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Towards a Community-Based Dementia Care Strategy:
How do we Get There from Here?

The Journey Towards Community-Based Dementia Care: The Destination,
Roadmap, Guide, Tour Group and the Conditions

Achieving the Goals of Dementia Plans: A Review of Evidence-Informed
Implementation Strategies

Mitigating Moral Distress in Dementia Care: Implications for Leaders in the
Residential Care Sector

THIS MAP SHOWS THE ESTIMATED NUMBER OF PEOPLE
LIVING WITH DEMENTIA IN EACH WORLD REGION, IN 2015.





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Dementia: A Situation for Concern

In this final issue of World Health and Population, the editors have elected to focus on issues related to dementia in elderly persons – and the demands caring for them places on health services delivery. In many parts of the world, aging populations are already causing a strain on health system budgets. Growing numbers of dementia patients further increase the load. The number of people living with dementia worldwide is currently at 50 million and will be approximately three times that number by 2050 (WHO 2019).

It is not just health services systems that feel the burden of caring for dementia patients. Care is often delivered by family members and other informal caregivers, who report feeling isolated and over-burdened (WHO 2019). WHO further reports that dementia has a significant physical, psychological, social and economic impact, not only on people with dementia, but also on their carers, families and the society at large (WHO 2019).

Clearly, the situation is cause for concern. The editors of World Health and Population have chosen to concentrate on three themes related to dementia care: strategies for dementia care; leadership in dementia and new models of care. The intent is to give readers an overview of each area – sharing ideas and policies that have been proven through lived experience.

Strategies for Dementia Care

The issue opens with a focus on strategies for dementia care that address the needs of patients and their families. Morton-Chang et al. (2016) start from the premise that most older persons living with dementia (PLWD) would prefer to age at home. Too often, however, PLWD end up in residential long-term care (LTC) or in hospital beds – a costly and sometimes damaging solution. The authors explore the “state of the art” in community-based care for PLWD, highlighting the importance of early and ongoing intervention. Drawing on results from a “balance of care” study they conducted earlier, the authors explain that with few viable community-based care options, PLWD can quickly “default” to institutional care. In the final section, the authors draw from national and international experience to identify the key strategic pillars to guide action towards a community-based dementia care strategy.

Responding to this proposed strategy, Nies (2016) describes the challenge of dealing with increasing numbers of PLWDs and describes potential solutions from the European and, in particular, Dutch perspectives. He concludes with discussion of strategies, required stakeholders, and what conditions need to be in place to arrive at the desired outcomes.

The third paper in this section focusses on achieving the goals of dementia plans through the lens of evidence-based implementation strategies. Hacker Teper and colleagues (2019) conducted a rapid review of provincial and national dementia plans from high-income countries, and reviewed studies on implementation strategies for dementia care. They advance seven key implementation strategies that may be useful for future dementia care reform.

Leadership in Dementia Care

Next, attention turns to leadership in dementia care, with specific emphasis on mitigating moral distress. Spenceley et al. (2017) report that while the majority of dementia patients live in the community, residential facility care by nursing providers is a common part of the dementia journey in most countries. The authors share findings from a two-year study of moral distress as experienced by nursing caregivers of residents with dementia in residential care settings in a Western Canadian province. The findings relate to strategies to reduce moral distress in this caregiving group, with a particular focus on the role of supportive and responsive leadership.

New Models of Dementia Care

The final section in this issue showcases a series of articles that display models of care proven to improve health outcomes, reduce costs and enhance the experience of dementia patients and their caregivers.

Puxty and colleagues (2012) developed a project aimed at facilitating improvements in outcomes for long-term care residents through the provision of knowledge-to-practice and quality improvement resources by trained facilitators. Point-of-care staff reported improved communication and collaboration, improved use of scope of practice and implementation of best

practice knowledge. Overall, participating long-term care homes demonstrated an enhanced capacity for common care issues of the elderly (pneumonia, falls, bacteriuria and behavioural and psychological symptoms of dementia) and the ability to effectively engage in quality improvement processes with efficient and effective use of healthcare resources.

Primary care collaborative memory clinics (PCCMCs) address existing challenges in dementia care by building capacity to meet the needs of persons living with dementia within primary care. Lee et al. (2019) describe the strategic implementation of the PCCMC care model in two regions within Ontario. Subsequent interviews and qualitative analysis generated five major themes: (1) earlier identification of dementia and intervention; (2) increased capacity for dementