Canada. Because the focus here is performance measurement for people with multimorbidity and complex health needs, a brief review of the care needs and appropriate goals for the health system for this population is necessary. I then turn to applicable measures and end with some suggestions for implementing and using performance measurement systems. Particularly in the case of people with multimorbidity and complex health needs, performance measures must move beyond measures specific to individual encounters to track care for people over time and space.

Current State of Performance Measurement

Performance measurement in healthcare has developed into a major activity for payers, regulators and providers. For decades, international comparisons of health system performance have reported health outcomes such as infant mortality, overall life expectancy and, more recently, disability-adjusted life expectancy or equivalent measures. The Organization for Economic Co-operation and Development, the World Health Organization and the Institute of Medicine, have developed comprehensive approaches to performance measurement that examine dimensions such as the accessibility, safety and effectiveness of healthcare services in addition to health outcomes.

Within health systems, a performance framework often determines the focus and selection of performance measures for reporting. Common frameworks applied to health service providers within health systems include Kaplan and Norton's balanced scorecard (BSC) (Kaplan and Norton 1992) and Donabedian's structure, process and outcome (SPO) frameworks (Donabedian 1966). While the BSC approach can be used in comparative analyses to identify areas for improvement, it fails to explicitly clarify the contributory relationships between dimensions of performance and overall health outcomes. The SPO approach, on the other hand, can be most clearly specified when applied to a specific production process for a defined care pathway but may be more difficult to use at a broad system level when many resources are simultaneously engaged in a wide variety of activities.

The more recent Triple Aim framework promoted by the Institute for Healthcare Improvement (Berwick et al. 2008) focuses on health experience and outcomes while considering costs (representing resources). Unlike other health system performance approaches, the Triple Aim does not explicitly specify attributes such as accessibility or safety. In comparison with the BSC and SPO frameworks, the Triple Aim also does not explicitly designate structural or organization-level measures. Rather than focusing on these activities, it suggests measuring the contribution of provider activities towards achievement of cost, experience and

health outcomes. It does however provide a more explicit assessment of value. Central to the Triple Aim is the identification of a defined population and emphasis on patient experience inclusive of patient engagement, continuity, safety and evidence-based clinical practices (Berwick et al. 2008).

Increasingly, health systems are adopting the Triple Aim framework and implementing more robust measurement of patient experience. Ensuring that the patient's perspective is included within a performance measurement system is the only way to evaluate progress towards providing truly patient-centred care (Cuthbertson 2015). Both patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) provide a mechanism to include patients' perspectives. However, the variability in patient care needs provides a challenge for the use and selection of standard measures (Miller et al. 2015). Most examples of PREMs and PROMs are based on specific encounters or episodes of care. However, outcomes and experience among individuals with multiple complex health needs are dependent upon the contributions from many different providers over extended periods. Generic health status measures are possible PROMs for individuals with complex health needs. Patient experience measurement must enable patients who receive care from multiple providers to report on their experience from many of these providers (Cuthbertson 2015). Experience across encounters can be tied together to assess the degree of coordination and integration across providers. In Ontario, The Change Foundation's Partners Advancing Transitions in Healthcare (PATH) project provided an opportunity for patients to report regularly on their experiences with various encounters and provide summative experiences of the degree of coordination across care providers (The Change Foundation 2016). But patients were not themselves directly consulted in determining what measures they would report on. If the aim of the measurement is to provide a patient-centred outcome, then patients themselves should be involved in the development of the measurement instruments (Trujols et al. 2013). Steele Gray and colleagues found that engaging with patients in designing measurement lead to a vastly different approach to measurement, focusing on individual goals and goal attainment (Steele Gray et al. 2016a).

What Characterizes Good Care for People with Complex Health Needs?

Accepting that health system performance measurement is important and that measures need to engage and be meaningful to people and providers, I turn now to consider what needs to be measured. To evaluate the Triple Aims of health, experience and cost for people with complex health needs, we will need a broad perspective. The health for this population is determined by a multiplicity of conditions and interventions. Many different providers are involved over time, and both medical and social care programs may be instrumental in achieving

health. An assessment of performance must be reflective of whether needs are being met and whether aims and goals are being achieved.

The Complexity Framework developed by Schaink and colleagues (2012) recognizes medical and physical health, mental health, demographics, health and social experiences and social capital as contributing factors to health among individuals with complex health needs. There are other factors, but these capture the essence that it is multifaceted. The complexity framework highlights that while some needs are clearly medical, there are many areas of need that are entirely outside of how most industrialized nations have implemented medical care. Within an individual with multimorbidity and complex health needs, these are not independent or isolated factors. There is clear interplay and interdependency among them. A heart failure patient without a scale will find it difficult to self-manage fluid retention and weight. A diabetic without enough money for healthy food will find it difficult to manage their diet. An adult with strong social capital, high education and adequate economic resources is likely to manage far better than a disenfranchised and isolated individual in the face of similar medical conditions. These are individual needs and they speak to the variability in individual complexity. Consequently, this conceptualization also highlights the challenge of having performance measures that are relevant to individuals with different care needs and are applicable across individuals with a wide variety of health and social circumstances. A system of measurement must be specific to individuals but still allow for a common approach to evaluating outcomes and aggregating these outcomes to provider and system levels.

Health outcomes for people with complex health needs must reflect overall quality of life resulting from having multiple needs met. Individual’s experience must capture dimensions of importance to people and providers. Focus groups with people with complex chronic disease and disability and their caregivers revealed specific needs including strong communication and dialogue between themselves and their providers, rapid access to appointments, transportation and cost (Steele Gray et al. 2014). Individuals must be respectfully engaged in planning and feel confident about managing their health as a result. Care must be delivered by a coordinated interdisciplinary team effort inclusive of all health and social services. In this regard, providers’ aims and contributions must also be considered. Good clinical care and an absence of conflicting treatments, such as from polypharmacy, are relevant and under the control of health providers. The economic goal is to ensure that resources are efficiently deployed to maximize health and experience. Resources include public spending for healthcare and social care and individuals’ own costs for obtaining health-producing services. Performance measurement for people with complex health needs must capture the summative experience and health outcomes across services that are needed to support this population.

Performance Measures for People with Multimorbidity and Complex Health Needs

The health system should improve patient and population health. It should address the needs of the population. It must also consider differential needs and goals among subgroups of the population. The majority of the population uses very few services, and their needs can be met with availability of primary care. In contrast, individuals with multimorbidity and complex health needs are met with a multiplicity of services and interventions. Because integrated care programs are the most appropriate organizational approach, recommended measures for such programs are a useful basis for departure (e.g., Palmer et al. 2006). The US National Quality Forum has gathered extensive information on management and measurement for people with multiple chronic conditions. It recommends the use of outcome measures when available and process measures that are most closely linked to outcomes otherwise (National Quality Forum 2012).

Organizing recommended measures along the Triple Aim framework enables measurement to be goal-oriented. Measures of health, experience and cost aims are needed. Measurement should encompass objective and subjective approaches within each aim. The core set of measures should apply to all of the population. In this regard, disease- or condition-specific measures that may be important for some (e.g., diabetes care measures) may not be suitable for people with complex health needs unless a vast majority of the population has the same clinical needs and desired outcomes for such measures. Table 1 suggests some sample measures of performance applicable to people with multimorbidity and complex health needs. It includes objective measures for health (e.g., potential years of life lost), experience (e.g., wait times for services) and cost. It also suggests subjective measures, including PROMs and PREMs and patient-reported costs.

TABLE 1.
Example performance measures for people with multimorbidity and complex health needs

Aim	Objective measures	Subjective measures
Health	<ul style="list-style-type: none"> Potential years of life lost Life expectancy 	<ul style="list-style-type: none"> Self-reported health EQ-5D, PROMIS or VR-12
	Disability-adjusted life years can incorporate both subjective health and objective measures of life expectancy	
Experience	<ul style="list-style-type: none"> Wait time for consultation or other service 	<ul style="list-style-type: none"> Continuity of care Involvement in care Coordination of care Self-activation Unmet needs (access) Caregiver experience
Cost	<ul style="list-style-type: none"> Health system cost Social service costs 	<ul style="list-style-type: none"> Individual and carer opportunity cost, including financial and non-financial

EQ-5D = EuroQOL group Health-Related Quality of Life measure; PROMIS = Patient-Reported Outcomes Measurement Information System; VR-12 = Veterans RAND 12-item survey.

In addition to life expectancy or potential years of life lost measures, disability-adjusted life years can be measured by combining life-expectancy with a preference- or utility-based measure that assesses health attainment. The EuroQOL-5 Dimension (EQ-5D) Survey is a utility-based measure widely used in Europe that captures health status while the Veterans RAND 12 Item Health Survey (VR-12) captures individual's capability in usual activities and roles; either would be appropriate for measuring individual and population health status.

The focus on people with complex health needs is relatively recent, and health systems have generally not fully addressed the needs of this population.

The National Institute of Medicine's PROMIS measures can also be suitable, though not all have preference-based measurement scales. From a subjective perspective, the simple question of health status on a scale from poor to excellent should not be overlooked. Measures that assess experiences with individual providers, including care planning and coordination of care across providers, are essential to assess value for people with complex health needs. Using composite measures that reflect care over time and across multiple providers can enable shared accountability among providers while still allowing constituent factors to be reported. Measuring cost to the payer and also to the individual patient and their caregivers is required to assess value in relation to the economic cost. Additional measurement of caregiver experiences is important to understand the contributory relationships between these factors and performance. This approach to measurement aligns with the Triple Aim goals of population health, patient experience and cost and can provide a strong foundation for health system performance measurement.

Table 1 is not intended to represent a complete set of measures. In addition to standardized PROMs, novel patient-defined outcomes are an important basis for measurement. Defining goals at the individual level through a discussion between individuals and their health providers and measuring achievement of goals using Goal Attainment Scaling techniques allow for an individualized and comparable approach to performance measurement (Steele Gray et al. 2016b). Measuring the extent of provider coordination of care that patients experience is important, but the provider perspective on this measure may also be important. Some have argued that provider-level measurement is an important gap in the Triple Aim framework (Bodenheimer and Sinsky 2014). Providers themselves can provide an important assessment of team functioning through a measure such as the Team Climate Inventory (Anderson and West 1998). Provider experience and engagement in their organizations may also be an important measure of the care that individuals experience as patients.

The Way Forward

Participants need to be involved in assessing the value created by the health system. This is particularly important for people with multimorbidity and complex health needs. We already have well-established measurement systems for population health outcomes. However, these data need to be harvested and reported at the individual, provider and local system levels. We lack rigorous implementation of patient experience measures, particularly for individuals with complex health needs who have many encounters with many providers to meet their care needs. We need to innovate performance measurement to be more person-centred.

The focus on people with complex health needs is relatively recent, and health systems have generally not fully addressed the needs of this population. Some more mature programs, such as the Program of All-Inclusive Care for the Elderly (PACE) in the United States, might offer some insight. PACE is one of the largest programs, and evaluations have assessed its value. PACE programs are required to track enrolments, annual assessments of physical and mental health, mortality, a few clinical indicators (falls, pressure ulcers) and a sample of participants' report on satisfaction and health-related quality of life using the VR-12 as well as self-reported activities of daily living (CMS 2011). However, the use of these measures in performance reporting to participants and providers is unknown. There are also many gaps relative to recommended measures for integrated care programs (Palmer et al. 2006).

Most promising programs are still in pilot, developmental or research stages. The PATH project in Ontario provided useful weekly feedback to providers regarding patient's experiences but participants did not engage fully in reporting (The Change Foundation 2016). The TAPESTRY program, also in Ontario, includes a patient-oriented approach to setting goals and sharing information. But the use of information collected for performance measurement purposes is not an apparent fixture of the program (<http://www.healthtapestry.ca/> accessed May 16, 2016). An upcoming trial of patient-centred goal-setting, goal-attainment measurement and health outcomes is similarly still experimental (Steele Gray 2016b).

While quality improvement and performance measurement are not the same in purpose and measurement and reporting needs differ, there is considerable overlap, and implementing a measurement system as part of care delivery can support measurement for both activities. Such alignment is necessary to be relevant to providers and the people that they care for. Although such systems are not currently widespread, they should be built-in to newly emerging patient-accessed health records systems. Payers are in a position to support the implementation and meaningful use of such systems, similar to the implementation of the Health Information Technology for Economic and Clinical Health (HITECH) Act in the US (Blumenthal and Tavenner 2010). Implementation should enable

patients, providers, payers and regulators to have access to performance results in order to guide system management and researchers to develop new knowledge and guide system improvement.

Measuring the value created by health services requires measurement of individual and population health outcomes, individual experience of care and the economic costs associated with health outcomes. For individuals with multimorbidity and complex health needs, assessing value requires innovations in measurement and reporting. Arguably, the patient experience should serve as the foundation for health system performance measurement, but, unequivocally, patient-determined outcomes are the most relevant outcomes for people with multimorbidity and complex health needs. Measurement that engages providers to optimize outcomes for people whose care they support will result in better value from the health system. **HQ**

References

Anderson, N.R. and M.A. West. 1998. "Measuring Climate for Work Group Innovation: Development and Validation of the Team Climate Inventory." *Journal of Organizational Behavior* 19: 235–58.

Berwick, D.M., T.W. Nolan and J. Whittington. 2008. "The Triple Aim: Care, Health, and Cost." *Health Affairs (Millwood)* 27(3): 759–69. doi:10.1377/hlthaff.27.3.759.

Blumenthal, D. and M. Tavenner. 2010. "The "Meaningful Use" Regulation for Electronic Health Records." *New England Journal of Medicine* 363: 501–04.

Bodenheimer, T. and C. Sinsky. 2014. "From Triple to Quadruple Aim: Care of the Patient Requires Care of the Provider." *Annals of Family Medicine* 12(6): 573–76.

CMS – Centres for Medicare and Medicaid Services. 2011. "Programs of All-Inclusive Care for the Elderly (PACE) Manual. Chapter 10: Quality Assessment and Performance Improvement." CMS Manual 100-11. Rev 2. Retrieved February 10, 2016. <https://www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/Internet-Only-Manuals-IOMs-Items/CMS019036.html>.

Cuthbertson, L. 2015. "Patient-Centred Measurement in British Columbia: Statistics without the Tears Wiped Off." *Healthcare Papers* 14(4): 46–54.

Donabedian, A. 1966. "Evaluating the Quality of Medical Care." *Millbank Memorial Fund Quarterly* 44(3): 691–729.

Kaplan, R. and D. Norton. 1992. "The Balanced Scorecard: Measures That Drive Performance." *Harvard Business Review* 70(1): 71–79.

Kuluski, K., A. Gill, G. Naganathan, R. Upshur, R.L. Jaakkimainen and W.P. Wodchis. 2013. "A Qualitative Descriptive Study on the Alignment of Care Goals Between Older Persons with Multimorbidities, their Family Physicians and Informal Caregivers." *BMC Family Practice* 14: 133. doi:10.1186/1471-2296-14-133.

Miller, D., C. Steele Gray, K. Kuluski and C. Cott. 2015. "Patient-Centered Care and Patient-Reported Measures: Let's Look Before We Leap." *Patient - Patient-Centered Outcomes Research* 8: 293–99.

National Quality Forum. 2012. "MCC Measurement Framework." Retrieved April 10, 2016. <http://www.qualityforum.org/Projects/Multiple_Chronic_Conditions_Measurement_Framework.aspx>.

Schaink, A.K., K. Kuluski, R.F. Lyons, M. Fortin, A.R. Jadad, R. Upshur et al. 2012. "A Scoping Review and Thematic Classification of Patient Complexity: Offering a Unifying Framework." *Journal of Comorbidity* 2(1): 1–9.

Palmer, L., K.L. Lanos, C. Tobias and M. Bella. 2006. *Integrated Care Program: Performance Measures Recommendations*. Center for Health Care Strategies. Retrieved June 27, 2016. <http://www.chcs.org/resource/integrated-care-program-performance-measures-recommendations/>.

Steele Gray, C., D. Miller, K. Kuluski and C. Cott. 2014. "Tying eHealth Tools to Patient Needs: Exploring the Use of eHealth for Community-Dwelling Patients with Complex Chronic Disease and Disability." *JMIR Research Protocols* 3(4): e67.

Steele Gray, C, A.I. Khan, K. Kuluski, I. McKillop, S. Sharpe, A.S. Bierman et al. 2016a. "Improving Patient Experience and Primary Care Quality for Patients with Complex Chronic Disease Using the Electronic Patient-Reported Outcomes Tool: Adopting Qualitative Methods into a User-Centered Design Approach." *JMIR Research Protocols* 5(1): e28.

Steele Gray, C., W.P. Wodchis, R. Upshur, C. Cott, B. McKinstry, B. Mercer, et al. 2016b. "Supporting Goal-Oriented Primary Health Care for Seniors with Complex Care Needs Using Mobile Technology: Evaluation and Implementation of the Health System Performance Research Network, Bridgepoint Electronic Patient Reported Outcome Tool." *JMIR Research Protocols* 5(2):e126.

The Change Foundation. 2016. "Charting a New Path: Part 2 – Creating Meaningful Partnerships in Care: Lessons from West Northumberland." Retrieved April 10, 2016. <http://www.changefoundation.ca/site/wp-content/uploads/PATH-report_pt2-final.pdf>.

Trujols, J., M.J. Portella, I. Iraurgi, M.J. Campins, N. Siñol and J.P.D.L. Cobos. 2013. "Patient-Reported Outcome Measures: Are They Patient-Generated, Patient-Centred or Patient-Valued?" *Journal of Mental Health* 22(6): 555–62.

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Realizing the Potential of Rehabilitative Care for People with Complex Health Conditions: The Time Is Now

Charissa Levy, Sue Balogh and Emmi Perkins

Abstract

In today's demographic landscape, with its aging population and increasing number of individuals who are living with multiple chronic conditions and comorbidities, the healthcare system is tasked with responding to the needs of medically complex individuals. However, the pressures arising from this emerging demographic are felt not only within the acute care sector at the point of medical crisis but along the entire continuum of the healthcare system. Rehabilitative care plays a key role in that continuum by providing the process through which individuals are engaged in interventions to address their functional (both cognitive and physical) and psychosocial care goals to help them carry on with the business of living.

“Once you set aside the acute phases or crises that mark injury or disease, much of modern health care is indeed rehabilitation in one form or another.” Naylor (2009).

This paper outlines the role of rehabilitative care in supporting the oftentimes complex needs of those with multimorbidities. It describes how the themes of rehabilitative care are reflected within recently published system-level reports and how rehabilitative care can be used to support health system directions. This paper also includes a particular focus on the work of the newly established provincial Rehabilitative Care Alliance to promote rehabilitative care across

Ontario in alignment with Ministry of Health and Long-Term Care priorities, including care for those with complex health conditions.

Rehabilitation within the Ontario Health System

Getting back to living one's life, once the medical crisis is addressed, falls very much within the purview of rehabilitation. Rehabilitation is “instrumental in enabling people with limitations in functioning to remain in or return to their home or community, live independently, and to participate in education, the labour market and civic life” (World Health Organization [WHO] 2016a, 2016b). Rehabilitation provides people with disabilities the structures and supports needed to attain independence and self-determination (WHO 2016a, 2016b).

Despite recognition of its important role, rehabilitation is not a comprehensive part of Canada's national health insurance plan. In Ontario, publicly funded rehabilitative care services are provided in varying degrees. Within hospitals, patients may receive rehabilitation as part of their acute care admission (including within an intensive care unit) if they are admitted to a designated rehabilitation bed or if they are admitted to a Complex Continuing Care (CCC) bed. In Ontario, rehabilitation or CCC beds may be located within an acute care hospital or may be within a free-standing rehab/CCC hospital where no acute care services are provided. In 2015, the Ministry of Health and Long-Term Care (MOHLTC) described complex

continuing care as a program that “provides continuing, medically complex and specialized services to both young and old, sometimes over extended periods of time. CCC is provided in hospitals for people who have long-term illnesses or disabilities typically requiring skilled, technology-based care not available at home or in long-term care facilities.”

Rehabilitative care is also provided in varying degrees to residents of long-term care homes through in-home care or to those seen in hospital-based outpatient/ambulatory rehabilitation programs or community-based physiotherapy programs. Outpatient/ambulatory rehabilitative care is not a universally insured service under the Canada Health Act (Government of Canada 1984), and, in the past few years, there has been an erosion of the number and scope of hospital-based outpatient/ambulatory rehabilitation programs in an effort to achieve cost containment (GTA Rehab Network 2011; Landry et al. 2009; Ontario Physiotherapy Association et al. 2011).

The Case for Rehabilitative Care

In a recent editorial in the journal *Clinical Rehabilitation*, the editor proposes: “Rehabilitation should be central to all healthcare at all times” (Wade 2015: 1041) and presents a comprehensive summary of evidence within the literature, illustrating “that rehabilitation is beneficial, both for the patient and for society” (Wade 2015: 1043). Similarly, a WHO report (2011: 96) provides a summary of evidence, including various Cochrane reviews, that illustrates the benefits of rehabilitation. “Rehabilitation – provided along a continuum of care ranging from hospital care to rehabilitation in the community can improve health outcomes, reduce costs by shortening hospital stays, reduce disability and improve quality of life. Rehabilitation that begins early produces better functional outcomes for almost all health conditions associated with disability.”

A focus on rehabilitative care in supporting individuals with multimorbidity is “softly” being acknowledged within the literature.

Multimorbidity and the Role of Rehabilitative Care

Within Ontario, the prevalence of multimorbidity is high with one in four Ontarians having at least two conditions, and for those aged 75 and older, the prevalence of multimorbidity increases to three in four Ontarians (Koné et al. 2013). Further, the link between multimorbidity and economic burden on Ontario’s healthcare system is significant such that healthcare costs per capita rise exponentially with increased number of health conditions, especially when the number of conditions increases from four to five or more conditions (Thavorn et al. 2013). The need to address the high utilization of healthcare resources and improve the quality and outcomes of care for people with medically complex conditions has been recognized

internationally (Mery et al. 2013) and also within Ontario with recent provincial initiatives such as Health Links and models of bundled funding to enhance the coordination of care for people with complex needs. These initiatives include a focus on patient-reported outcomes.

A focus on rehabilitative care in supporting individuals with multimorbidity is “softly” being acknowledged within the literature. However, most evidence in rehabilitative care is based on single conditions and specific functional elements. It is not necessarily applicable to individuals with multiple health issues requiring personalized care plans designed with an interdisciplinary team. In an effort to help inform health system changes to improve care for patients with chronic conditions, Boulton et al. (2009: 2331) conducted a literature review and summarized high-quality studies with a variety of designs. The authors identified 15 models of comprehensive healthcare that have shown the potential to improve the quality, efficiency or health-related outcomes of care for older persons with chronic conditions. One of these was “proactive rehabilitation.” Boulton et al. (2009: 2332) indicate that studies on “proactive rehabilitation” have demonstrated beneficial effects on physical function, with reductions in hospital, emergency department or home care use also being reported, albeit less frequently. The authors also indicate: “in a quasi-experimental study, subjects receiving restorative care had a significantly greater likelihood of remaining at home.” Yet, despite this review, there is still much to learn in terms of effective rehabilitative care practice for people with multiple health issues.

In a 2011 study, Fried et al. sought to elicit the health outcome priorities of older persons. In consideration of four universal outcomes, including staying alive, pain relief, maintaining independence and symptom relief, the health outcome that was ranked as most important by the largest proportion of participants (76%) was maintaining independence. While the terminology in this study does not explicitly reflect rehabilitative care, interventions provided by rehabilitative care providers have a direct role in helping people enhance and/or maintain independence and optimize societal roles within the context of their environment. Unfortunately, the lack of a clear and fully formed policy framework and integrated funding mechanisms for rehabilitative care services currently limit the extent to which the role of rehabilitative care can support these outcomes within community ambulatory-based settings.

A Focus on Rehabilitative Care Supports Health System Priorities

The 2011 Walker Report, commissioned to provide recommendations to the MOHLTC regarding Alternate Level of Care (ALC) in Ontario, outlined the importance of understanding ALC pressures because this issue is very much related to complex care for all ages. “Alternate Level of Care

is the designation given by a physician to a patient who is occupying a bed in a hospital while not requiring the intensity of resources or services provided in that particular care setting” (Access to Care 2016). The Walker report (2011: 19) acknowledges that challenges in enhancing access and flow across services are not limited to ALC issues alone and that broader health system changes are required to meet the needs of Ontario’s aging population. A primary message of the Walker report is that an “Assess and Restore” philosophy and function should be considered central to the care delivery for seniors, regardless of their point of entry into the health-care system. Dr. Walker described potential pathways where direct access to such programs offered within rehabilitation or complex continuing care (CCC) beds would be beneficial in preventing further decline and enhancing individuals’ level of functioning. Further, in addition to the role of bedded levels of rehabilitative care, best-practice rehabilitative care pathways and community rehab services were highlighted as key enablers to improve patient flow across the system. As described later in this paper, work of Ontario’s Rehabilitative Care Alliance has started to build on this alternate pathway in support of direct access to rehabilitative care for individuals with medically complex needs.

The 2012 Commission on the Reform of Ontario’s Public Services, also known as the Drummond (2012) Report, endorsed the recommendations of the Walker Report and, in particular, recommended that the government prioritize six of the recommendations from the Walker Report (2011). Of these, one recommendation was to enhance programs aimed at restoring and “reactivating” the functional level of older adults with opportunities to enhance community-based care and ongoing supports, the focus of which directly aligns with the objectives of rehabilitative care.

The need to integrate more comprehensive and robust rehabilitative care services across the continuum, specifically for persons with complex, multiple morbidities, as a key enabler to health system changes is not unique to Ontario or even to Canada. It is a direction that has also been highlighted internationally. In a 2011 report from The King’s Fund and Nuffield Trust, Goodwin et al. (2011: 15) outline the position that care for people with complex healthcare and social care needs must be made a priority for both the government and health service providers, pointing to the need to “... develop capacity in primary and community care, to prioritise investment in social care to support rehabilitation and re-ablement, and to take forward the subsequent downsizing of activity undertaken in acute hospitals.”

Despite rehabilitative care’s recognized contribution to supporting health system priorities and improving patient outcomes, there has been a lack of standardization in rehabilitative care across Ontario. This lack of standardization across

the province has resulted in variability in the use of system resources and patient outcomes and continues to undermine the ability of rehabilitative care providers to address the complex needs of patients with multimorbidities. There is significant variation in the availability and type of rehabilitative care services provided across the province, which affects people’s access to these services (Auditor General of Ontario 2013). Whether patients are able to access the type of rehabilitative care that is needed should not depend on where patients live, how many health conditions they have or how complex their conditions may be. “There is a need for a provincially co-ordinated rehabilitation system. Ontario’s population is aging, so there will be an even greater need for rehabilitation services in the future.” (Auditor General of Ontario 2013: 223).

... lack of standardization across the province has resulted in variability in the use of system resources and patient outcomes ...

The Provincial Rehabilitative Care Alliance

The Rehabilitative Care Alliance was established in 2013 with a focus on improving and standardizing rehabilitative care services at the system level across age spans and populations. Given the pressures on the system to address the needs of people with medical complexity and frailty, along with concurrent political and healthcare sector attention to the recommendations of the Walker Report (2011), Senior Friendly Hospital Report (Wong et al. 2011) and Sinha Report (2012), a provincial-wide focus on rehabilitative care emerged, including an emphasis on medically complex, frail seniors.

The Rehabilitative Care Alliance (RCA), funded by Ontario’s 14 Local Health Integration Networks (LHINs), is a provincial task-oriented, collaborative group created to effect positive change in rehabilitative care across Ontario. It was initially established with a two-year mandate.

At the outset, the RCA laid a path for success by building on the strong foundation and leadership of the GTA Rehab Network and recommendations of the Rehabilitation and Complex Continuing Care (CCC) Expert Panel (2011). The Rehab Care Alliance engaged a small but highly productive secretariat, strong executive leadership and a diverse, provincial roster of clinicians, administrators and policy makers to advance the work. It further reinforced its efforts through a commitment to broad stakeholder engagement to help inform the development of key deliverables.

The following overview of select RCA initiatives includes highlights of specific areas where the RCA’s work addresses care delivery and service planning for persons with complex care needs. To address key system gaps and issues within

rehabilitative care, the RCA developed an initial two-year work plan (April 2013–March 2015) focused on four key priorities:

1. Definitions Framework for Rehabilitative Care
2. Capacity Planning & System Evaluation
3. Frail Senior/Medically Complex
4. Outpatient/Ambulatory Rehabilitative Care Data

Each priority was supported by both a Task and Advisory group with cross-province representation. This work has led to an unprecedented level of engagement across the province, which has continued into the second two-year mandate (April 2015–March 2017) of the Alliance, ensuring that deliverables truly reflect a provincial lens.

In its first mandate, the RCA developed standardized definitions frameworks for bedded and community levels of rehabilitative care. While the rehabilitation and CCC sectors have developed considerable expertise to manage the care of patients with complex needs (Ontario Hospital Association 2006), the frameworks, for the first time, establish provincial standards for the comprehensive scope of rehabilitative care. They provide clarity for patients, families and referring professionals regarding the focus and clinical components within each level of rehabilitative care and describe expected service levels to guide capacity planning – in conjunction with the RCA’s Capacity Planning Framework.

In short, the RCA Definitions Frameworks for Rehabilitative Care are the standards by which the provincial rehabilitative care system can begin to ensure equitable access to consistent, high-quality rehabilitative care services. The frameworks support a common understanding and expectations of rehabilitative care services, including the inherent features that, when delivered in a reliable and predictable way, ideally position the rehabilitative care system to support the functional needs and goals of persons with complex and multiple morbidities. Although the frameworks are not population-specific (i.e., provide standards for each and every rehab population group), the Definitions Framework for Bedded Levels of Rehabilitative Care includes two levels of rehabilitative care specific to patients who require short- and long-term complex medical management. Inclusion of these two levels acknowledges that medical complexity, in and of itself, should not serve as a barrier to receiving rehabilitative care. The frameworks go even further by making explicit statements in their eligibility criteria and definition of restorative potential that patients requiring short- or long-term complex medical management may benefit from rehabilitative care and that the presence of cognitive impairment, depression or delirium should not be used in isolation to determine the restorative potential of the patient. This perspective provides an opportunity to standardize the approach to supporting the rehabilitative care needs for all patients with multimorbidities across the province of Ontario.

Supporting Direct Access to Rehabilitative Care Beds for Community-Based “At Risk” Adults

In alignment with the provincial reports “Living Longer, Living Well” (2012) and “Ontario’s Action Plan for Seniors” (MOHLTC 2013) and in direct support of operationalization of the Assess and Restore Guideline (MOHLTC 2014), RCA stakeholders prioritized the development of a “Provincial Priority Process to Support Direct Admissions to Bedded Levels of Rehabilitative Care from the Community/ED.” This process supports access to bedded levels of rehabilitative care for high-risk older and/or medically complex adults in the community who are at imminent risk of institutionalization due to recent functional decline. The “Priority Process” is not intended to replace community-based options that are available to support achievement of the client’s/patient’s functional goals. Rather, it serves as a mechanism to remove acute care as the sole point of access to rehabilitative care beds for frail, complex individuals in the community with potentially reversible functional decline for whom community-based rehabilitative care options are either not available or appropriate (Rehabilitative Care Alliance 2015).

The frameworks support a common understanding and expectations of rehabilitative care services ...

Assessment and Treatment of Geriatric Syndromes by Rehabilitative Care Providers

Additionally, a “Compendium of Rehabilitative Care Best Practices to Support the Assessment and Treatment of the Geriatric Syndromes” was created to support an “Assess and Restore” approach to care across the rehabilitative care continuum. It was intended to support an increased awareness of the geriatric syndromes that contribute to frailty, as well as increased capability amongst rehabilitative care professionals to assess and treat geriatric syndromes.

The “Compendium” is a concise summary of existing best practices from gold-standard literature that describes tools, measures, practices and interventions that are within the scope of rehabilitative care providers and which enable comprehensive assessment and treatment of the geriatric syndromes that may contribute to frailty amongst persons with complex, multiple morbidities (Rehabilitative Care Alliance 2015).

Standardized Data Collection in the Outpatient/Ambulatory Rehabilitative Care Setting

Opportunities to provide high-quality, cost-effective ambulatory-based care to a variety of populations, including those with multimorbidity, are the basis for the RCA’s initiative to develop a minimum data set (MDS) for MOHLTC-funded, outpatient/ambulatory (OP/AMB) rehabilitative care programs. In a recently published three-year study, Wodchis et al. (2016) found that use

of healthcare services by high-cost users was sustained over time and that most spending for high-cost users was for institutional care, while among low-cost users, spending was predominantly for ambulatory care services. The OP/AMB MDS was developed by the Rehabilitative Care Alliance to address the long-acknowledged lack of standardized data reporting from publically funded ambulatory rehabilitative care services and highlights the role that outpatient/ambulatory rehabilitative care can play to inform development of new community-based, cost-effective models of care. Elements within the data set include evaluation of not only patients' presenting issue but also other issues that may impact functional recovery and engagement within the context of their environment (e.g., participation in paid work; voluntary or other social activities; the extent to which a fear of falling impacts on activity participation; and engagement in instrumental activities of daily living). The OP/AMB MDS will inform the planning of sufficient rehabilitative care capacity to enable the system to respond to the needs of all populations, including, as a priority, those with complex, multiple morbidities. This capacity is required, as part of the MOHLTC's focus on bundled funding models of care, Health Links and other chronic disease management strategies, to ensure the system is able to effectively support the functional challenges encountered by persons with complex, multiple morbidities in the community. The OP/AMB MDS is currently being piloted by multiple health service provider organizations across Ontario and can be accessed through the Rehabilitative Care Alliance.

Assess and Restore

In addition to the initiatives described above, the RCA is also supporting the LHINs as they operationalize the MOHLTC's Assess and Restore Guideline through focused Ministry funding of initiatives targeted at high-risk frail seniors and others with restorative potential. The RCA is playing a key role in supporting the evaluation of the impact of the "Assess and Restore" funding on key outcomes for the frail senior/medically complex population.

In summary, the described RCA deliverables serve to standardize and enhance the approach to rehabilitative care for persons with complex, multiple comorbidities. Work of the Rehabilitative Care Alliance was recognized in the 2013 report of the Auditor General of Ontario as "focusing on system accessibility and quality" and "in defining best practices in rehabilitation that are expected to help standardize the definitions of regular and restorative rehabilitation to better track services and costs" (p. 226). Implementation of these quality-focused, standardized approaches to care will optimize system resources and ideally position rehabilitative care to contribute to optimal outcomes. As Oliver (2016), consultant in geriatrics and acute general medicine, commented in the online "Views & Reviews" section of the *BMJ*, "Rehabilitation is part of medicine ... That's the way of modern healthcare." **HQ**

References

- Access to Care. 2016. "Definition of Alternate Level of Care." Retrieved February 29, 2016. <www.accesstocare.on.ca/cms/One.aspx?portalId=120513&pageId=121468>.
- Auditor General of Ontario Annual Report. 2013. "Reports on Value-for-Money Audits, Chapter 3, Rehabilitation Services at Hospitals." Retrieved January 16, 2016. <www.auditor.on.ca/en/reports_en/en13/308en13.pdf>.
- Boult, C., A.F. Green, L.B. Boult, J.T. Pacala, C. Snyder and B. Leff. 2009. "Successful Models of Comprehensive Care for Older Adults with Chronic Conditions: Evidence for the Institute of Medicine's 'Retooling for an Aging America' Report." *American Geriatrics Society* 57(1): 2328–37.
- Drummond, D. 2012. "Commission on the Reform of Ontario's Public Services". Chapter 5: Health. Retrieved January 6, 2016. <www.fin.gov.on.ca/en/reformcommission/chapters/report.pdf>.
- Fried, T.R., M.E. Tinetti, L. Iannone, J.R. O'Leary, V. Towle and P.H. Van Ness. 2011. "Health Outcome Prioritization as a Tool for Decision Making among Older Persons with Multiple Chronic Conditions." *American Medical Association* 171(20): 1854–56. Retrieved February 28, 2016. doi:10.1001/archinternmed.2011.424.
- Goodwin, N., J. Smith, A. Davies, C. Perry, R. Rosen, A. Dixon et al. 2011. "Integrated Care for Patients and Populations: Improving Outcomes by Working Together." Report to the Department of Health and NHS Future Forum from The King's Fund and Nuffield Trust, p. 1. Retrieved January 17, 2016. <www.kingsfund.org.uk/sites/files/kf/integrated-care-patients-populations-paper-nuffield-trust-kings-fund-january-2012.pdf>.
- Government of Canada. 2016. *Canada Health Act, 1984*. Retrieved January 23, 2016. <<http://laws-lois.justice.gc.ca/eng/acts/c-6/index.html>>.
- GTA Rehab Network. 2011. "Outpatient Rehabilitation in the GTA: Understanding the Current State". June 2011. Retrieved January 23, 2016. <www.gtarehabnetwork.ca/uploads/File/reports/report-outpatientrehab-june2011.pdf>.
- Koné, A., W. Wodchis, A. Gruneir, S. Bronskill, C. Maxwell, K. Thavorn et al. "Prevalence and Characteristics of Multimorbidity in Ontario". Poster session presented at Health System Performance Research Network Symposium, October 22, 2013, Toronto, ON. Retrieved February 28, 2016. <[http://hsprn.ca/uploads/files/Kone%20CAHSPR%20poster%20epi%20of%20MM%20in%20Ontario_\(2013_05_17\)_FINAL.pdf](http://hsprn.ca/uploads/files/Kone%20CAHSPR%20poster%20epi%20of%20MM%20in%20Ontario_(2013_05_17)_FINAL.pdf)>.
- Landry, M.D., M.C. Verrier, A.P. Williams, D. Zakus and R.B. Deber. 2009. "Strategic Responses to Fiscal Constraints: A Health Policy Analysis of Hospital-Based Ambulatory Physical Therapy Services in the Greater Toronto Area (GTA)." *Physiotherapy Canada* 61: 221–30. doi:10.3138/physio.61.4.221.
- Mery, G., W.P. Wodchis, A. Bierman, M. Laberge. 2013. "Caring for People with Multiple Chronic Conditions: A Necessary Intervention in Ontario". Working Paper Series. Vol 2. Toronto: Health System Performance Research Network.
- Naylor, D. 2009. Former President, University of Toronto, Personal Communication, February 2009.
- Oliver, D. 2016. "Rehabilitation Is Part of Medicine." *BMJ* 352: i270. doi:10.1136/bmj.i270.
- Ontario Hospital Association. 2006. *Optimizing the Role of Complex Continuing Care and Rehabilitation in the Transformation of the Health Care Delivery System*. Ontario Hospital Association. Retrieved June 17, 2016. <https://www.oha.com/CurrentIssues/keyinitiatives/eHealth/Documents/Optimizing_the_Role_of_CCCandRehab.pdf>.

Ontario Ministry of Health and Long-Term Care. 2013. "Independence, Activity and Good Health." *Ontario's Action Plan for Seniors Care*. Retrieved January 31, 2016. <www.ontario.ca/page/ontarios-action-plan-seniors>.

Ontario Ministry of Health and Long-Term Care. 2014. *Assess and Restore Guideline*. Toronto, ON: Ontario Ministry of Health and Long-Term Care. Retrieved June 17, 2016. <http://www.health.gov.on.ca/en/pro/programs/assessrestore/docs/ar_guideline.pdf>.

Ontario Ministry of Health and Long-Term Care. 2015. *Complex Continuing Care*. Retrieved February 26, 2016. <www.health.gov.on.ca/en/public/publications/chronic/chronic.aspx>

Ontario Ministry of Health and Long-Term Care. 2015. "Patients First. A Roadmap to Strengthen Home and Community Care." Retrieved January 30, 2016. <www.health.gov.on.ca/en/public/programs/ccac/roadmap.pdf>.

Ontario Physiotherapy Association, Ontario Society of Occupational Therapists, Ontario Bone and Joint Health Network and the Ontario Orthopedic Expert Panel. 2011. "Current State Review of Outpatient Rehabilitation Services Available at Ontario Acute and Rehabilitation Hospitals and Recommendations to Optimize the System." Retrieved July 7, 2016. <<http://docplayer.net/11620713-Current-state-review-of-outpatient-rehabilitation-services-in-ontario-2.html>>.

Rehabilitation and Complex Continuing Care Expert Panel. 2011. "Phase I Report." Retrieved March 3, 2016. <www.gtarehabnetwork.ca/uploads/File/PublicationsLHINreports/Phase-I-Summary-Report-Final-Draft-June-20-2.pdf>.

Rehabilitative Care Alliance. 2015. "Inspiring New Directions in Rehabilitative Care, 2013–2015 Report." Retrieved July 7, 2016. <www.rehabcarealliance.ca/mandate-1-final-report>.

Sinha, S. 2012. "Living Longer, Living Well." Report Submitted to the Minister of Health and Long-Term Care and the Minister Responsible for Seniors on recommendations to Inform a Seniors Strategy for Ontario. Retrieved July 7, 2016. <http://www.health.gov.on.ca/en/common/ministry/publications/reports/seniors_strategy/>.

Thavorn, K., W. Wodchis, C. Maxwell, A. Koné, A. Gruneir, S. Bronskill et al. "Economic Burden of Multimorbidity in Ontario's Health Care System" 2013. Poster session presented at Health System Performance Research Network Symposium, October 22, 2013, Toronto.

Wade, D. "Rehabilitation – a New Approach. Overview and Part One: The problems". *Clinical Rehabilitation* 29(11): 1040. doi:10.1177/0269215515607138.

Walker, D. 2011. "Caring For Our Aging Population and Addressing Alternate Level of Care." Report Submitted to the Minister of Health and Long-Term Care. Retrieved July 7, 2016. <http://www.health.gov.on.ca/en/common/ministry/publications/reports/walker_2011/walker_2011.aspx>.

Wodchis, W.P., P.C. Wodchis and D.A. Henry, 2016. "A 3-Year Study of High-Cost Users of Health Care." *CMAJ* 188(3): 182–88.

Wong, K., D. Ryan and B. Liu. 2011. "Senior Friendly Hospital Care across Ontario Summary Report and Recommendations." Retrieved March 1, 2016. <<http://rgp.toronto.on.ca/PDFfiles/SFHPProvincialReportFINAL.pdf>>.

World Health Organization. 2011. *World Report on Disability*. Chapter 4, Rehabilitation, p. 96. Retrieved January 9, 2016. <www.who.int/disabilities/world_report/2011/report.pdf>.

World Health Organization. 2016a. Rehabilitation. Retrieved January 16, 2016. <www.who.int/topics/rehabilitation/en/>.

World Health Organization. 2016b. "Rehabilitation and Habilitation." Retrieved January 16, 2016. <www.who.int/disabilities/care/en/>.

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It Takes Two to Tango: Researchers and Decision-Makers Collaborating to Implement Practice Changes for Patients with Multimorbidity

Martin Fortin, Martine Couture, Tarek Bouhali, Esther Leclerc and Moira Stewart

Abstract

An integrated knowledge translation strategy is a key factor in fostering the implementation of practice changes. Building on a 15-year history of projects that include close collaboration between researchers and decision-makers in the Saguenay region of Quebec (Canada), the authors identify several key elements that resulted in practice changes in primary care and improved outcomes for patients with multimorbidity.

Background

Health system researchers and decision-makers typically deal with very different work contexts. As a result, they often have different perspectives on how to most effectively use research findings to improve health services despite the use of rigorous processes to ensure that recommendations are evidence-based (WHO 2004). Developing research projects and generating evidence requires significant effort as well as considerable human and financial resources. Therefore, finding ways to ensure that relevant evidence is used by decision-makers is important. However, decision-makers have to consider a range of factors when creating policies aimed at improving health. These include the following:

- Ensuring the feasibility of programs while balancing economic, political and technical aspects.
- Questioning the sustainability of tested innovations against the context in which they will be implemented.

- Attempting to satisfy competing demands and recommendations for healthcare improvement from diverse stakeholder groups.

We know that decision-makers pay more attention to evidence when they already have invested funds and time to develop it (Martens and Roos 2005). They often turn to internal research support services or to researchers with whom they already have a good working relationship (Wilson et al. 2015). They may also turn to special advisers, experts, opinion formers and even to lobbyists or pressure groups (Greenhalgh and Russell 2006).

Knowledge of effective researcher–decision-maker collaborations is important for both sides. As an example of a long-term collaboration, we will describe the engagement of decision-makers and researchers of the Saguenay-Lac-Saint-Jean (SLSJ) region of Quebec (Canada) in introducing integrated chronic disease prevention and management (CDPM) services to the region.

The Context of the Story

In the SLSJ region, CDPM services were implemented in 2001 under the leadership of the regional health authority. These CDPM services, including integrated and evidence-based interventions (Agence de la santé et de services sociaux du Saguenay-Lac-Saint-Jean 2006; CSSS de Chicoutimi 2004), were grouped into a program called *Programme régional de la*

Trajectoire de services de réadaptation intégrés pour les maladies chroniques (referred to as the *Trajectoire* in the following text). The *Trajectoire* addressed a number of different chronic diseases (CD) in silo: cardiovascular disease (CVD), heart failure, chronic obstructive pulmonary disease (COPD), asthma and diabetes. The *Trajectoire's* objectives were three-fold: (1) to reduce modifiable risk factors; (2) to support patient self-efficacy and self-management; and (3) to improve patient functional autonomy and biopsychological and social balance (CSSS de Chicoutimi 2004). Services were delivered by various professionals, including nurses, nutritionists, pharmacists, psychologists, and medical specialists. (CSSS de Chicoutimi 2004). The original intent was for patients to be referred to the program by their healthcare providers; however, the majority of referrals followed an acute episode of care or hospitalization. The *Trajectoire* program is still ongoing and has not been evaluated since its implementation.

In 2007, the Université de Sherbrooke created the Research Chair on Chronic Diseases in Primary Care in collaboration with key decision-makers from the healthcare organizations of the SLSJ region (Guyatt et al. 2013). The Chair aimed to develop and disseminate knowledge to help primary healthcare (PHC) professionals of all disciplines interact efficiently with patients with CD, to train researchers in applied studies on PHC services, to support the alliance between researchers and decision-makers and to promote knowledge translation. The work of the Chair was also supported by a research award (Research Chair on Health Services and Policy Research) from the Canadian Institutes of Health Research (CIHR) and the Canadian Health Services Research Foundation from 2009 to 2014.

... the implementation of the intervention created synergistic interactions and successful relationships among all stakeholders ...

The Story

In 2010, a collaboration between researchers associated with the Chair and local decision-makers resulted in a regional CIHR-funded dissemination meeting, bringing together more than one hundred stakeholders (Chouinard et al. 2011). Patients from the *Trajectoire* were involved in this process. The goal of the meeting was to appraise existing regional CDPM services and to suggest potential improvements. Several areas for health system improvement were identified, among which were (1) coordination of patient navigation in the healthcare system; (2) integration of CDPM services into primary care practices; (3) better communication and collaboration between PHC professionals and family physicians to maintain patient motivation; (4) dissemination of clinical guidelines; (5) focus on multimorbidity; and (6) linking CDPM services to community resources.

The 2010 meeting motivated researchers and decision-makers, in collaboration with healthcare professionals, to apply to the Fond de Recherche du Québec – Santé (FRQ-S) in response to a request for proposals targeting innovations in chronic disease management in primary care.

In December 2010, the *Programme de réadaptation intégré en première ligne pour les maladies chroniques* (PR1MaC) received funding from the FRQ-S. The clinical components and the implementation of the program consisted of many steps articulated in a logic model. The first step consisted of a needs assessment conducted with primary care professionals. The second step consisted of adapting and implementing CDPM services into the participating practices. The third step was the implementation of a support mechanism by the research team, along with a follow-up with the participating clinics, to ensure a seamless integration.

In many aspects, PR1MaC could be considered as a pilot. The effectiveness of the intervention was measured using mixed pragmatic methods. The complete protocol is described elsewhere (Fortin et al. 2013). After three months, the intervention showed benefits in improving various patient self-reported outcomes (self-management, fruit and vegetable consumption, physical activity and quality of life). Improvements continued even after one year (Fortin et al 2016).

The PR1MaC study also demonstrated that it was possible to implement an intervention integrating CDPM services for several chronic conditions in primary care settings. The recommendations from the 2010 meeting had been successfully acted upon. The development of the proposal and the implementation of the intervention created synergistic interactions and successful relationships among all stakeholders, particularly decision-makers and researchers who played a central role. Their commitment went beyond the usual boundaries. Without this successful relationship, the story could have ended there with an effective pilot intervention but no scaling up and long-term implementation.

The Next Step of the Story

In 2015, the Quebec Ministry of Health and Social Services invited all regional health authorities to apply for funding for the implementation of CDPM services in primary care practices. Strengthened by the successful relationship developed previously, the team of decision-makers and researchers submitted a proposal to implement, on a permanent basis, CDPM services in the 11 Family Medicine Groups (FMGs) of the SLSJ region. The *Démarche Intégrée en Maladies Chroniques de la région 02* (DIMAC02) was born. Much of this initiative built on the PR1MaC experience and results with some inspiration from other clinical and research projects that also have generated evidence in the SLSJ region (Chouinard et al. 2013). There was also an opportunity at this time for the FMGs to welcome professionals other than primary care

physicians and nurses into their organizations (nutritionists, kinesiologists, pharmacists, etc.). The resulting submission was an operationalization of the Chronic Care Model, along with training for health professionals in motivational interviewing, self-management support, case management, interprofessional collaboration and patient-centred approaches, with a special focus on patients with multimorbidity who are so prevalent in primary care (Barnett et al. 2012; Fortin et al 2005, 2012). To strengthen the proposal, DIMAC02 included an innovative evaluation framework developed as part of a CIHR-funded team grant from the Community-Based Primary Health Care Signature Initiative: “Patient Centered Innovation for Persons with Multimorbidity” (PACE in MM) (Angold et al. 1999; Cornell et al. 2007). PACE in MM involves researchers and decision-makers from six Canadian provinces but is mostly a Quebec–Ontario research program. The main goal of PACE in MM is to change primary healthcare and community-based chronic disease prevention and management programs in order to move from a single-disease focus to a multiple disease focus, to centre not only on disease but on the patient and to realign the healthcare system from separate silos into coordinated collaborations in care. In this respect, there was a good synergy with the DIMAC02.

DIMAC02 was one of the three initiatives funded by the Quebec Ministry of Health and Social Services and as such acknowledged the good relationship between decision-makers and researchers in the SLSJ region. The implementation of DIMAC02 started gradually in June 2015 and included the training of 70 non-physician primary care providers. The project was closely monitored by an executive committee, including managers of each participating FMG. The evaluation process is ongoing since the regional ethics board approval.

Lessons Learned

With this story of collaboration between researchers and decision-makers in the SLSJ region, we describe in this section the key elements that helped us (researchers and decision-makers) to overcome the challenges of participating in the development and use of evidence while working in a real-life environment.

Trust takes years to build, and a moment to destroy

Honesty and loyalty are vital ingredients in all relationships, including the one between researchers and decision-makers. Such a relationship takes time and commitment to build and needs to be preserved from any harm through misconduct or miscommunication.

Involving all stakeholders at early stages

Partners in general and decision-makers in particular are more devoted to projects and ideas they own or with/in which they

are integrally involved. When the partners are invited to participate in a study, they want to know exactly what their roles are and what their contribution looks like in terms of time and effort. They also want to create innovations that are well-aligned with their policies. Sometimes, partners feel intimidated by the strange world of research. Similarly, researchers are often unaware of the equally strange (to them) world of healthcare policy (Lomas 1997).

Relationships create opportunities

Sustainable and successful relationships between researchers and decision-makers multiply the potential for collaboration. Most of the funding agencies highly value the existing collaborations that have led to results.

Keep the partner close to the research

Researchers need to make an effort to ensure that the research becomes part of the decision-makers’ world. The worst scenario is to involve decision-makers only when their support is needed, such as at the funding stage and later when the research is over. They need to be involved at every step to allow evidence to be integrated seamlessly and to prepare for scale-up of successful innovations. The best scenario is when a sustainable relationship that goes beyond a single project is created.

Sometimes, partners feel intimidated by the strange world of research.

Get to know the partner’s entourage

The healthcare system imposes frequent changes in governmental and non-governmental positions. The best way to ensure continuity of the work and to bridge a potential gap between the clinical world, the research world and the governing world is to invest in communication within and between different levels and persons. People change and new relationships have to be built!

Researchers need to adapt the agenda, timelines and deadlines to the partners and expect the same from them

Researchers and decision-makers look at the same things from different angles. They allocate time and resources according to their own point of view. If they have to adapt to other partners, at least they should be aware of such different realities.

Rigor and flexibility are not contradictory concepts

When researchers are in charge of the clinical application of the evidence they generated, they may, naturally, act as gatekeepers because they are those who know in what context and conditions an intervention led to a given outcome. This rigor is important to make evidence-based changes. However, the real

world of clinical practice and decision-making may require some adjustment. Flexibility has to be introduced early in the research process to allow for a later implementation in a real-world environment. Pragmatic interventions offer an alternative that bridges rigor and flexibility.

Researchers have to think, talk and write like decision-makers to communicate effectively with decision-makers

To succeed in knowledge translation, researchers have to adapt the message to each target audience. Lengthy reports are unlikely to be read unless they are preceded by a short executive summary that highlights the key findings and their meaning. The message from the researchers should take into account the world of the decision-makers and the policies in place or to be implemented and be coherent with them in order to have an impact (Grimshaw et al. 2012).

Managing expectations

After generating evidence, and working on its translation, researchers may be disappointed if their recommendations do not lead to real and rapid changes in the system. Researchers should live with high ambitions and moderate expectations. Change involves usually more effort than generating evidence. Researchers have to learn to be patient when engaging in the translation of evidence into action. They have to consider this as a learning process that will affect their future research and inspire new research ideas and new challenges.

Considering the successes as well as the failures

Decision-makers and researchers build on previous successes. Researchers need to learn how to capitalize on each success and think of it as a pilot experience for the next bigger one. However, there is usually much to learn from less successful experiences, and all partners should openly try to learn from them by identifying factors that led to undesired results as well as desired ones.

Agreements are more efficient when they are clear, understood and followed by all partners

Once all partners invest the necessary effort and time to reach agreements, mechanisms should be set to ensure that decisions, tasks and timelines are equally understood by all partners. If necessary, written conclusions could be used to guarantee the engagement of everyone over time.

Discussion

This paper describes a retrospective overview of a local longitudinal experience of collaboration over 15 years. This case study may not reflect all facets or all the ups and downs of interactions between the moving planets of decision-makers

and researchers. Little is known about the real place of research in decision-making. Consequently, every experience could represent a significant addition to fill the gaps in knowledge on the effectiveness of the process of translation of research evidence into decisions and on-the-ground change. This paper is co-authored by researchers and decision-makers who have succeeded in building a relationship of personal trust. Among the authors, two (MC and EL) are alumni of the EXTRA: Executive Training Program for Research Application from the Canadian Foundation for Healthcare Improvement (see: <http://www.cfhi-fcass.ca/whatwedo/extra>). One can assume that the ideas in this paper reflect different points of view that make this paper relevant for researchers and decision-makers who are looking for an effective process to make research relevant for decision-making.

Researchers need to learn how to capitalize on each success and think of it as a pilot experience for the next bigger one.

The Tango Metaphor

In the tango of researchers and decision-makers, there are quick changes in direction indicating flexibility of the process within a rigorous structure. Each partner scans the 360-degree horizon with head movements bringing observation to the process. Most importantly, the partners alternate being the lead to create a harmonious flow of exchanges of information, interpretations, feedback and continuous adjustments. Good tango dancers are skilled communicators. Researchers and decision-makers who learn how to tango can really make a difference. **HQ**

References

- Angold, A., E.J. Costello and A. Erkanli. 1999. "Comorbidity." *Journal of Child Psychology and Psychiatry, and Allied Disciplines* 40(1): 57–87.
- Barnett, K., S.W. Mercer, M. Norbury, G. Watt, S. Wyke and B. Guthrie. 2012. "Epidemiology of Multimorbidity and Implications for Health Care, Research, and Medical Education: A Cross-Sectional Study." *Lancet* 380(9836): 37–43.
- Chouinard, M.C., M. Fortin and S. Tremblay. 2011. *Table Ronde sur les Maladies Chroniques au Saguenay Saguenay-Lac-Saint-Jean : Constats et Recommandations*. Chicoutimi, QC: Agence de santé et de services sociaux du Saguenay-Lac-Saint-Jean.
- Chouinard, M.C., C. Hudon, M.F. Dubois, P. Roberge, C. Loignon, E. Tchouaket et al. 2013. "Case Management and Self-Management Support for Frequent Users with Chronic Disease in Primary Care: A Pragmatic Randomized Controlled Trial." *BMC Health Services Research* 13: 49.
- Cornell, J., J. Pugh, J. Williams, L. Kazis, M. Parchman and J. Zeber. 2007. "Multimorbidity Clusters: Clustering Binary Data from a Large Administrative Medical Database." *Applied Multivariate Research* 12(3): 163–82.

Fortin, M., G. Bravo, C. Hudon, A. Vanasse and L. Lapointe. 2005. "Prevalence of Multimorbidity among Adults Seen in Family Practice." *Annals of Family Medicine* 3: 223–28.

Fortin, M., M.C. Chouinard, T. Bouhali, M.F. Dubois, C. Gagnon and M. Belanger. 2013. "Evaluating the Integration of Chronic Disease Prevention and Management Services into Primary Health Care." *BMC Health Services Research* 13(1): 132.

Fortin, M., M.C. Chouinard, M.F. Dubois, M. Bélanger, J. Almirall, T. Bouhali et al. (in press). "The PR1MaC Study: A Pragmatic Randomised Trial of the Integration of Chronic Disease Prevention and Management Services into Primary Care." *CMAJ Open*.

Fortin, M., M. Stewart, M.E. Poitras, J. Almirall and H. Maddocks. 2012. "A Systematic Review of Prevalence Studies on Multimorbidity: Toward a More Uniform Methodology." *Annals of Family Medicine* 10(2): 142–51.

Greenhalgh, T. and J. Russell. 2006. "Reframing Evidence Synthesis as Rhetorical Action in the Policy Making Drama." *Healthcare Policy* 1(2): 34–42.

Grimshaw, J.M., M.P. Eccles, J.N. Lavis, S.J. Hill and J.E. Squires. 2012. "Knowledge Translation of Research Findings." *Implement Science* 7: 50.

Guyatt, G.H., K. Thorlund, A.D. Oxman, S.D. Walter, D. Patrick, T.A. Furukawa et al. 2013. "GRADE Guidelines: 13. Preparing Summary of Findings Tables and Evidence Profiles-Continuous Outcomes." *Journal of Clinical Epidemiology* 66(2): 173–83.

Lomas, J. 1997. "Improving Dissemination and Uptake in the Health Sector: Beyond the Sound on One Hand Clapping." *Policy Commentary, C97-1*. Hamilton, ON: McMaster University Center for Health Economics and Policy Analysis.

Martens, P.J. and N.P. Roos. 2005. "When Health Services Researchers and Policy Makers Interact: Tales From The Tectonic Plates." *Healthcare Policy* 1(1): 72–84.

Agence de sante et de services sociaux du Saguenay-Lac-Saint-Jean. 2006. *Trajectoire de services de réadaptation intégrés pour les maladies chroniques: Cadre de référence*. Chicoutimi, QC: Jean.

CSSS de Chicoutimi. 2006. *Trajectoire de services de réadaptation intégrés pour les maladies chroniques, Centre ressource régional: Cadre clinique. Programme régional de la Trajectoire de services de réadaptation intégrés pour les maladies chroniques*. Chicoutimi, QC: CSSS de Chicoutimi.

Wilson, M.G., J.N. Lavis and F.P. Gauvin. 2015. "Developing a Rapid-Response Program for Health System Decision-Makers In Canada: Findings from an Issue Brief and Stakeholder Dialogue." *Systematic Reviews* 4: 25.

World Health Organization. 2004. "The Mexico Statement on Health Research. Knowledge for Better Health: Strengthening Health Systems." Retrieved January 29, 2016. <www.who.int/rpc/summit/agenda/en/mexico_statement_on_health_research.pdf>.

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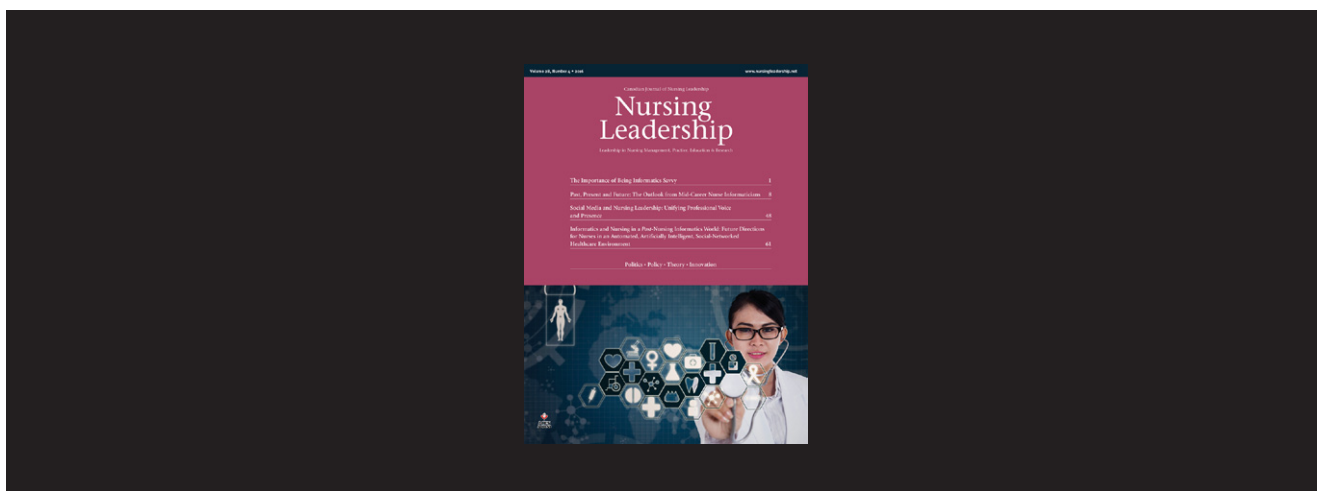
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Building Bridges to Integrate Care (BRIDGES): Incubating Health Service Innovation across the Continuum of Care for Patients with Multiple Chronic Conditions

Onil Bhattacharyya, Michael Schull, Kaveh Shojania, Vicky Stergiopoulos, Gary Naglie, Fiona Webster, Ricardo Brandao, Tamara Mohammed, Jennifer Christian, Gillian Hawker, Lynn Wilson and Wendy Levinson

Abstract

Integrating care for people with complex needs is challenging. Indeed, evidence of solutions is mixed, and therefore, well-designed, shared evaluation approaches are needed to create cumulative learning. The Toronto-based Building Bridges to Integrate Care (BRIDGES) collaborative provided resources to refine and test nine new models linking primary, hospital and community care. It used mixed methods, a cross-project meta-evaluation and shared outcome measures. Given the range of skills required to develop effective interventions, a novel incubator was used to test and spread opportunities for system integration that included operational expertise and support for evaluation and process improvement.

Introduction

Patients with complex medical, mental health and social needs account for a large proportion of healthcare costs, and they often receive suboptimal care in systems built around specific diseases and institutions (Anderson 2010; Curry and Ham 2010). Improving system integration has been touted as a way to improve the experience of care, reduce costs and improve outcomes with some promising examples in the United States like Accountable Care Organizations (Jacob 2015; Nyweide et al. 2015). In Ontario, it is estimated that better integration of care would result in savings of \$4–\$6 billion per year from reductions in redundant services, improved coordination and provision of more appropriate services (Drummond 2012).

In the past two years, integration of care for people with complex needs has become a major priority in Ontario. This focus is timely, because a recent 10-country survey by the Commonwealth Fund found that Canadian primary care providers ranked seventh to tenth on perceived preparedness to manage care of people with a range of complex needs (Osborn et al. 2015). However, programs to design and rigorously evaluate the impact of new models of care integration are needed, as their effects have been highly variable. For example, of the 34 programs in the Medicare demonstration projects on disease management and care coordination, 19 had no significant impact on costs or hospitalizations, whereas 4 increased costs with no impact on quality (Nelson 2012). This variation in effectiveness could be addressed with structures that support iterative improvement and evaluation. Incubators, which started in the business sector, improve the capabilities of early-stage organizations and develop infrastructure that will allow them to flourish (Dutt et al. 2015). This approach could be applied to nascent health services, with direct support for program development and to promote policies that support the sustainability and spread of those programs. While there have been reviews of models of care for high-need, high-cost patients across the United States (Mcarthy et al. 2015), here we present an approach to developing a suite of new models within a jurisdiction as a way of increasing their collective impact (Dyck 2009). Building Bridges to Integrate Care (BRIDGES)

adapted the incubator model to support evaluation and shared learning about integration of care for people with complex needs to enable system change. This paper will describe the model, how it was deployed and its findings to date.

Intervention

BRIDGES solicited new healthcare delivery models from the practice community, selected promising ones and supported their evaluation and potential spread. The project was funded until 2015 by the Ontario Ministry of Health and Long-Term Care and co-led by the University of Toronto's Departments of Medicine, Family and Community Medicine and Psychiatry. It had a governance committee with senior health system leaders representing different sectors and a scientific advisory committee. The project started in 2011. Final results for all projects are expected by 2017, and these will be reviewed by the Ministry as they are received.

The BRIDGES initiative was managed by an executive committee composed of representatives from the three departments and their respective chairs, with input from a scientific review committee and a governance committee. BRIDGES had three components: an incubator that selected and provided financial and consultative support for individual projects in model design and evaluation; a collaborative that supported shared learning across projects; and a coordinating body that linked with system stakeholders to promote collective impact. BRIDGES funded a range of projects, because system change may be more easily achieved by engaging with a diversity of providers and organizations than through the discrete efforts of a single group. Solutions to complex problems are unlikely to come from single programs that are carefully described and, if effective, scaled up across a system (Kania and Kramer 2013). To increase the likelihood of collective impact, BRIDGES had a shared vision to improve care for people with complex needs, shared measurement across projects, promoted mutually reinforcing activities and had a mechanism for communicating with other health system stakeholders (Kania and Kramer 2011). The key components are described below.

Project selection

BRIDGES solicited proposals from individuals affiliated with the three university departments (medicine, family medicine and psychiatry) and selected projects with the criteria that they targeted patients with complex medical, mental health and social needs; partnered with hospital, community services and primary care; and they appeared feasible and scalable. Proposals were reviewed by the executive and scientific review committee for scientific rigour and by the governance committee for system relevance and sustainability. Selected teams received feedback from the review and revised their proposals prior to final approval.

Financial and consultative support

Each successful project team received up to \$200,000 per year for two years and agreed on quarterly milestones to qualify for ongoing funding during that time. BRIDGES funded the evaluation of projects, but the operating costs were covered by the implementing institutions to increase the likelihood of sustainability. Teams had access to advisory support for study design, quantitative and qualitative data analysis, database management and economic evaluation from the BRIDGES team and Hub Research Solutions, a research methods and trial support centre based at the University of Toronto. The BRIDGES executive encouraged testing underlying assumptions of the respective healthcare delivery model used for each project to identify and address problems early in implementation. All projects used quantitative methods to evaluate emergency department (ED) visits, hospitalizations and length of stay in hospital, in addition to project-specific outcomes. Economic evaluations included costs incurred to develop and maintain the intervention, with standard costs for ED visits and hospitalization. Each project also used qualitative methods. They shared a common interview guide and coding framework for patient, provider and caregiver interviews. In addition, interviews from most projects were combined to conduct a meta-analysis of broad themes related to inter-organizational integration from patient, caregiver and clinician perspectives (Webster et al. 2015).

Building a collaborative of project teams

The BRIDGES projects occupy a common geography, and many had been developing strategies and testing integration prior to BRIDGES. BRIDGES created an infrastructure that strengthened collaborations and further promoted the evolution of these integrated models. The teams had quarterly in-person meetings and a conference each year of the project to share lessons learned, encourage collaboration and address common challenges.

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Change Process/Methodology/Results Funded projects' characteristics

Approximately 20 proposals were submitted in each of the three rounds of funding from 2011 to 2013, with nine projects being selected. They included multidisciplinary home-based primary care for frail elderly (Smith-Carrier et al. 2012), ongoing and transitional case management for high-burden conditions (COPD and atrial fibrillation) (Meshkat et al. 2013), transitional case management for frequent ED users

for mental health (Kahan et al. 2016), simultaneous multi-disciplinary case conferences for people with complex needs (Tracy et al. 2013) and rapid access to addiction medicine or psychiatric care. Two other models supported solo family physicians engaged in the care of people with complex needs, either over the phone or through a mix of consultation and shared care. Patients were recruited from the ED in four projects and referred by family physicians in five others. The evaluations included three randomized controlled trials (where individuals are randomized to receive the intervention or usual care), three interrupted time-series (where trends in service use by individuals are tracked before and after the intervention with no control group), two propensity-matched cohorts (where patients in the intervention are matched with similar patients from an administrative database) and one process evaluation (which tracked the implementation and key activities over time, with no outcomes measured). Participating hospitals and clinics included academic and non-academic facilities (Table 1).

Supporting health service evaluation: Processes and challenges

The levels and types of support were tailored to teams’ needs, as some groups were undertaking their first program evaluation, while others were experienced health services researchers. The initial evaluation strategy comprised a short period of iterative improvement during early implementation, followed by full implementation with standardized data collection. In practice, many challenges arose after formal implementation began. As a result, we encouraged ongoing model refinement while rigorously measuring outcomes. Most projects had unanticipated difficulties with recruitment that required changing inclusion criteria, adding sites or revising recruitment methods, so the period of support was extended. Sample sizes varied from 124 to 530 patients, with six out of nine groups completing recruitment within two years. The largest study completed recruitment in three years, and two studies are still recruiting (despite no longer receiving funding from BRIDGES).

TABLE 1.
BRIDGES projects

Project	Patient population	Intervention	Number and type of sites
Coordinated Access to Care from Hospital Emergency Departments (CATCH ED)	Frequent ED users in mental health	Intensive case management for 4–6 months, to connect patients with primary, specialty care and community mental health services	Six EDs, four community health centres and five community mental health agencies
Hospital-based Services for Opioid and Alcohol Addicted Patients (H-SOAP)	Alcohol- and opioid-addicted patients	Consultation service for patients in community-based withdrawal management services, with outreach to ED and support for hospital and community providers	Two academic hospitals
Integrated Community Care Team (ICCT)	Complex older patients cared for by a solo primary care physician	Integrated interprofessional team with primary, community, specialty and acute care resources to support solo primary care providers in caring for complex older patients	One geriatric health care centre, one community hospital and two CCACs
Integrated Home-Based Primary Care (IHBPC)	Frail home-bound elders	Interprofessional primary care teams with specialist consult support providing ongoing care in the home	Six family health teams, one community service agency and one CCAC
Interprofessional Model of Practice for Aging and Complex Treatments (IMPACT+)	Complex elderly	Case conference with primary care team, hospital specialists and community support workers to develop comprehensive care plan with patient and caregiver	Four family health teams, one community health centre and one CCAC
Program of Integrated Care for Patients with Chronic Obstructive Pulmonary Disease and Other Comorbidities (PIC COPD)	Patients with chronic obstructive pulmonary disease and comorbidities	Nurse case management and self-management support with respirologist, with coordination of specialty services and outreach to family practice	Two community hospitals
Rapid Access for Psychopharmacologic Treatment (RAPT)	Patients needing rapid but not urgent psychiatric care	Rapid psychiatric consultation and brief follow-up offered to family practice patients, along with ongoing e-mail and telephone support of referring primary care providers	One community hospital, three family health teams and one nurse-practitioner-led clinic
Seamless Care to Optimize the Patient Experience (SCOPE)	Solo general practitioners with high numbers of ED visits from patients	Hospital-based navigation hub with one number for family physicians to call with direct access to an internist, a nurse acute care coordinator and a community service coordinator. Outreach to practices with support for quality improvement	Two academic hospitals with 30 general practitioners, and one CCAC
Transitioning Atrial Fibrillation Management (TEAM)	Patients with atrial fibrillation in ED	Nurse practitioner and pharmacist care coordination and education with internal medicine, cardiology and electrophysiology support; direct access to clinician hotline for patients and family physicians	One hospital department and three emergency departments

ED = emergency department; CCAC = community care access centre.

Support for project refinement and iterative testing improved over the three rounds of projects but required a high level of trust and access to operational data for the core team to provide useful input. There was a tension between designing an intervention to address a local need and trying to understand the underlying logic of the intervention for broader transferability of findings. The requirements of project teams were very high. They needed to understand the literature and theory behind their project, to engage stakeholders from multiple sites and types of institutions, implement a complex intervention with a short timeline and oversee study design, data management and cost-effectiveness analysis. Few groups had all of these skills, and despite the range of supports offered by BRIDGES, there were gaps in some of the projects, particularly in the area of implementation. Strong leadership with a drive to understand and improve a model rather than prove its success made it easier to benefit from BRIDGES advisory supports.

Building a high-functioning, integrated inter-organizational team often took 12–18 months because developing relationships and trust was necessary to overcome the inevitable policy and institutional barriers. Though it ran in parallel with implementation, evaluation was on an even longer timeline. Over half of the projects had to wait six or more months to get Research Ethics Board approval at participating sites. Three out of nine programs added sites during implementation due to slow recruitment, which added up to four months to their timeline. Depending on the project, enrolled patients needed to receive the intervention for 3–12 months to experience a benefit. On top of this, there was an additional nine-month delay to measure the impact through administrative data. So the initial two-year funding period was extended to three for many projects, and data on total health service utilization will not be available until four years after the start of funding for most projects.

Integrating across the continuum

Many of the key mechanisms and drivers of integration of care for high users of the health system are not well understood, so the solutions were tentative and many challenges arose. For instance, one project (Integrated Clinical Care Team) formed an integrated care team including staff from a geriatric hospital, a community hospital, community care access centres from two different regions and primary care physicians. Team members from different institutions entered the same data independently into different IT platforms because there was no mechanism for sharing information across institutions caring for the same patient. These types of workarounds were common when functionally integrated providers from different organizations tried to create one team at the point of care. It also highlighted the need to work within existing structures while developing the optimal

model for the future. Another project, Coordinated Access to Care from Hospital Emergency Departments, involved case managers from different organizations. They all had different skill sets and modes of practice and required additional training and common supervision to ensure the quality of their work. Outreach to primary care was a key expectation of projects based in hospitals or specialty care, but this process showed mixed results. Strategies such as faxing updates, telephone contact and email often generated limited response from primary care providers (PCPs). One project, SCOPE, provided solo PCPs with direct phone access to specialists and community resources. The project team invited them to presentations and dinners, visited clinics and used local champions. These strategies resulted in greater involvement of PCPs, but at a greater expense.

All of the projects included partners from across the continuum. Some focused on a single disease such as COPD, which created an integrated approach for one disease but sometimes generated new fragmentation in the process. Patients in the ED were invited to be seen in a clinic with a nurse case manager and specialist, but some had pre-existing respirologists not involved in the project and either declined or ended up seeing a new specialist during the transition.

Mental health issues were identified as a major contributor to individual disease burden in many projects. Therefore, the Department of Psychiatry was invited to co-lead BRIDGES in the second year, given the wide range of patients with co-morbid conditions, which helped promote functional integration between the physical and mental health parts of the system that have often had little cross-communication.

Many of the key mechanisms and drivers of integration of care for high users of the health system are not well understood ...

Value-add from the learning and practice collaborative

The project teams were able to share experiences and solutions regarding research methods, recruitment, interventions and care of specific patients. They shared study protocols, ethics review board submissions and data collection forms. Some of the projects in the third round approached projects from the earlier rounds to help design interventions with similar populations. The Toronto Central Community Care Access Centre was a co-lead or partner on five of the nine projects, which supported its overall strategy and made sharing across projects easier. Finally, some hospitals are the focus of multiple BRIDGES-supported projects, which has encouraged project leads to consider how the models complement each other and in one case, combining several distinct models into a seamless process.

Discussion

In this article, we have described the initial experiences of an incubator to develop nine new models of care for patients with complex needs that span primary care, hospital and community services. The initiative supported each model's evaluation, built a collaborative to share experiences across projects and promoted collective impact through close linkage with system stakeholders involved in related efforts.

BRIDGES provided a link between practitioners invested in improving care for their patients, researchers trying to produce more generalizable knowledge and policy makers looking for practical solutions to system problems; it also helped manage the tension between these perspectives. It used an incubator model for support that is very hands-on, overseeing qualitative evaluation across all projects and supporting central databases for quantitative evaluation, which allowed for cross-project synthesis and supported data integrity. Also, the initiative supported changes that would optimize effectiveness versus the standard intervention study. Centralizing project support helped tailor approaches for teams with different levels of expertise and early pilots as well as more mature care models. This approach created greater overhead costs but allowed for economies of scale, operational learning across nine projects and flexibility with reallocation of funds across projects based on progress and need.

BRIDGES focused on coordination across providers and institutions to deliver integrated care to patients with complex needs (Curry and Ham 2010; Leutz 1999). There were stronger partnerships between hospitals, family health teams and community service organizations and weaker linkages with solo primary care providers that focus on direct care to patients with limited time for coordination. Models that were initiated by primary care teams were better at incorporating the patient's pre-existing circle of care than those that were specialist-driven or disease-specific. Primary care has a dearth of leaders and researchers and often uses visit-based models of care that do not serve the needs of complex patients. They are unlikely to change on their own, but we have shown that those with an interest can be supported, and mechanisms for shared accountability and standards for coordination would likely encourage others to make care of this population a priority. Risk-adjusted funding that considers the total cost of care for people with complex needs has given rise to a range of new models in the United States. They could be considered within our own blended funding models. BRIDGES has given rise to a strong partnership between primary care and specialists and found that collaborative leadership between clinicians, researchers, administrators and community partners is particularly powerful.

This is a challenging area to work in, and our experience suggests that models targeted at high users can take several years to get "right." While it is relatively easy to see if things are going wrong early on, it takes time to determine if they

are having an impact on health status and service use. Future evaluation programs should be tailored to a model's stage of maturity. This initiative is based in a well-resourced urban setting with many different providers, which may have different integration challenges than other environments. The choice of primary outcome measures, hospitalization and ED visits are of interest to the government but may not be a sensitive way to capture improvement in the care of complex patients, particularly in early phases of implementation. Finally, rapid learning is challenging when project timelines are long, but iterative testing of key hypotheses regarding mechanism of action and user uptake can identify positive and negative signals that inform ongoing design of the intervention.

Policy implications

The Ontario health system is trying to promote integration of care for people with complex needs in different regions through initiatives such as Health Links, a partnership between hospitals, primary care and community services to create coordinated care plans for people with complex needs (Ronson 2013). This initiative began after the start of BRIDGES, and its emerging evaluation strategy is informed by the BRIDGES experience. Many of the BRIDGES 28 project leads have become clinical champions for integration, with several leading Health Links initiatives. BRIDGES adapted its approach to cross-project evaluation to 35 Medically Complex Patient demonstration projects across the province of Ontario, in an attempt to make it more scalable.

The recent Naylor report outlined the need for a national strategy around the development, testing and scale-up of care integration models (Advisory Panel on Healthcare Innovation 2015). Though it predates the report, BRIDGES has operationalized many of its recommendations, such as support for provinces and regions "in adapting, scaling-up and spreading partial integration models." The report also recommends new funds to generate information on impacts on health outcomes, scalability and sustainability of new models. In BRIDGES, operating funds were covered by the implementing institutions, and, so far, eight out of nine projects have been sustained, while three are scaling up, in one case with support from Health Quality Ontario's Adopting Research to Improve Care program. This approach may inform federal efforts to support health service integration. There have been recent reports on key features of models to care for high-need, high-cost patients in the U.S. setting (McCarthy 2015). The final results of BRIDGES will identify effective models, as well as a process to develop new models for the Canadian context.

Conclusion

BRIDGES has helped develop and test nine new models of care integration for the highest users of the system through tailored project supports, a collaborative and a structure to communicate

lessons learned for system stakeholders. To demonstrate the broader applicability of the approach, BRIDGES has adapted its intensive evaluation of local efforts to a lighter touch evaluation of demonstration projects across Ontario. Given the difficulty finding and implementing care models that improve outcomes and reduce costs for complex patients in a given jurisdiction, incubators for innovation linking front-line clinicians with system stakeholders and academics are a promising way forward. **HQ**

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References

- Advisory Panel on Healthcare Innovation. 2015. "Unleashing Innovation: Excellent Healthcare for Canada." Retrieved January 8, 2016. <<http://www.healthycanadians.gc.ca/publications/health-system-systeme-sante/report-healthcare-innovation-rapport-soins/alt/report-healthcare-innovation-rapport-soins-eng.pdf>>.
- Anderson, G. 2010. *Chronic Care: Making the Case for Ongoing Care*. Princeton, NJ: Robert Wood Johnson Foundation. Retrieved May 9, 2013. <<http://www.rwjf.org/en/research-publications/find-rwjf-research/2010/01/chronic-care.html>>.
- Curry, N. and C. Ham. 2010. *Clinical and Service Integration – the Route to Improved Outcomes*. London, UK: The King's Fund. Retrieved May 9, 2013. <<http://www.kingsfund.org.uk/publications/clinical-and-service-integration>>.
- Drummond, D. 2012. "Commission on the Reform of Ontario's Public Services." Retrieved May 9, 2013. <<http://www.fin.gov.on.ca/en/reformcommission/chapters/report.pdf>>.
- Dutt, N., O. Hawn, E. Vidal, A. Chatterji, A. McGahan and W. Mitchell. 2016. "How Open System Intermediaries Address Institutional Failures: The Case of Business Incubators in Emerging-Market Countries." *Academy of Management Journal* 59(3):818–40.
- Dyck, J. 2009. "Introduction to Case Studies on Integration." *Healthcare Quarterly* 13(Suppl): 55.
- Jacob, J. 2015. "Medicare ACOs Improving Quality of Care: CMS Report." *JAMA* 314(16):1683.
- Kahan, D, M. Leszcz, P. O'Campo, S.W. Hwang, D.A. Wasylenko, P. Kurdyak et al. 2016. "Integrating Care for Frequent Users of Emergency Departments: Implementation Evaluation of a Brief Multi-Organizational Intensive Case Management Intervention." *BMC Health Services Research* 16(1):156–65.
- Kania, J. and M. Kramer. 2011. "Collective Impact Stanford Social Innovation Review." Retrieved May 9, 2013. <http://www.ssireview.org/articles/entry/collective_impact>.
- Kania, J. and M. Kramer. 2013. "Embracing Emergence: How Collective Impact Addresses Complexity Stanford Social Innovation." Retrieved May 9, 2013. <http://www.ssireview.org/blog/entry/embracing_emergence_how_collective_impact_addresses_complexity>.
- Leutz, W. 1999. "Five Laws for Integrating Medical and Social Services: Lessons from the United States and the United Kingdom." *Milbank Quarterly* 77(1): 77–110.
- Mcarthy, D. J. Ryan and S. Klein. 2015. "Models of Care for High-Need, High-Cost Patients: An Evidence Synthesis." Retrieved January 11, 2016. <<http://www.commonwealthfund.org/publications/issue-briefs/2015/oct/care-high-need-high-cost-patients/#5>>.
- Meshkat, N., K. Leblanc, S. Bhatia and D. Morra et al. 2013. "Atrial Fibrillation Innovation Program: Transitioning Emergency Atrial Fibrillation Management (Team) – Lessons from a Feasibility Trial." *Canadian Journal of Cardiology* 29(10, Suppl): S99.

Nelson, L. 2012. "Congressional Budget Office." In *Lessons from Medicare's Demonstration Projects on Value-Based Payment*. Working Paper 2012-02" Retrieved May 9, 2013. <http://www.cbo.gov/sites/default/files/cbofiles/attachments/WP2012-01_Nelson_Medicare_DMCC_Demonstrations.pdf>.

Nyweide, D., W. Lee, T. Cuedon, H. Pham, M. Cox, R. Rajkumar et al. 2015. "Association of Pioneer Accountable Care Organizations vs Traditional Medicare Fee for Service with Spending, Utilization, and Patient Experience." *JAMA* 313(21): 2152–61.

Osborn, R., D. Moulds, E. Schneider, M. Doty, D. Squires and D. Sarnak. 2015. "Primary Care Physicians in Ten Countries Report Challenges Caring for Patients with Complex Health Needs." *Health Affairs* 34(12): 2104–12.

Ronson, J. 2013. "Health Links: How to Successfully Execute a Great Idea." Toronto, ON: Longwoods.com. Retrieved March 24, 2015. <<http://www.longwoods.com/content/23366>>.

Smith-Carrier, T., S. Akhtar, T. Pham and S. Sinha. 2012. "Home-Based Primary Care for Frail Older Homebound Adults: An Innovative Solution for a 21st-Century Challenge." *Canadian Geriatrics Society Journal of CME* 2(1): 26–29.

Tracy, C.S., S.H. Bell, L.A. Nickell, J. Charles and R.E. Upshur. 2013. "The IMPACT Clinic: Innovative Model of Interprofessional Primary Care for Elderly Patients with Complex Health Care Needs." *Canadian Family Physician* 59(3): e148–55.

Webster, F., J. Christian, E. Mansfield, O. Bhattacharyya, G. Hawker, W. Levinson et al. 2015. "Capturing the Experiences of Patients across Multiple Complex Interventions: A Meta-Qualitative Approach." *BMJ Open* 5(9): e007664. doi:10.1136/bmjopen-2015-007664.

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A “Simple” Evidence-Based Intervention to Improve Care Transitions for Frail Patients with Complex Health Conditions: Why Didn’t It Work as Expected?

David McNeil, Roger Strasser, Nancy Lightfoot and Raymond Pong

Abstract

The transition from hospital to home is a vulnerable period for patients with complex conditions, who are often frail, at risk for adverse events and unable to navigate a system of poorly coordinated care in the post-discharge period. Care transition interventions are seen as effective care coordinating mechanisms for reducing avoidable adverse events associated with the transition of the patient from the hospital to the home.

A study was undertaken to evaluate the effectiveness of a care transition intervention involving a hand-off between a hospital-based care transitions nurse and a community-based rapid response nurse. Two focus groups were held, one involving rapid response nurses and the other involving care transition nurses. Individual interviews were conducted with the managers ($n = 2$) and executives ($n = 2$) to identify the factors that facilitated or were barriers to its implementation.

Using thematic content analysis, it was found that the effectiveness of transitional coordination efforts was thwarted by ineffective communication, which affected the quality of the underlying relationships between the two teams. Other barriers to achieving the desired outcomes included the following: issues of role clarity, role awareness and acceptance, the adequacy and reinforcement of coordinating mechanisms, the effectiveness of the information exchange protocols and the absence of shared measures of accountability.

Clinical integration initiatives have fewer human resource and financial implementation barriers compared with organizational integration efforts but are complex undertakings requiring clear alignment between organizations, shared accountability measures, effective communication processes and relationships of trust and respect between interprofessional teams.

Background

Patients are being discharged more quickly, allowing less time for providers to prepare patients and their families for discharge (Anthony and Hudson-Barr 2004; Bowles et al. 2002; Chapin et al. 2014; McMurray et al. 2007). Patients are more medically complex (Chapin et al. 2014) and are sometimes discharged from hospital before they have completely recovered (Bull and Jervis 1997; Coleman 2003; Laugaland et al. 2012).

Achieving seamless transitions and coordination of post-discharge care is challenging, given the high degree of system fragmentation (MacAdam 2008). Medical specialization and organizational separation between community, hospitals and physician services create a degree of system complexity that increases the probability of failed communication and discontinuity of care between providers (Chapin et al. 2014; Geary and Schumacher 2012). The information transition from one provider to another is often incomplete as the patient moves from one care setting to another (Chapin et al. 2014; Coleman 2003; Rooney and Arbaje 2012).

Achieving seamless transitions between care settings is viewed as crucial to high-quality care, particularly for the frail older person; adverse events, at the point of transition, occur with regular frequency (Boling 2009; Forster et al. 2003, 2004; Tsilimingras and Bates 2008). These include the following: medication errors; communication breakdowns between providers; incomplete and inaccurate transfer of information; inadequate patient and caregiver education; complex and poorly understood discharge instructions; errors in follow-up of diagnostic tests; infections, falls and complications related to procedures; and limited access to services (Darwin and Parrish 2008; Forster et al. 2004; Moore et al. 2003; Soares et al. 2012).

In recent years, significant interest has developed around the implementation of care transition interventions, as care coordinating mechanisms, to reduce avoidable readmissions and other adverse events in the post-discharge period.

... the relevance of the work was not well understood by staff members not directly involved in the work ...

Study Overview

A mixed-methods study was undertaken at Health Sciences North, an academic health sciences centre located in the City of Greater Sudbury in northeastern Ontario (Canada) and the Northeast Community Care Access Centre, an organization responsible for providing community-based home care. Appropriate ethics approvals were obtained.

The first phase of the study involved a randomized controlled trial (RCT) that evaluated the efficacy of a care transitions nurse and a rapid response nurse, home follow-up intervention and referral to hospital-based chronic disease management clinics. The aim was to lengthen the time to first readmission or emergency department visit and reduce total post-discharge inpatient and emergency department use. The results of this RCT demonstrated no statistically significant differences between the intervention and control groups.

The second phase of the study involved a qualitative analysis using focus groups involving rapid response and care transitions nurses and individual interviews with managers ($n = 2$) and executives ($n = 2$) to identify why the intervention did not achieve the outcomes expected. Although the number of respondents for this analysis was small, the results were deemed to be very informative about the intervention. The results of the second phase of the study are highlighted in this paper.

Results

Five key themes emerged from the focus groups and interviews: (1) clarity about the intended purpose; (2) poor alignment of organizational mandates and care processes; (3) patient complexity, selection process and criteria; (4) relationships

and communication challenges between the teams; and (5) inadequate awareness of outcomes.

Clarity about the intended purpose

The teams did have a common understanding of the intervention’s purpose, which was to improve patient transitions, reduce readmissions, improve information transfer and enhance patient satisfaction. This common perspective is reflected in the comments of one of the community-based rapid response nurses, “... the goals for sure are patient-oriented and the purpose is to work with each other and them (the hospital care transitions nurses) to get the inside info for us and to pass that on so we can continue in the community.”

Poor alignment of organizational mandates and care processes

Achieving agreement on work processes was difficult due to organizational mandates that were described by one participant as “not necessarily being the same.” This lack of alignment was reinforced by a sense of competition and issues of trust as a result of different views of work ownership, “... because they do not trust either CCAC or the services that are already out in the community.” The community-based rapid response nurses raised concerns that the hospital’s involvement in post-discharge aftercare would lead to duplication of effort, “... if the hospital starts getting into the community services and duplicates what is already there ...” and reinforce the hospital’s dominance as the location for care delivery within the community, “keep the hospital in the hospital you know because if people are in and out of the hospital, where is going to be the place to go? It is going to be Emerg.”

Role clarity, role awareness and the degree of acceptance of the roles were consistently identified as a challenge for both the care transitions nurses and rapid response nurses within each of their respective organizations. The work of transitions was not well integrated into the daily workflows of the respective organizations. Further, the relevance of the work was not well understood by staff members not directly involved in the work, as articulated by a care transitions nurse, “... there is ... staff out there who just see what we do as frivolous.” While formal mechanisms of accountability, policies, processes and joint committees for coordinating work between the teams were established, the study revealed a lack of reinforcement of these formal mechanisms, making the task of coordination and integration of the interdependent work processes more difficult.

The focus groups revealed the work process complexities of managing patient transitions between the two organizations, “... having two separate organizations doing part of the process is doable but it makes it more complex.” There were challenges with referral coordination between the two teams and other community service providers, leading to poor service

coordination and service duplication. Once home, patients experienced interactions with multiple providers through home visits or telephone calls that left them feeling overwhelmed, as one nurse reported, “... they see so many people, they are getting so many phone calls that they are overwhelmed.”

Communication between the care transitions nurses and rapid response nurses was described as neither open nor effective ...

Patient complexity, selection process and criteria

The screening tools and protocols used to identify patients selected were described as effective in identifying the intended patient population but labour-intensive. The patient population served was described as highly frail and vulnerable with complex medical conditions and uncertain outcomes. Nurses identified challenges with patient motivation and health literacy, with most concluding that the patient population was simply too frail to benefit from the intervention as designed, “a lot of people are going to come continuously back, but that is going to happen no matter what, because sometimes there is nothing we can do for them; they are sick and they have to come back ...”

The perspective of nurses delivering care was that the transitional intervention was patient-centred, that it facilitated the establishment of a strong therapeutic relationship through the comprehensive care planning, medication reconciliation, reassurance, prioritization of care activities and the strengthening of the patient’s self-management capabilities through education and coaching.

Relationship and communication challenges between the teams

Communication between the care transitions nurses and rapid response nurses was described as neither open nor effective, “I do not know why open communication is such a problem.” Several mechanisms were experimented with, including weekly meetings, web-portals and teleconferences but were considered inconvenient, untimely and inconsistent. The absence of regular and effective communication left members of the teams feeling demeaned, uninformed and frustrated and resulted in the deterioration of an already strained working relationship, as reflected in a comment from the focus groups: “... the lack of communication, you are not from the same team.”

At the provider level, the participants clearly reflected the lack of mutual recognition and respect for each other’s role, reinforcing a sense of competition rather than collaboration, as reflected in the comments from one of the nurses in the focus group, “there is a lot of that going on and I just feel that we are always working against each other, instead of with each other.” But there was a clear desire for change and a sharing of ideas on how things could improve, “... okay I am open, let’s hear it, let’s work together.”

The transfer of patient information is a specific aspect of communication that was analyzed. The demands of the patient information transfer were significant due to the clinical complexity and the uncertainty of the patient’s condition. The mechanisms that facilitated the information transfer included multidisciplinary team interactions, daily bullet rounds, a team assistant for the community care access centre and faxes.

The qualitative interviews revealed that the care transitions nurses went through considerable effort to provide patients, rapid response nurses, primary care providers and chronic disease management clinics with an extensive amount of information, “on discharge, we fax packages to each area that is going to be part of the patient’s out-of-hospital care ... everyone is made aware.” But the relevance of the information provided was not clear and was described as flowing only one way. The mechanisms used to flow information were identified as cumbersome, resulting in information that was not always available in a timely manner.

Inadequate awareness of outcomes

The focus groups revealed the absence of well-defined feedback mechanisms to enable the evaluation of the patient’s post-discharge plan of care. The absence of adequate feedback did not allow for mutual problem solving, as reflected in the comment from a care transitions nurse, “We would know if it was beneficial to them. What the rapid response nurse did when they were there ... that would be nice to know.” Finally, there were few monitoring processes or outcome measures at any level, inhibiting the establishment of effective mechanisms of accountability between the two organizations.

Discussion

This care transition intervention differed from others such as Naylor’s (1999) Care Transitions Model, Coleman’s Care Transition Program (2003) and others (Manderson et al. 2012), which used liaison or navigator roles to serve a system-spanning function, linking and coordinating care by facilitating the flow of information between care settings (Dohan and Schrag 2005). Accomplishing similar outcomes in the transition from the hospital to home, between two organizations, while identified by the participants in this study as achievable, was difficult in the absence of similar views on mandate, shared accountability and alignment between providers for the outcomes. The idea of creating alignment through measurement accountability has been suggested by others as a way to force the forging of partnerships between providers to create a greater degree of mutual accountability to each other, the patient and the system (Burke et al. 2013).

The task of transitions in this intervention operated in a sequentially interdependent manner (Nadler and Tushman 1988). The lack of feedback mechanisms posed a barrier to the

effective exchange of patient information, the appropriateness of referrals, the relevance and timeliness of the information provided and the outcomes of care (Gittell and Weiss 2004). The intervention design would have benefited from a better-established mechanism of two-way information sharing with a focus on solving care coordination problems (Havens et al. 2010).

A fundamental issue in the design of the intervention was that the home follow-up period was limited to 30 days. Given the frailty of the population, the 30-day follow-up period was probably insufficient. Transitional interventions that have longer periods of follow-up have demonstrated longer-term success in changing health status and health utilization behaviours of the population they serve (Counsell et al. 2007; Enderlin et al. 2013; Manderson et al. 2012; Naylor et al. 2004). The current intervention may have been more suitable for a less frail patient population.

Limitations

In addition to several of the challenges identified above, a limitation of this study is the small sample size of the focus groups and the number of participant interviews. Additional time may have allowed the teams to improve their work processes and address their challenges related to both communication and relationship. At the time of writing this paper, these approaches are in fact happening. Finally, understanding how inpatient and emergency services were being used and not just the amount would have provided additional understanding of patient need and the effectiveness of the transitional intervention.

Policy implications

Care transitions arrangements are a form of integration focused on coordinating care at the patient or clinical level where existing organizational arrangements are retained, but explicit structures, protocols, individuals and other resources are applied to managing the care needs of specific patient populations, such as the elderly or patients with chronic diseases (MacAdam 2008). The main advantage of care transitional arrangements as an integration activity is that significant improvements in patient care can be achieved with fewer financial and human resource barriers to implementation, as compared with organizational or system integration (Curry and Ham 2010; McDonald et al. 2007; Peikes et al. 2009).

Care transitions initiatives have the patient as the object of integration and differ in focus from integration initiatives focusing on organizations as the objects of integration. There is an implicit assumption that organization-based integration activities achieve better care coordination and patient outcomes (Singer et al. 2010). These authors suggest that study results are mixed and limited in terms of the effectiveness of integration models involving organizations and health systems. Fleury (2006) argues that integration efforts that are more focused

around targeted, patient-specific groups such as the elderly or those with specific diagnosis are more effective.

Although nominally patient focused, the current study demonstrates the complexities of integrating care activities across multiple organizations and identifies potential enablers to achieve more effective integration through care coordination activities such as care transitions initiatives. These enablers are discussed below and summarized in Table 1.

TABLE 1.
Enablers of effective care transitional interventions

Enablers	Enabler Impact
Clarity and alignment of purpose	A key enabler to the alignment of work processes, role clarity and relationships of trust and respect
Shared measures of accountability	Shared process and outcomes measures reinforce accountability and transparency of commitments
Open, direct communication	Open, direct communication between providers is foundational to relationships of trust and respect
Relationships of trust and respect	A prerequisite for effective coordination and integration of care between providers and organizations
Efficient information transfer	Efficient, direct transfer of relevant patient information between providers to support continuity and coordination of care
Appropriate patient selection	Patient risk stratification and distinct transitional pathways for low-, medium- and high-risk patients
Ongoing feedback	Patient-level feedback from patients and providers to identify opportunities for improvement
Investment effect	Integrating transitional work processes within existing organizational arrangements takes time

Clear alignment of the purpose and shared measures of accountability are key enablers. Accountability measures should focus on processes of care delivery and the resulting outcomes to the patient and system. As well, the establishment of relationships of trust and respect amongst care providers supported by effective mechanisms of communication, clearly defined roles and effective mechanisms for the transfer of patient information are crucial for effective care transitions, coordination and integration initiatives involving multiple organizations (Gittell 2002; Gittell and Weiss 2004).

The transitional intervention needs to be targeted at the right patient population. Through the application of relatively simple patient stratification tools, it is possible to categorize patients from low, to medium and high intensity, based on the complexity and uncertainty of patient outcomes. In the current study, the patients may have been too frail to have benefitted from the pathway as designed. In the transition of patients from the hospital to home, different pathways should exist. These might include pathways for patients with moderate care needs, such as those with chronic diseases amenable to

improved management. Alternative pathways should exist for high-risk, frail patients for whom the impact of multimorbidity, complexity and frailty is the prevailing concern and where it is more appropriate to focus on establishing “goals of care” that incorporate advance care planning and potentially a more palliative care pathway.

Finally, there is an investment effect; that is, achieving the intended results of the intervention takes time and that time needs to be invested in establishing the relationships at all organizational levels (Manderson et al. 2012). This study provides further evidence of this requirement. Modifications to any intervention need to occur along the way: an intervention should not be seen as a rigid approach. The idea is to optimize the effectiveness with improvements to the intervention over time.

Conclusion

Effective patient transitions between organizations are achievable but are complex undertakings and weakened by a lack of clear alignment, common accountability, clarity in roles, communication and information transfer mechanisms and relationships of mutual respect. These are barriers amenable to improvement. Consequently, it is recommended that implementation of patient care transitions across organizations should be designed with a clear focus on the patients’ best interests and require care providers to develop, implement and evaluate clear and effective mutually respectful communications, which include regular, meaningful feedback to all involved individuals, including the patients, as well as the participating organizations. **HQ**

References

Anthony, M. K. and D. Hudson-Barr. 2004. “A Patient-Centered Model of Care for Hospital Discharge.” *Clinical Nursing Research* 13(2): 117.

Boling, P.A. 2009. “Care Transitions and Home Health Care.” *Clinics in Geriatric Medicine* 25(1): 135.

Bowles, K.H., M.D. Naylor and J.B. Foust. 2002. “Patient Characteristics at Hospital Discharge and a Comparison of Home Care Referral Decisions.” *Journal of the American Geriatrics Society* 50(2): 336.

Bull, M.J. and L.L. Jervis. 1997. “Strategies Used by Chronically Ill Older Women and Their Caregiving Daughters in Managing Post Hospital Care.” *Journal of Advance Nursing* 25(3): 541.

Burke, R.F., S. Kripalani and E.E. Vasilevskis. 2013. “Moving Beyond Readmission Penalties: Creating an Ideal Process to Improve Transitional Care.” *Journal of Hospital Medicine* 8: 102–09.

Chapin, R. K., D. Chandran, J.F. Sergeant and T.L. Koenig. 2014. “Hospital to Community Transitions for Adults: Discharge Planners and Community Service Providers’ Perspective.” *Social Work in Health Care* 53(4): 311.

Coleman, E.A. 2003. “Falling through the Cracks: Challenges and Opportunities for Improving Transitional Care for Persons with Continuous Complex Care Needs.” *Journal of the American Geriatrics Society* 51(4): 549.

Counsell, S.R., M. Callahan, D.O. Clark, W. Tu, A.B. Buttar, T.E. Stump et al. 2007. “Geriatric Care Management for Low Income Seniors: A Randomized Control Trial.” *JAMA* 298(22): 2623.

Curry, N. and C. Ham. 2010. *Clinical and Service Integration: The Route to Improved Outcomes (Report)*. Retrieved June 20, 2016. <<https://www.kingsfund.org.uk/sites/files/kf/Clinical-and-service-integration-Natasha-Curry-Chris-Ham-22-November-2010.pdf>>.

Darwin, B. and M. Parrish. 2008. *Navigating Care Transitions in California: Two Models for Change (Report)*. Retrieved June 20, 2016. <<http://www.chcf.org/publications/2008/09/navigating-care-transitions-in-california-two-models-for-change>>.

Dohan, D. and D. Schrag. 2005. “Using Navigators to Improve Care of Underserved Patients.” *Cancer* 104(4): 848. doi:10.1002/cncr.21214.

Enderlin, C.A., N. McLeskey, J.L. Rooker, C. Steinhauser, D. D’Avoilio, R. Gusewelle et al. 2013. “Review of Current Conceptual Models and Frameworks to Guide Transitions of Care in Older Adults.” *Geriatric Nursing* 34(1): 47–52.

Fleury, M.J. 2006. “Integrated Service Networks: The Quebec Case.” *Health Services Management Research* 19: 153.

Forster, A.J., H.D. Clark, A. Menard, N. Dupuis, R. Chernish, N. Chandok et al. 2004. “Adverse Events among Medical Patients after Discharge from Hospital.” *Canadian Medical Association Journal* 170(3): 345–49. <<http://www.cmaj.ca/content/170/3/345.abstract=20>>.

Forster, A.J., H.J. Murff, J.F. Peterson, T.K. Gandhi and D.W. Bates, 2003. “The Incidence and Severity of Adverse Events Affecting Patients after Discharge from the Hospital.” *Annals of Internal Medicine* 138(3): 161.

Geary, C.R. and K.L. Schumacher. 2012. “Care transitions: Integrating Transition Theory and Complexity Science Concepts.” *Advances in Nursing Science* 35(3): 236.

Gittell, J.H. 2002. “Coordinating Mechanisms in Care Provider Groups: Relational Coordination as a Mediator and Input Uncertainty as a Moderator of Performance Effects.” *Management Science* 48(11): 1408. <<http://search.ebscohost.com/login.aspx?direct=true&db=bth&AN=8644940&site=bsi-live>>.

Gittell, J.H. and L. Weiss. 2004. “Coordination Networks Within and Across Organizations: A Multi-level Framework.” *Journal of Management Studies* 41(1): 127. doi:10.1111/j.1467-6486.2004.00424.x.

Havens, D.S.F., J. Vasey, J.H. Gittell and W.-T. Lin. 2010. “Relational Coordination among Nurses and Other Providers: Impact on the Quality of Patient Care.” *Journal of Nursing Management* 18(8): 926. doi:10.1111/j.1365-2834.2010.01138.x.

Laugaland, K., K. Aase and P. Barach. 2012. “Interventions to Improve Patient Safety in Transitional Care – A Review of the Evidence.” *Work* 41: 2915.

MacAdam, M. 2008. *Frameworks of Integrated Care for the Elderly: A Systematic Review*. Canadian Policy Research Networks (Report). Retrieved June 20, 2016. <www.cprn.org/documents/49813_EN.pdf>.

Manderson, B., J. McMurray, E. Piraino and P. Stolee. 2012. “Navigation Roles Support Chronically Ill Older Adults through Healthcare Transitions: A Systematic Review of the Literature.” *Health and Social Care in the Community* 20(2): 113. doi:10.1111/j.1365-2524.2011.01032.x

McDonald, M., V. Sundaram, D. M. Bravata, R. Lewis, N. Lin, S.A. Kraft et al. 2007. “Closing the Quality Gap: A Critical Analysis of Quality Improvement Strategies.” Technical Review. Agency for Healthcare Research and Quality 7(9): 1.

McMurray, A., P. Johnson, M. Wallis, E. Patterson and S. Griffiths. 2007. “General Surgical Patients’ Perspectives of the Adequacy and Appropriateness of Discharge Planning to Facilitate Health Decision-Making at Home.” *Journal of Clinical Nursing* 16: 1602–09.

Moore, C., J. Wisnivesky, S. Williams and T. McGinn. 2003. “Medical Errors Related to Discontinuity of Care from an Inpatient to an Outpatient Setting.” *Journal of General Internal Medicine* 18(8): 646–51.

Nadler, D. and M. Tushman. 1988. *Strategic Organization Design: Concepts, Tools and Processes*. Glenview IL: Scott Foresman and Company.

Naylor, M.D., D. Brooten, R. Campbell, B.S. Jacobsen, M.D. Mezey, M.V. Pauly et al. 1999. “Comprehensive Discharge Planning and Home Follow-Up Of Hospitalized Elders: A Randomized Clinical Trial.” *JAMA* 281(7): 613–20.

Naylor, M.D., D.A. Brooten, R.L. Campbell, G. Maislin, K.M. McCauley and J. S. Schwartz. 2004. “Transitional Care of Older Adults Hospitalized with Heart Failure: A Randomized Clinical Trial.” *Journal of American Geriatrics Society* 52(5): 675.

Peikes, D., A. Chen, J. Schore and R. Brown. 2009. “Effects of Care Coordination on Hospitalization, Quality of Care, and Health Care Expenditures among Medicare Beneficiaries: 15 Randomized Trials.” *JAMA* 301(6): 603.

Rooney, M. and A. I. Arbaje. 2012. “Changing the Culture of Practice to Support Care Transitions-Why Now?” *Generations* 36(4): 63.

Singer, S. J., J. Burgers, M. Friedberg, M. B. Rosenthal, L. Leape and E. Schneider. 2010. “Defining and Measuring Integrated Patient Care: Promoting the Next Frontier in Healthcare Delivery.” *Medical Care Research & Review* 68(1): 112.

Soares, M. M., K. Jacobs, K. Laugaland, K. Aase and P. Barach. 2012. “Interventions to Improve Patient Safety in Transitional Care – A Review of the Evidence.” *Work* 41: 2915.

Tsilimingras, T. and D. W. Bates. 2008. “Addressing Post-Discharge Adverse Events: A Neglected Area.” *Joint Commission Journal on Quality and Patient Safety* 34(2): 85.

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Improving Outcomes through Transformational Health and Social Care Integration – The Scottish Experience

Anne Hendry, Alison Taylor, Stewart Mercer and Peter Knight

Abstract

The Scottish Parliament recently passed legislation on integrating healthcare and social care to improve the quality and outcomes of care and support for people with multiple and complex needs across Scotland. This ambitious legislation provides a national framework to accelerate progress in person-centred and integrated care and support for the growing number of people who have multiple physical and mental health conditions and complex needs. Additional investment and improvement capacity is helping to commission support and services that are designed and delivered with people in local communities and in partnership with housing, community, voluntary and independent sectors.

Introduction

The Scottish Parliament recently passed ambitious legislation on integrating healthcare and social care to improve the experience and quality of care for the growing number of people in Scotland who have multiple conditions, complex care and support needs or challenging life circumstances. This paper describes the health and care context in Scotland and the drivers for healthcare and social care integration underpinned by analysis of data on the changing population and needs for healthcare and social care. It outlines the anticipated outcomes from integrated care and highlights progress in Reshaping Care for Older People through support and services that are designed and delivered with

people in local communities and in partnership with housing, community, voluntary and independent sectors.

Drivers for Change

The population of Scotland is projected to rise by 7% from 5.4 million in 2014 to 5.7 million in 2039 (National Records Scotland 2015). The population aged 75 years and over – the highest users of health and care services – is projected to increase by 85% over that period. The prevalence of long-term conditions increases with age, from 25% of adults aged 16–24 to 77% of those aged 75 and over (Scottish Health Survey 2015). Overall, 46% of adults had one or more long-term conditions (31% limiting and 15% non-limiting), and 19% of children had a long-term condition. In the 2013 Scottish Household Survey, 34% of households reported at least one adult or child with a long-standing illness, health problem or disability (Scottish Government 2014a, 2014b). This figure rises to 45% in households with an income of £20,000 or less.

Recent epidemiological research in Scotland, which included 32 physical conditions and eight mental health conditions, found that 24% of the primary-care population have two or more long-term conditions (multimorbidity). The onset of multimorbidity occurs 10–15 years earlier in deprived areas compared with affluent areas, and socioeconomic deprivation was particularly associated with multimorbidity that included

mental health disorders (Barnett et al. 2012). A combination of physical and mental health problems increases clinical complexity and is generally associated with negative outcomes for individuals and families (Naylor et al. 2012).

Based on the evidence of this changing demography, it was clear that separate, and often fragmented, healthcare and social care systems could no longer meet the needs and expectations of the growing number of people in Scotland who have multiple, complex, long-term conditions and who require well-coordinated, person-centred and integrated care that offers empathy, continuity of care and collaborative relationships with professionals (Mercer et al. 2012a).

Table 1, adapted from “Delivering for Health” (Scottish Executive 2005), illustrates the paradigm shift required to create a system that will be attuned to multimorbidity and complexity. The core element is well-coordinated and integrated healthcare and social care.

TABLE 1.
A paradigm shift to create a future system

Current system	Future system
Geared to acute/single condition	Designed around people with multiple conditions
Hospital-centred	Embedded in local communities and their assets
Doctor-dependent	Multiprofessional and team-based care
Episodic care	Continuous care and support when needed
Disjointed care	Well-coordinated and integrated health and care
Reactive care	Preventive and anticipatory care
Patient as passive recipient	Informed and empowered patients and clients
Self-care infrequent	Self-management/Self-directed support enabled
Carers undervalued	Carers are supported as full partners
Low tech	Technology enables greater choice and control

The Scottish Health and Care Landscape

Since 1999, the Scottish Parliament and the Scottish Government (known as the Scottish Executive until 2007) have had full legislative control of healthcare and social care, resourced through the block grant to Scotland from the UK Treasury. Fourteen NHS Health Boards are responsible for planning and delivering hospital, primary-care and community services for their local populations, working closely with 32 local authorities (local government organizations) that directly provide or commission social care and housing services from the independent and third sectors. These local authorities also lead the Community Planning Partnerships (CPPs), which involve the local NHS Board, police, fire, transport, voluntary, community and private sector organizations. Ham et al. (2013) describe in detail how these arrangements differ from the rest of the UK.

Collaboration between healthcare and social care partners in Scotland has been actively promoted since the report of the Joint Future Group (Scottish Executive 2000). Although the Community Care and Health (Scotland) Act 2002 conferred powers to create pooled budgets between healthcare and social care, this legislation resulted in few examples of effective joint planning and shared resources (Audit Scotland 2011). Integrated care has featured in most healthcare policy documents for over a decade (Scottish Executive 2005, Scottish Government 2010a, 2010b) and is one of the 12 priorities in the route map to the 2020 vision for the future of healthcare in the face of changing demographics and increasing demand for services. Service integration at a local level, a greater shift towards prevention, addressing health inequalities and improving outcomes for individuals are key priorities within the Christie Commission Report on the Future Delivery of Public Services (Scottish Government 2011). So how did we take these priorities forward?

The Path to Legislation

The degree of cross-party support for the policy direction on integration is illustrated by the fact that all major political parties included a commitment to integrate healthcare and social care in their manifestos for the 2011 Scottish Parliament Election (Taylor 2015). During 2012, the Scottish Government consulted on proposals for the integration of adult healthcare and social care (Scottish Government 2012). The vision was to ensure better health and well-being outcomes for people at home and in local communities through care and support designed around the patient/service user and commissioned through effective cross-sectoral planning for the needs of the local population (Scottish Government 2013a, 2013b). There was agreement that services need to be planned and budgeted for across the whole pathway of care, drawing on the assets of local, voluntary and community resources that help to improve health and well-being and with a stronger leadership role for professionals.

The Public Bodies (Joint Working) Scotland Bill was introduced to the Scottish Parliament in May 2013 to provide a firm legislative framework for the integration of adult healthcare and social care services in Scotland. The Act received Royal Assent on 1 April 2014 and requires the local integration of adult healthcare and social care services with the option to include children’s healthcare and social care services, criminal justice social work and housing support services in local integrated arrangements.

This unique and internationally groundbreaking legislation (Scottish Government 2014a, 2014b, 2014c) is grounded in a set of principles that explain what people using services and their carers can expect from integrated services and from the individuals and organizations delivering care and support.

- Services must be integrated from the point of view of service users and planned and led locally in a way that engages the community (in particular service users, carers and those involved in the provision of healthcare or social care) and enables participation by service users in the community in which they live.
- Services must take account of the characteristics, circumstances and needs of different service users and people from different areas in the local community.
- Services will be provided in a way that respects the rights and dignity of service users; improves quality of care and protects and improves the safety of service users; best anticipates needs and prevents them from arising; and makes best use of available facilities, people and other resources.

Health Boards and Local Authorities were required to establish one of two models of integrated partnership arrangements by April 2016: delegation of functions and resources between Health Boards and Local Authorities (Lead Agency) or delegation of functions and resources to a Body Corporate (Integrated Joint Board). Only one partnership (NHS Highland and Highland Council) adopted a Lead Agency model. The remaining partnerships have established Integrated Joint Boards, each with a Chief Officer providing a single point of management for the integrated services and related budget.

By 1 April 2016, each Integration Authority will oversee an integrated budget to support delivery of the integrated functions that have been agreed upon. The new arrangements will manage more than £8 billion of healthcare and social care resources, including all adult social care, adult primary and community healthcare and those aspects of adult hospital care that are most amenable to redesign through enhanced primary and community care. This approach generally includes specialist hospital services for older people and emergency medical care that may be improved through whole-system pathways for prevention and coordination of chronic care and support, palliative care, ambulatory care and intermediate care at points of transition.

Local communities are acknowledged to be the engine room of integrated care and the space to best engage and empower those who deliver and receive healthcare and social care support. Therefore, each Integration Authority will establish locality planning arrangements as a forum for strong local professional leadership and engagement of local, voluntary and independent sectors in service planning. A strategic plan and integrated budget, developed with involvement of providers, non-statutory partners, patients, carers and service-user representatives, will commission the required range of integrated services and community support to improve local population health.

Services must take account of the characteristics, circumstances and needs of different service users ...

Building on Strong Foundations

This legislation builds on a strong platform of improvement and innovation in care for older people and adults with long-term conditions in Scotland. In 2008, the Long-Term Conditions Alliance Scotland (LTCAS), an umbrella organization of voluntary sector organizations (now known as the Health and Social Care Alliance) developed “Gaun Yersel,” the strategy for Self Management in Scotland (LTCAS 2008). This strategy and the chronic care model (Wagner 1998) formed the basis of Improving the Health and Wellbeing of People with Long-Term Conditions in Scotland: A National Action Plan (Scottish Government 2009). A national improvement collaborative from 2008–2011 supported adoption of high-impact changes across three work streams: self-management, condition management and complex care for people with long-term conditions (NHS Scotland 2012). Between 2006/2007 and 2010/2011, the rate of inpatient bed days for coronary heart disease, diabetes, asthma and chronic obstructive pulmonary disease reduced by 14%.

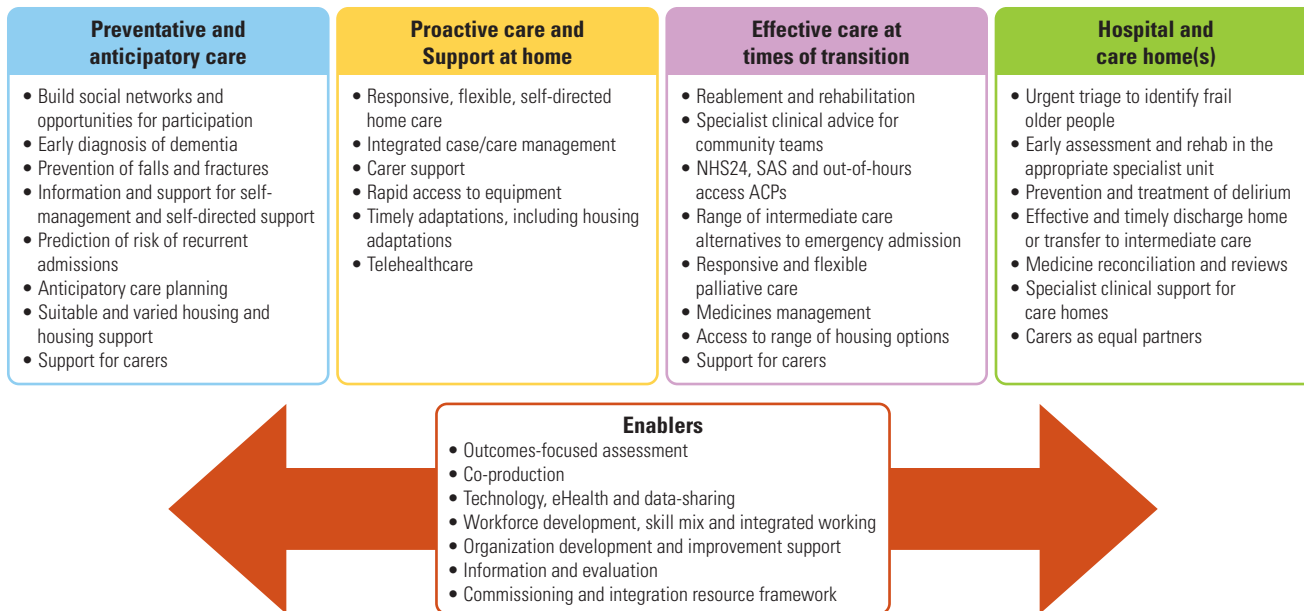
The system learning from the Long-Term Conditions program informed the Reshaping Care for Older People (RCOP) program (Scottish Government 2010a, 2010b). For four years from April 2011, a £300-million Change Fund (around 1% of the healthcare and social care budget for older people) was introduced but dedicated for the specific purpose of local transformation. Local health, social care, housing, third sector and independent sector partners worked together to use this funding to enhance the well-being and independence of older people and their carers; prevent, reduce or delay dependency; improve experience and personal outcomes; and increase the resilience of the system.

The Joint Improvement Team supported the local partnerships to implement a set of interventions across the four pillars of the RCOP pathway (Figure 1) and to learn together as a cross-sector improvement network (Joint Improvement Team 2013). This network adapted breakthrough collaborative methodology to test new approaches, spread good practice, tackle variation and track progress on a core set of improvement measures. The specific aims, ethos, interventions and improvement indicators are all highly transferable to Canada and to other healthcare systems. More information can be accessed at <www.jitscotland.org> and at <www.gov.scot/Topics/Health/Policy/Adult-Health-SocialCare-Integration>.

The Reshaping Care and Change Fund Building on Progress Report (Joint Improvement Team 2015) contains over 100 case study examples and key lessons from the partnerships.

Box 1 illustrates progress made against the core RCOP indicators.

FIGURE 1.
Reshaping Care Pathway



BOX 1.
Progress from Reshaping Care and the Change Fund by April 2015

- 39% of the Change Fund provided support for carers including assessments, short breaks, information, advice, training, income maximization and advocacy.
- Around 16% of the Change Fund was invested in the voluntary sector.
- 85% of older people receiving support at home now benefit from telecare.
- 17% reduction in rate of conveyance by Ambulance to the Emergency Department for older people who have fallen and are not injured.
- The hospital bed day rate for people aged 75+ following an emergency admission reduced by 10.3% from 2009/2010 to 2014/2015. In absolute terms this equates with a reduction of around 2% in the number of beds used, despite the increasing number of older people.
- In 2014, there were at least 5500 fewer older people in care homes than projected based on the 2009 rate and demographic trends. Older people spent around 2.5 million more days at home in 2014/2015 than would have been expected based on previous balance of care and population ageing analyses.

Improving Health and Well-being Outcomes for Adults with Complex Needs

While Barnett et al. (2015) found that multimorbidity increases with age, more people under the age of 65 years have multimorbidity in Scotland than those aged over 65 years. Health has not improved quickly enough among the most vulnerable groups in society and entrenched inequalities remain (Audit Scotland 2012). The Ministerial Task Force on Health Inequality (Scottish Government 2008) set the national approach to

tackling this issue through the development of social capital, a specific focus on the 15–44 age group and the development of a Place Standard to improve living environments.

The Public Bodies (Joint Working) Scotland Act requires integration of healthcare and social care for all adult care groups. Integration Authorities are tasked with contributing to reducing health inequalities as one of nine health and well-being outcomes that are the framework for measuring progress in integrated healthcare and social care in Scotland:

- People are able to look after and improve their own health and well-being and live in good health for longer.
- People, including those with disabilities, long-term conditions or frail physicality, are able to live, as far as reasonably practicable, independently and at home or in a homely setting in their community.
- People who use healthcare and social care services have positive experiences of those services and have their dignity respected.
- Healthcare and social care services are centred on helping to maintain or improve the quality of life of people who use those services.
- Healthcare and social care services contribute to reducing health inequalities.
- People who provide unpaid care are supported to look after their own health and well-being, including to reduce any negative impact of their caring role on their own health and well-being.

- People who use healthcare and social care services are safe from harm.
- People who work in healthcare and social care services feel engaged with the work they do and are supported to continuously improve the information, support, care and treatment they provide.
- Resources are used effectively and efficiently in the provision of healthcare and social care services.
- improved coordination and continuity of care and support planned around the needs of the individual throughout their whole pathway between home and hospital, including access to specialist support at home and closer to home.

It acknowledges the crucial role of the voluntary sector in supporting the assets of individuals and communities ...

Extending Prevention and Early Intervention

Building on the learning from the older people Change Fund that concluded in March 2015, the Scottish Government introduced an Integrated Care Fund (£300 million, in total, over three years from April 2015) to help Integration Authorities extend prevention and early intervention approaches to all adult care groups and strengthen their focus on tackling inequalities. Partnerships are expected to plan to reduce future demand and to address issues around the inverse care law, where people who most need care are least likely to receive it (Mercer et al. 2012b).

Guidance or advice on the use of the Integrated Care Fund (Scottish Government 2014a, 2014b, 2014c) encourages investment in preventative supports and interventions for adults with multimorbidity through a stronger focus on personal outcomes, supporting health literacy and adopting a co-production approach; using technology to enable greater choice and control; and adopting an assets-based societal model to improve population health and well-being. It acknowledges the crucial role of the voluntary sector in supporting the assets of individuals and communities so that people can have greater control over their own lives and develop capacity and confidence in self-management.

The guidance encourages the extension of successful chronic care approaches to all adult care groups as described in the Many Conditions One Life, a national action plan for multimorbidity (Joint Improvement Team 2014). The Health and Social Care ALLIANCE involvement network of people who live with multiple conditions supported the Joint Improvement Team to develop this action plan to outline how the Integrated Care Fund can be used to support adults with multiple conditions to live well and to experience well-coordinated, person-centred and integrated care. Individuals and their carers describe the impact on their lives from the practical actions that local partnerships can take:

- anticipatory and collaborative conversations between the person and the professional in every consultation, with a focus on the outcomes that matter to the individual, their carers and families;
- new ways for health and care professionals to work together and with volunteers and local community resources that help people to stay well, in multiprofessional teams configured around clusters of general practices; and

Lessons for Other Systems

The ambitious top-down legislation has been supported by a compelling narrative and extensive engagement on improving outcomes for individuals. Audit Scotland, the independent public spending watchdog, found widespread support for the principles of integration (Audit Scotland 2015). Success factors include a consistent policy direction, strong local and national leadership and the opportunity to build local readiness for change.

“The Change Fund has been a positive catalyst for change, allowed new service models to be nurtured and developed and to begin to change our approach to supporting people in line with the national and local vision.” (Joint Improvement Team 2015)

Practical support is an important enabler for transformation. Support provided includes guidance on the new planning, commissioning, governance and management arrangements; access to data for strategic planning and investment decisions; and phased targeted investment. In addition to the two phases of innovation funding (Change Fund followed by the Integrated Care Fund), a further £250-million investment in social care announced in the Scottish Government’s draft budget for 2016/2017, and in telehealth and telecare, primary care and mental health services will build capacity in community services to reform complex and high-cost service models that are, in many cases, not delivering the outcomes that people need, especially in less affluent areas (Scottish Government 2015a, 2015b).

The conditions in Scotland are set for a unique and large-scale transformation in healthcare and social care. This is not a quick fix. The April 2016 milestone marks the start of a highly ambitious and intensive period of reform. Perhaps the most urgent challenge for the new Integration Authorities will be transforming their workforce in line with the future paradigm described in Table 1. This must happen at pace and scale and at a time when many organizations face significant recruitment challenges. Growing recognition by all professions that the current paradigm is neither desirable nor sustainable offers a strong platform for the required transformation. **HQ**

References

- Audit Scotland. 2011. *Community Health Partnerships*. Edinburgh: Author. Retrieved June 15, 2016. <www.audit-scotland.gov.uk/docs/health/2011/nr_110602_chp.pdf>.
- Audit Scotland. 2012. Health Inequalities in Scotland. Edinburgh: Audit Scotland. Retrieved June 15, 2016. <www.audit-scotland.gov.uk/docs/health/2012/nr_121213_health_inequalities.pdf>.
- Audit Scotland. 2015. Health and Social Care Integration. Edinburgh: Audit Scotland. Retrieved June 15, 2016. <www.audit-scotland.gov.uk/uploads/docs/report/2015/nr_151203_health_socialcare.pdf>.
- Barnett, K., S.W. Mercer, M. Norbury, G. Watt, S. Wyke and B. Guthrie. 2012. "Epidemiology of Multimorbidity for Health Care, Research, and Medical Education: A Cross-Sectional Study." *Lancet* 380(9836): 37–43.
- Ham, C., D. Heenan, M. Longley and D. Steel. 2013. *Integrated Care in Northern Ireland, Scotland and Wales. Lessons for England*. London: The King's Fund.
- Joint Improvement Team. 2013. *Change Fund Progress Report*. Retrieved June 15, 2016. <www.jitscotland.org.uk/wp-content/uploads/2014/11/Change-Fund-2013-14-Progress-Report-November-2013-final.pdf>.
- Joint Improvement Team. 2014. *Many Conditions, One Life. Living Well with Multiple Conditions*. Retrieved June 15, 2016. <www.jitscotland.org.uk/wp-content/uploads/2014/11/Multiple-Conditions-20pp-new.pdf>.
- Joint Improvement Team. 2015. *Reshaping Care for Older People Change Fund. Building on Progress Report*. Retrieved June 15, 2016. <www.jitscotland.org.uk/resource/reshaping-care-for-older-people-change-fund-building-on-progress-june-2015/>.
- Long Term Conditions Alliance Scotland. 2008. *Gaun Yersel: The Self-Management Strategy for Long Term Conditions in Scotland*. Glasgow: Long Term Conditions Alliance Scotland. Retrieved on June 15, 2016. <www.alliance-scotland.org.uk/what-we-do/self-management/>.
- Mercer, S., J. Gunn, P. Bower, S. Wyke and B. Guthrie. 2012a. "Managing Patients with Mental and Physical Multimorbidity." *BMJ* 345: e5559.
- Mercer, S., B. Guthrie, J. Furler, G.C.M. Watt and J.T. Hart. 2012b. "Multimorbidity and the Inverse Care Law in Primary Care." *BMJ* 344: e4152.
- National Records Scotland. 2015. "Projected Population of Scotland (2014-based)." Retrieved June 15, 2016. <www.nrsotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/population/population-projections/population-projections-scotland/2014-based>.
- Naylor, C., M. Parsonage, D. McDaid, M. Knapp, M. Fossey and A. Galea. 2012. "Long-term Conditions and Mental Health. The Cost of Co-morbidities." London: The King's Fund and Centre for Mental Health.
- NHS Scotland. 2012. *Long Term Conditions Collaborative*. Retrieved June 3 2013. <www.qihub.scot.nhs.uk/quality-and-efficiency/outpatient-primary-and-community-care/long-term-conditions-collaborative.aspx>.
- Scottish Executive. 2000. *Community Care: A Joint Future*. Edinburgh, UK: Author.
- Scottish Executive. 2005. *Delivering for Health*. Edinburgh: Scottish Executive. Retrieved June 15, 2016. <www.gov.scot/Resource/Doc/76169/0018996.pdf>.
- Scottish Government. 2008. *Equally Well: Report of the Ministerial Task Force on Health Inequalities*. Retrieved June 15, 2016. <www.gov.scot/resource/doc/229649/0062206.pdf>.
- Scottish Government. 2009. *Improving the Health and Wellbeing of People with Long Term Conditions in Scotland: A National Action Plan*. Edinburgh, UK: Author. Retrieved June 15, 2016. <www.gov.scot/Resource/Doc/294270/0090939.pdf>.
- Scottish Government. 2010a. *Reshaping Care: A Programme for Change 2011–2021*. Edinburgh, UK: Author. Retrieved June 15, 2016. <www.gov.scot/Resource/Doc/924/0114884.pdf>.
- Scottish Government. 2010b. *The Healthcare Quality Strategy for NHS Scotland*. Edinburgh, UK: Author. Retrieved June 15, 2016. <www.gov.scot/Publications/2010/05/10102307/0>.
- Scottish Government. 2011. *Report of the Commission on Future Delivery of Public Services*. Edinburgh, UK: Author. Retrieved June 15, 2016. <www.gov.scot/Publications/2011/06/27154527/0>.
- Scottish Government. 2012. *Integration of Adult Health and Social Care in Scotland: Consultation on Proposals*. Edinburgh, UK: Author. Retrieved June 15, 2016. <www.gov.scot/Publications/2012/05/6469/downloads>.
- Scottish Government. 2013a. *Integration of Adult Health and Social Care in Scotland Consultation: Scottish Government Response*. Edinburgh, UK: Author. Retrieved June 15, 2016. <www.gov.scot/Resource/0041/00414332.pdf>.
- Scottish Government. 2013b. *Route Map to the 2020 Vision for Health and Social Care*. Edinburgh, UK: Author. Retrieved June 15, 2016. <www.gov.scot/Topics/Health/Policy/2020-Vision>.
- Scottish Government. 2014a. Public Bodies Joint Working (Scotland) Act 2014. Edinburgh, UK: Author. Retrieved June 15, 2016. <www.legislation.gov.uk/asp/2014/9/pdfs/asp_20140009_en.pdf>.
- Scottish Government. 2014b. *Integrated Care Fund. Guidance for Local Partnerships*. Edinburgh, UK: Author. Retrieved June 15, 2016. <www.gov.scot/Resource/0046/00460952.pdf>.
- Scottish Government. 2014c. "Scotland's People. Annual Report: Results from 2013 Scottish Household Survey." Edinburgh, UK: Author. Retrieved June 15, 2016. <www.gov.scot/Resource/0048/00487157.pdf>.
- Scottish Government. 2015a. *Draft Budget 2016–2017*. Edinburgh, UK: Author. Retrieved June 15, 2016. <<http://news.scotland.gov.uk/Speeches-Briefings/Draft-Budget-2016-17-2089.aspx>>.
- Scottish Government. 2015b. *The Scottish Health Survey*. Edinburgh, UK: Author. Retrieved February 29, 2016. <www.gov.scot/Resource/0048/00485587.pdf>.
- Taylor, A. 2015. "New Act, New Opportunity for Integration in Scotland". *Journal of Integrated Care* 23(1): 3–9.
- Wagner, E. 1998. "Chronic Disease Management: What Will It Take to Improve Care for Chronic Illness?" *Effective Clinical Practice* 1: 2–4.

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2016 Ted Freedman Award



CONGRATULATIONS!

The **2016 Ted Freedman Award** was awarded to the **Institute for Clinical Evaluative Sciences (ICES)**, **Health Quality Ontario (HQO)**, and the **Institute of Health Policy, Management and Evaluation (IHPME)** in recognition of: *Quality Improvement (QI) at the Frontline: Improving and Driving Excellence Across Sectors (IDEAS)*. The award was presented at CAHSPR 2016 in Toronto and accepted by Vivian Ng, Ximena Camacho and Jennie Pickard.

▲
The Ted Freedman Award for Innovation in Education: a self-portrait in bronze of the artist as a patient recovering from brain surgery, by award-winning sculptor Amy Switzer.

► From left to right:
Ximena Camacho, Vivian Ng
and Jennie Pickard.
Photo courtesy of HQO.



An Honourable Mention goes to Silvia Lizett Olivares Olivares, Mildred Vanessa López Cabrera, Martha Ruth Loyola Segura, and Jorge Eugenio Valdez García at the **School of Medicine at Tecnológico de Monterrey**. In recognition of: *Competency-based Faculty Development Program for Clinical Educators*.

In Conversation with

Nick Goodwin

Co-Founder and CEO, International Foundation for Integrated Care

Renee Lyons



The Dutch-based International Foundation for Integrated Care (IFIC) is a not-for-profit membership-based network that crosses organisational and professional boundaries to bring people together to advance the science, knowledge and adoption of integrated care in policy and practice (<http://integratedcarefoundation.org/about-ific>). Guest editor, Renee Lyons, recently spoke with IFIC's co-founder and CEO, Nick Goodwin, about examples of excellence in the adoption of integrated care around the world, as well as the challenges that lie ahead in realizing its full potential across health and social care systems.

Renee: How did you get interested in integrated care?

Nick: I'm a social scientist and have worked in academia and the third sector all my life. I started off at The King's Fund – the health charity in London – as a researcher and then moved to the Health Services Management Centre at the University of Birmingham. In each of those roles, I focused on issues related to the service delivery and organisation of primary and community care and specifically the role of primary care organizations in commissioning. Integrated care became part of my

portfolio in the late 1990s and in 1999 I met up with a group of academics from different disciplines in Almere, Netherlands where we founded the *International Journal of Integrated Care* (www.ijic.org) and from which IFIC was later to emerge (Nick is currently the Editor-in-Chief of IJIC).

It has been 16 years since that original meeting. Over time, we recognised that there was a case to be made to support a ‘movement’ towards integrated care. Other than the original fascination as a social scientist in observing the complexities of integrated care, my own motivation comes from seeing first hand how the lack of care coordination has such a terrible impact on older people with multiple needs. It is a fact that people who would most benefit from care coordination – for example, older adults, those living in poverty, those from ethnic minorities, people living in rural communities and children and adults with chronic conditions who will require health and social services over their lifetime – are the ones who are least likely to receive it (Øvretveit 2011). So, despite integrated care being pro-equity in its philosophy, there’s currently an “inverse care law” in how care is designed and delivered that needs to be addressed. I became very motivated about that, and it was in 2011 – when we officially founded IFIC – that we began to tease out what the Foundation might do.

... integrated care should be a program for people with complex needs that improves health and reduces costs. However ... we see a lot of failure to achieve these aims.

Renee: You’ve interacted with so many people who are testing out innovations in integrated care. If you were to pick three or four places that you think are leaders in this area, what would they be?

Nick: That’s a really interesting question. In my view, integrated care should be a program for people with complex needs that improves health and reduces costs. However, because we typically assess short-term pilot projects, we see a lot of failure to achieve these aims.

My vision of what a system should attempt to do is very much population health focused to improve health outcomes for communities and involving communities in their own care. It’s really through an inclusive and collective vision, and the ability to engage effectively with people and professionals through empowerment and engagement strategies, that you begin to really see transformational change in care.

When you look around the world, there is a definite trend towards population-based and more integrated delivery systems that bring together a capitated budget for that population and seek ways to make the best use of that money through multi-agency partnerships, networks and alliances.

A good example of this is in Counties Manukau, New Zealand. This area, to the south of Auckland, has a high percentage of Pacific Highlanders and Maori, many of whom have lifestyle factors that mean they have a greater susceptibility to chronic illness. A key philosophy in Counties Manukau has been the need to invest in communities and families to be able to improve health as a whole. Projects include the development of four local community partnerships (LCPs) that use a global budget to shift care into the community to focus more on prevention and early intervention whilst improving processes through investing in multi-disciplinary teams and redesigning care pathways (Counties Manukau Health n.d.)

Another excellent example is the NUKA health system in Alaska where healthcare to the 60,000 people in the Alaskan Native Community has been significantly improved through developing community-owned and integrated health-care solutions around people’s needs. In 1997, the Alaskan Congress passed a law that allowed Alaska Native people to obtain the ownership and management of their health system. As a result, the Southcentral Foundation established a range of primary care centres that offer an interdisciplinary set of services including home health, health education and specific programs to support the elderly and children. Active ownership of the Foundation by the local community (so called ‘consumer-owners’) and ‘walking with communities’ to achieve change has been central to its success. Key results since 1997 include:

- increased enrolment in primary care from 35% to 95% of the population;
- same day access for routine appointments, down from 4 weeks;
- waiting lists for behavioural health consultations eliminated through having integrated physical and mental healthcare services;
- increased patient and staff satisfaction with a greater respect to culture and traditions, with reduction in staff turnover of 75%;
- a 36% reduction in hospital bed days; 42% reduction in visits to the emergency department; and a 58% reduction in treatment at specialist clinics;
- reduced disparities and improved care outcomes for people with cancer, obesity, diabetes, and dental caries; plus
- reduced levels of child abuse, child neglect, domestic violence, substance abuse and suicide (Gottlieb 2013; Kyle 2016).

The key to NUKA’s success lies in relationship-building. By engaging with the local population around their healthcare needs they have enabled a culturally sensitive way of working to get the best outcomes.

Population health approaches are happening in many other places. There's a unique initiative called *Gesundes Kinzigtal* (meaning "Healthy Kinzigtal") that is the only population-based integrated care approach in Germany. The system is run by a regional health management company in cooperation with a physicians' network. A key feature in *Gesundes Kinzigtal* has been the development of a 'shared health gain' approach by means of a shared savings contract, and the model has attracted non-health partners (e.g. leisure centres and other community groups) to become stakeholders (Lupianez-Villanueva and Theben 2013). Having started in 2006, continued investment in preventive and health promotion programs have led to a reduction in morbidity and mortality compared to comparator regions, and reduced overall costs to the insurer (Barnes et al. 2014).

Renee: So what is it about the context that contributes to such changes?

Nick: There is something important about the capacity of the community to respond and engage in their own health and welfare. So if you go to somewhere like Kazakhstan, for example, there is no recognition that part of the social compact between care providers and patients is that patients should be empowered and take responsibility for managing their own health. In any country where there is an entitlement-based or demand-led culture it can be much more difficult to engage people in their health behaviours. Unless you can have that two-way conversation with the local population to make things better, so that people feel a responsibility to their own care and that of the community, then you're not going to get far in dealing with today's challenges.

Integrated care at its most ambitious aims to bring together all of your community assets, along with your healthcare providers, with a remit to improve health. When that happens, there is the greatest potential for truly transformational effect in terms of health and well-being within those communities. There are enough examples now across the world to demonstrate this to be true, but of course they're isolated examples, highly context-specific, and so difficult to replicate.

Renee: What can we take away from these examples?

Nick: One cannot simply adopt or transfer a specific model of care. One has to take the lessons from how change has been implemented and start, probably from scratch, in working with the local community and the various health and care stakeholders to devise your own solution. Hence, the process needs a guiding coalition, a common purpose, and a shared vision. Underpinning these must be

a compelling narrative on what partners must do together to influence and change the way care is organised and delivered. All should be convinced that it is likely to lead to better health outcomes, improve care experiences, and more affordable and sustainable services. It's about creating a business model that people can understand and from which all will ultimately benefit.

There is something important about the capacity of the community to respond and engage in their own health and welfare.

Renee: It's very much a community development model that you're talking about. I want to ask you about government's role in scaling up and sustaining effective practices. What does government need to consider to support this kind of work and sustain it over time?

Nick: There are two streams of thought here. On one level, you need governments to be able to provide the vision for the system to move forward and so take steps to create an enabling platform for change. For example, in The Basque Country, Spain, they basically set out a mission to become the "best chronic care system in the world" and set out policies, targets and a range of support mechanisms (such as electronic health records and new payment models) to encourage change from the top. However, they also recognised that change would only be delivered by care professionals with the drive and commitment from the "bottom-up," so within that national directive was a significant degree of support for local innovation (Bengoia 2013).

Today, the Basque system has progressed to create Integrated Healthcare Organizations (IHOs) with a single governance structure to oversee care in primary, community and hospital settings whilst promoting less formal care co-ordination approaches with social care (Toro Polanco et al. 2015). The speed of innovation in the Basque country is impressive, and in part this is because they have adopted integrated chronic care as a consistent national strategy.

However, the problem in most countries is that there is not the same political stability to stick with coherent integrated care policies into the long-term. Moreover, since public finances are increasingly tight, you see the strains of that – particularly in Europe in the current economic crisis. Too often integrated care is used as a policy to cut or contain costs, rather than a force for quality improvement, and this leads to short-term thinking as the primary focus is managing austerity rather than the fundamental transformation that is required of care systems that focus on people-centred integrated care and have a chance to change the cost curve.

In my own country, England, this is absolutely the case. At a local level, there is great innovation but also tight control over what can and cannot be expended, meaning that it's almost impossible to properly invest in that innovation. Whereas in the Basque Country, they do not have the same financial problems as they have a political pact with the people to more generously fund health and social care. They have let innovation bloom because they have the political mandate to do so and feel it will lead to better outcomes.

The role of government is to provide the policy and have the enabling architecture in place – finance, accountability, and information technology. But it shouldn't micro-manage the process. It's much better to set the vision for a local community, give them a capitated budget and say, "These are the outcomes we're looking for. You've got the experience; you know all of the providers – off you go." Government can also help with information exchange and knowledge transfer, so that people don't replicate practices, and they bring in good practices. There are lots of things government can do, but micro-management kills it. Although that, of course, is very common.

Renee: Do you see tensions between physicians and the other parts of the healthcare system, in terms of moving change forward?

Nick: Absolutely. Even where you manage to create recognition that by working together they can achieve better outcomes, it's very easy for it to fall apart for two main reasons: first, the win-win situation isn't there, so one organization is benefiting when another one is not; or second, there's the perception that someone within a partnership is not doing a job that others are professionally happy about.

A study from the Netherlands, led by Pim Valentijn, found this situation when looking at the more successful Dutch Care Groups that were utilising bundled payments to manage people with chronic disease (Valentijn 2016). The Care Groups that were less successful were more likely to report dissonance between partners in care through a lack of mutual gain and poor process management. There is a need to build collaborative capacity, but there also has to be something concrete underpinning integrated care that demonstrates its benefits to different professional groups and organizations (for example, financially, through higher quality of care, or a better work-life balance). Otherwise, no matter how motivated people are, they're not going to get engaged.

Hospitals, for example, are often perceived negatively when it comes to integrated care, yet have the resources and knowledge to play a huge and positive role in integrated care. For

example, in the case of the Hospital Clinic Barcelona, where they have evolved a program of chronic care management from the late 1990s to create a project called *Barcelona Esquerra* that helps to provide community-based and integrated chronic care through a population health-based approach to the 'left' side of Barcelona (Font et al. 2016). This has included investing and building primary care facilities, which they own and operate, and enabling a close relationship between GPs and specialists. The outcomes for people with chronic illness, such as the numbers of people coming into the hospital with exacerbations that need an emergency or acute response, have been reduced.

Even where you manage to create recognition that by working together they can achieve better outcomes, it's very easy for it to fall apart ...

Renee: The process of making things work in a specific context may misalign with budgets and indicators. There's this sort of tension, isn't there?

Nick: Time is a big factor. It takes a long time to invest in public health and engage with the community. If you're running one-year budget cycles where you have a specific budgetary target to meet within a year, then long-term thinking to invest in integrated care becomes impossible, which destroys such initiatives quite quickly. Most of the time, complex service innovations like integrated care are being evaluated within such a short time frame that it is impossible to see any financial benefit from it. It may take seven or eight years of hard work and effort for integrated care systems to mature.

Renee: Any thoughts on the current "evidence" in complex care?

Nick: There is a lot of evidence to demonstrate how integrated care, and the components that make up an integrated care strategy, can improve care experiences and outcomes for people. There is less convincing evidence when it comes to costs and, in particular, of evaluations of strategic initiatives to adopt integrated care in different countries – such as the Integrated Care Pioneers in the UK (Erens et al. 2016).

For me, as an advocate for integrated care, this negative evidence provides difficulties. It is clearly a problem when I've stood up in front of an audience and somebody very clever has said, "Well, we tried this in Australia three years ago and it didn't work then. Why should it work now?" You have to take them through a process, describing to them why it didn't work three years ago.


In most cases, these failures result because these initiatives did not – fundamentally – implement integrated care in the sense of promoting better coordinated and people-centred care. They might, perhaps, have implemented a merger of two organizations or created some common governance and financial arrangements, but the implementation aspect – the essential integration of care at a clinical and service level around people’s needs – may have been underdeveloped and so represent just a partial response of what the capability should be. The evidence on case management is very clear in this respect where you often see the creation of excellent multi-disciplinary teams, but which sit within an uncoordinated system. This means you might find it impossible to draw upon the other essential services needed to support care to people with complex needs regardless of the commitment and quality of the professionals coordinating the care.

One has to be very careful, therefore, about interpreting the evidence. We know that if the components of integrated care programs are broken down – supported self-care, medications management, care pathways – there’s a huge amount of evidence for positive benefits. Yet somehow we’ve layered it all together and called it *integrated care*, and what we actually end up looking at is a merger between the health and the social care department or something at a very abstract level. That’s not what integrated care is. The good things about integrated care happen at a personal and clinical level. That’s where you’re going to have all of your influence. So until you get a real understanding of what is actually happening at the business end, with patients managing their lives better and coordinating their services more appropriately, they’re not going to get the answer to the question they’re looking for.

Moreover, integrated care is a complex service innovation and you can’t expect any level of certainty through an evaluation within a typical 12- or 18-month period. Also, evaluations do not tend to know enough about the actual interventions undertaken because they are not written up that way. It’s a black box exercise. Unless you go into the black box and see what they actually did, you’re just ticking off a marker at an abstract level.

That’s not how these complex service innovations need to be evaluated and researched, and it’s why our Foundation’s mission to advance the science behind integrated care is very important. We’ve got to try to find a way to create more appropriate evaluation methods for these types of investigations, for example on health economics where the existing hierarchy of evidence will need to be challenged given the inappropriateness of RCTs in this area. If you look at the studies of chronic illness, frail older people and people with multiple co-morbidities are almost always screened out from the beginning.

So the evidence we have is thin and we need to find new evaluation methodologies. Fundamentally, current research methods examining integrated care schemes are often not properly formulated or implemented.

Renee: Thanks so much for this interview, Nick. You have provided important, practical insights that will resonate with health providers and researchers alike. 

References

- Barnes, A., L. Unruh, A. Chukmaitov and E. van Ginneken. 2014. “Accountable Care Organizations in the USA: Types, Developments and Challenges.” *Health Policy* 118(1): 1–7.
- Bengoa, R. 2013. “Transforming Health Care: An Approach to System-Wide Implementation.” *International Journal of Integrated Care* 13(3): e039.
- Counties Manukau Health. N.D. *Integrated Care*. Retrieved June 14, 2016. <<http://countiesmanukau.health.nz/about-us/performance-and-planning/integrated-care/>>.
- Erens, B., G. Wistow, S. Mounier-Jack, N. Douglas, L. Jones, T. Manacorda et al. 2016. *Early Evaluation of the Integrated Care and Support Pioneers Programme: Final Report*. London: Policy Innovation Research Unit
- Font, D., J. Escarrabill, M. Gómez, R. Ruiz, B. Enfedaque and X. Altimiras. 2016. “Integrated Health Care Barcelona Esquerra (Ais-Be): A Global View of Organisational Development, Re-Engineering of Processes and Improvement of the Information Systems. The Role of the Tertiary University Hospital in the Transformation.” *International Journal of Integrated Care* 16(2): 8.
- Gottlieb, K. 2013. “The Nuka System of Care: Improving Health through Ownership and Relationships.” *International Journal of Circumpolar Health*. Retrieved June 20, 2016. <<http://www.circumpolarhealthjournal.net/index.php/ijch/article/view/21118>>.
- Kyle, A. 2016. *Engaging the Community in Health Care Relationships and Customer-Ownership*. Paper to the 16th International Conference on Integrated Care, Barcelona. Retrieved June 20, 2016. <http://icic16barcelona.s3.amazonaws.com/Day_2_Plenary_3_Advancing_People_Care_Barcelona_April_Kyle.pdf>.
- Lupianez-Villanueva, F. and A. Theben. 2014. *Gesundes Kinzigtal (Germany) Case Study Report, Strategic Intelligence Monitor on Personal Health Systems Phase 3*. Luxembourg: JRC Science and Policy Reports.
- Øvretveit, J. 2011. *Does Clinical Coordination Improve Quality and Save Money?* London, UK: The Health Foundation. Retrieved June 20, 2016. <www.health.org.uk/publications/does-improving-quality-save-money/>.
- Toro Polanco, N., I. Berraondo Zabalegui, I. Pérez Irazusta, R. Nuño Solinis and M. Del Río Cámara. 2015. “Building Integrated Care Systems: A Case Study of Bidasoa Integrated Health Organisation.” *International Journal of Integrated Care* 15(2):e026.
- Valentijn, P. 2016. “Rainbow of Chaos: A Study into the Theory and Practice of Integrated Primary Care.” *International Journal of Integrated Care* 16(2): e1–4.

CEO Perspective: A Health System for Patients with Complex Conditions: Reflections from Bridgepoint's Transformation

Marian Walsh

Introduction

How can a traditional chronic care and rehabilitation hospital transform itself to provide high-quality care to people with complex health conditions – those with multiple health problems together with psycho-social issues – who need a thoughtful, evidence-informed but personalized approach to healthcare? How can health policy support this type of innovation? Bridgepoint has been on a journey for almost 20 years to transform care for the growing population at large and within our healthcare system, with increasingly complex health conditions. Until very recently, those of us who are convinced that both chronic disease and complexity are the next frontier of modern healthcare were lonely voices. Recent recognition of the existence of these patients, through analysis of healthcare utilization and accounts of inadequate care, is a critical development. Recognition is the first step to challenging the current construct of our healthcare system to make the necessary changes to deliver better care for patients and create better value for governments and taxpayers. Having places like Bridgepoint share their journey will also open up key insights into new roles for healthcare services and pathways that governments can use to support them in this journey.

Bridgepoint

Bridgepoint is a hospital, a family health practice and a research collaboratory in Toronto. It recently amalgamated with Mount Sinai Hospital and affiliated with Circle of Care (a home care agency) to form the Sinai Health System.

Bridgepoint has been on the front line of dealing with patients with complex health conditions, who are the most visible symbol of both the progress in our health and care delivery systems as well as of a critical need for transformative change. Thanks to the success of modern medicine, people are living longer, and experiencing increasingly complex health conditions.

I often describe the existence of these patients and our response to them as the great paradox of modern medicine – all the hype, noise and public and political outcry about the sustainability of our healthcare system are actually because we've been so spectacularly successful.

Healthcare Advances

The first part of the last century saw the greatest improvement in population health in human history, at least in the developed world. And that improvement was overwhelmingly driven by advances in public health. Clean water and better hygiene, combined with immunizations, helped us conquer infectious disease. Healthcare played a part, too, through interventions like antibiotics and better access to medical care. These great advances in public health resulted in new challenges. As the incidence of diseases like cholera plummeted, cancer rates grew. People began living long enough to develop more cancer, heart disease, diabetes and other conditions.

A second era of innovation took the spotlight, focusing mainly on basic science and life-saving acute care, delivered

primarily through hospitals. From the 1950s through to the turn of this century, science and medicine turned their attention to understanding human biology and how to diagnose and treat when things go wrong. Our acute hospital-centric system was designed – well designed, in fact – to treat these new disease states and provide focused interventions. And it worked. The death rate from cardiovascular disease dropped by more than half. Joint replacements, unknown fifty years ago, enable 60,000 Canadians a year to regain mobility. Disease by disease, intervention by intervention, at every age cohort, the list of successes goes on. But what does that mean for the health of the population and for our healthcare system? Well, it's now full of survivors.

The Complexity Challenge

The reality in Ontario today is that 13 million people – roughly 70% – have one chronic condition, 80% have two or more and we've now heard from the Institute for Clinical Evaluative Sciences (ICES), Canadian Institute for Health Information (CIHI) and the government about the 5% of patients who use 70% of all healthcare resources. The result is that we are now managing something that was unknown 50 years ago – complex patients living for years with multiple chronic conditions. These are the patients of Bridgepoint. But because they utilize healthcare resources in huge quantities, they are also the patients of our entire healthcare system. Bridgepoint identified and started to focus on this issue almost 20 years ago.

In 1997, the Ontario Government's Health Services Restructuring Commission decided that hospitals like Bridgepoint (then Riverdale Hospital) that, more through good luck than good planning, had come to specialize in providing care for patients with chronic and increasing complex illnesses, were no longer necessary. This policy direction certainly caught our attention and started us on what has turned out to be an evolving transformation in our understanding of patients with complex health issues and how to serve them.

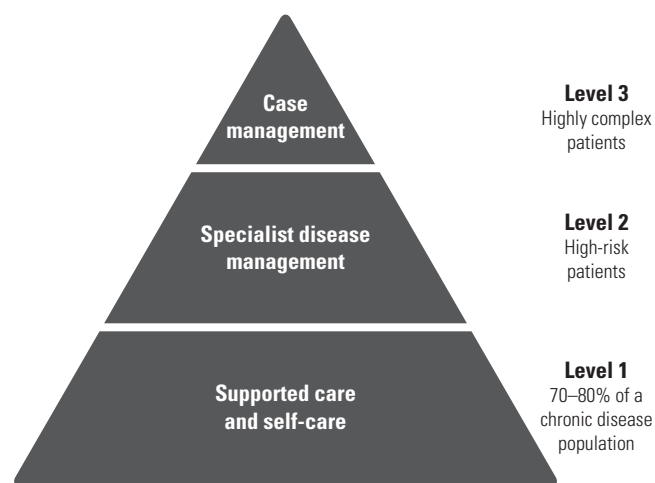
We started by looking for evidence to support our intuition that what we were seeing in our hospital – a huge change in the complexity of the people we were serving – might be a prevalent phenomenon, with implications for not just our future, but also for that of our entire healthcare system. We decided to dig deeper into this issue. The early evidence we uncovered convinced us, and ultimately the Government of Ontario, that chronic disease and complexity were on the rise and that hospitals like Bridgepoint should not be closed; it was not closed.

Bridgepoint – Understanding the Complex Patient Population and Its Needs

With that crisis resolved, we set ourselves on a course to use Bridgepoint and the patients we serve as a living laboratory to gain insight into what we really need to do as a healthcare system and society to address this emerging need. We

looked at leading systems and health maintenance organizations (HMOs) around the world and found resonance in Kaiser Permanente's Population Stratification Model (Figure 1) – this was a moment of insight for us.

FIGURE 1.
Population Stratification Model



Adapted from: Taylor, W. 2007. Population Management for Chronic Conditions – Overview. Retrieved July 7, 2016. <www.hpm.org/Downloads/Events/Warren_Taylor_120107.pdf>.

We started to look at our own population and health system through this lens.

Of course, what we uncovered is now a recognized global phenomenon: in Ontario, 170,000 patients use \$9 billion of healthcare funding per year and are not getting good outcomes.

These are the people at the top of the Kaiser pyramid, characterized by multiple, complex health issues, yet we knew very little about them apart from utilization data. We also could not find many insights into how to manage these patients, except for the Chronic Disease Management (CDM) concepts of intensive case management and interprofessional care. There was very little evidence-based medicine, and there were no clinical pathways for treating these patients. Virtually all clinical trials and most clinical pathways are conducted on or created for patients without complications. Therefore, the vast majority of our most complex patients are actually excluded from “evidence-based” healthcare.

In 2005, we declared that there is a new disease out there. It's not just chronic disease – it's illness combinations such as “neurodiabetes,” “osteocanceritis,” and the list goes on! We also declared that the growing incidence and prevalence of complex health conditions is a game changer for health systems and policy.

The Strategy

Against that backdrop, Bridgepoint developed a bold, 10-year strategy and vision to transform itself to respond to Ontario's and Canada's biggest healthcare challenge. We made it our mission

to revolutionize care delivery, create new science, develop new curricula, and forge new relationships with innovators in the field to “change the world for complex patients.”

To deliver on our vision and mission, we did the following:

- Established the Bridgepoint Collaboratory for Research and Innovation, the first in the world devoted entirely to developing the evidence and new models required to address the needs of these patients.
- Established the Bridgepoint family health team as an incubator and exemplar of primary care models and practices that could effectively manage and prevent chronic disease and complexity in the population.
- Developed new models and competencies to address the growing needs of these patients.
- Became affiliated with the University of Toronto to drive evidence-based practice and lay the ground for new curriculum.
- Built a new hospital and campus of care, the first of its kind, designed specifically to meet the needs of complex patients.

The Bridgepoint Collaboratory started its work with a piece of groundbreaking research – “The Bridgepoint Study” – which confirmed many of the things we had already suspected. The study showed that the complex patient’s journey often presents with a single chronic disease that is just the “tip of the iceberg.” What appears at first belies the multiple layers of potential complexity that, left unaddressed, will erupt into a complex patient.

Complex patients are characterized by clinical complexity: multimorbidity, polypharmacy, high treatment burden and fragmented care (in our predominately acute, reactive, highly specialized and fragmented healthcare delivery system).

These patients are also characterized by social complexity: social vulnerability, depression, addiction, social isolation and coping and adaptation challenges.

The study revealed high variability in the complex patient population and significant gaps between our current system and their needs:

- Existing data systems do not capture complexity.
- The current acute, episodic system is a poor fit for complex patients.
- Care plans do not address coping, adaptation or transitions effectively.
- Significant missed opportunities exist for prevention all the way through these patients’ trajectory.

These results led us to conclude that we need fundamental change at all levels of our healthcare system: (a) at the level of the patient in the evidence used to treat them; (b) at the level

of the system in how we organize care delivery; and (c) at the policy, planning and research levels and in the data we use for decision-making, outcome and performance measurement.

The model is based on the idea that addressing the needs of these patients begins with a fundamental paradigm shift.

Bridgepoint's Transformation

With that evidence in hand, we started our transformation journey, beginning at the level of the patient. Our team designed a new approach to care, which included:

- A comprehensive 360-degree assessment by an interprofessional team, which has been implemented on our complex medical care units
- Treatment and management strategies for physical as well as psychosocial issues
- A shift in focus to optimal function and compression of morbidity and risk
- A high quality, safe experience in and out of hospital
- Support for coping and adaptation
- Advocacy, training and support for formal and informal caregivers
- Creating and offering a community-connecting, health-promoting environment

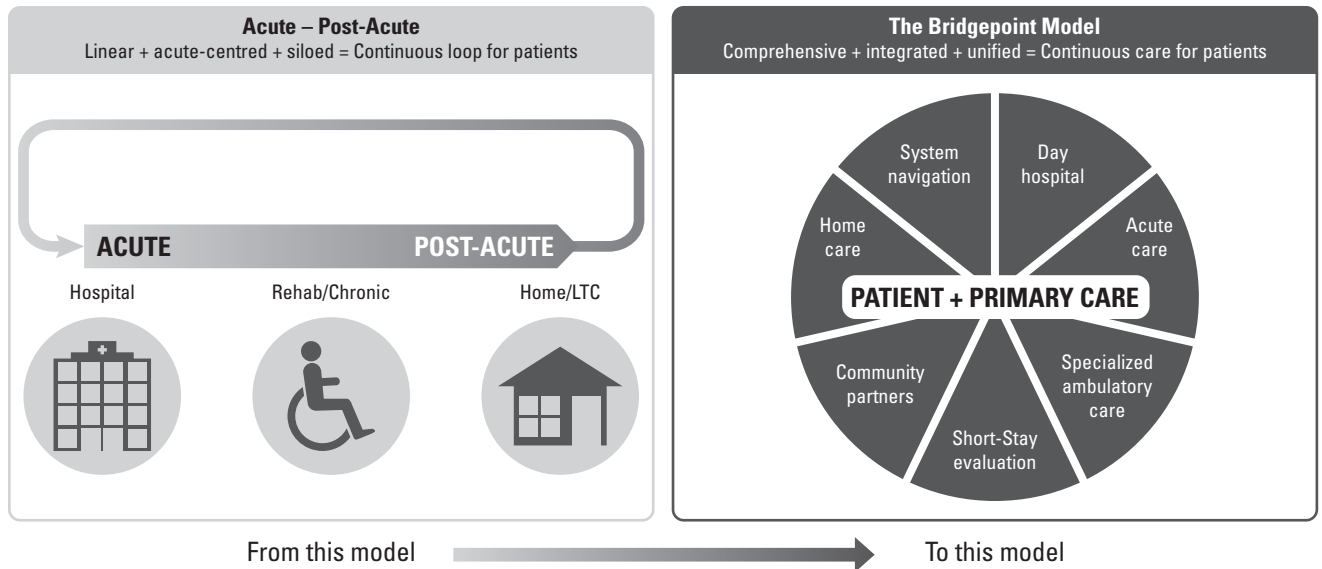
We redefined which outcomes it would be appropriate to focus on for these patients: optimized health and well-being; improved quality of life; optimized functionality; improved coping, adaptation and self-efficacy; reduced risk and health-care utilization and enhanced social capital.

At the level of the system, the Bridgepoint team developed a new model of care delivery. The model is based on the idea that addressing the needs of these patients begins with a fundamental paradigm shift. That paradigm shift would evolve and replace our acute, episodic, reactive care model – where acute care hospitals are the entry point to everything – with a proactive, comprehensive, integrated, continuous “health hub,” with primary care and patients at the centre (Figure 2).

We began implementing the Bridgepoint Model by partnering with primary care and community providers in our catchment area, developing a short-stay evaluation unit with direct access from primary care; implementing complexity clinics; and starting a new “Bridges to Home” program, to follow high-risk patients in “shared care” with their primary care doctors.

While Bridgepoint made good progress on its own in rethinking and reorganizing care for these patients, we ultimately knew that in order to make meaningful inroads, the whole system would need to change.

FIGURE 2.
The Bridgepoint evolution



The Case for Integration Within a Bigger System

There is abundant evidence that without a comprehensive, integrated health and care system, we create unnecessary burden of illness in the population; utilize more healthcare resources and subject patients to duplication that is unnecessary at best and harmful at worst. Nowhere is this more evident than in the care of complex patients. There is a huge role and a missed opportunity for hospitals to engage in primary and secondary prevention. When complex patients do need care, they need a single care plan, single care team, aligned goals and incentives, across the life course and across the continuum.

Hospitals and the people in them need to see themselves as part of the community, not separate from it. They also need to be full partners, not just with patients and their families while they are in our care, but with primary care, public health and the community in preventing and managing the increasing burden of illness in the population.

Funding for the care also needs to be better integrated so that there is incentive in the system to truly provide care in the right place at the right time. Our current siloed, industrial funding model, which promotes reactive, episodic, volume-based care, is totally misaligned with the needs of patients with complex health conditions.

That's why Bridgepoint reimagined itself as part of a hub and spoke model, in partnership with the community and primary care. That is also why we joined with Mount Sinai Hospital (an academic, acute/tertiary care hospital) and Circle of Care (a multi-service home support agency) to create an exemplar of an integrated healthcare system – bringing together all the elements required to address the needs of complex patients.

Sinai Health System

The vision of Sinai Health System is to create Canada's leading integrated health system, pushing the boundaries to realize the best health and care, from healthy beginnings to healthy aging for people with complex health needs. We will achieve this vision through delivering exceptional care in hospital, community and home, focusing on the health conditions with the greatest impact on the overall health of the population.

We are also committed to discovering and translating scientific breakthroughs, developing practical health solutions, educating future clinical and scientific leaders, and leading efforts to eliminate health inequities. This is our mission!

As a vertically integrated system, we are now implementing seamless care across more of the continuum, such as admitting patients directly to Bridgepoint from the emergency department without requiring an acute admission. We are also bringing an increasingly capable group of specialists and sub-specialists into interprofessional care teams to develop integrated care plans for a wide range of complex patients. Ultimately, patients will be enrolled and followed on a proactive basis by Sinai Health System, in partnership with primary care.

Beyond Sinai Health System, at the macro level, our broader system needs major change to enable us and others to provide truly comprehensive and integrated care, in the areas of money, integration, data and intervention research, assessment and performance tools, and training.

1. Money

Funding and incentives need to support and reward earlier treatment and prevention and treatment in the right setting

of care. We know that is true for all patients, but with no other population is it more urgent than for patients with complex health issues, who are the highest users of health services. Risk-adjusted, bundled payments for the care of specific populations, especially complex patients, are the way of the future.

2. Integration

We are convinced that the kind of vertical integration Sinai Health System has helped to pioneer will need to continue, with more elements of the care continuum for complex patients within integrated provider organizations that are accountable for a complex patient's whole experience and capable of managing the most important parts of it.

3. Data and intervention research

Our health system needs data, research and new evidence to help us understand and address the numerous clinical and health system questions that arise when dealing with people who have multiple health conditions and need complex care. We simply do not have solid evidence on what works – or even what constitutes safe care – for a patient with six conditions and 12 medications.

Sinai Health System is dramatically expanding the research on complexity pioneered by Bridgepoint's Collaboratory for Research, within the Lunenfeld-Tanenbaum Research Institute, and connecting the network of clinicians and scientists in our organization and around the world who are focused on clinical and health services research in the field of complexity. A number of research teams and collaborations have been developed over the last five years.

4. Assessment and performance tools

From a patient quality and safety perspective, our current acute-focused approach and many of the tools that have been enormously successful with single illnesses and disabilities will be insufficient to address complexity. There is no checklist for a patient with diabetes, Parkinson's disease and a broken hip, who is on 14 medications and appears to be reacting badly. At a minimum, research needs to inform principles, guidelines and standards on providing quality care, as do the health performance organizations like the Institute for Healthcare Improvement (IHI), Canadian Patient Safety Institute, and others.

5. Training

We need to develop and teach new curriculum, based on evidence specific to these patients. We will always need oncologists, but we will also need "complexity specialists" – hospital and community-based professionals with deep training in how to manage multiple conditions in the same patient. We will also need health policy experts and administrators who are trained in complexity and health systems reform.

The evolving success Sinai Health System has begun to experience in advancing care for complex patients is rooted in deeply held values of patient-centredness, the dignity of individual patients and caregivers, and a belief that we really can make these people's lives better. Each of the organizations that came together to form Sinai Health System was originally founded to address some health inequity. It is that tradition that now inspires us to focus on complex patients.

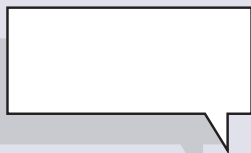
Conclusion

I began by saying that it is encouraging that the healthcare world is beginning to take notice and focus on the central challenge and opportunity of complexity in our health system. As I reflect on what Bridgepoint – now Sinai Health System – has accomplished, I am even more encouraged because we see the path ahead and are already producing results.

Sinai Health System is just one organization. While we have the advantage of being highly focused on people with complex conditions, truly changing the world for these patients will require a national and global effort. I look forward to the help of the growing community of clinicians, researchers and policy makers who share my conviction that addressing the needs of people living with complex health conditions truly is the next frontier of healthcare. As others begin to focus on this issue – and I would encourage them to do so – they have willing partners and collaborators in Sinai Health System. There is much to learn and much to do better. **HQ**

About the Author

Marian Walsh, long-time president and CEO of Bridgepoint Active Healthcare, is now associate CEO and chief transformation officer of Sinai Health System, which includes: Bridgepoint; Mount Sinai Hospital; and Circle of Care, a home and community support agency. Marian has had a 30-plus year career as a CEO in healthcare and has been an effective advocate for transforming the healthcare system to meet the evolving needs of patients.



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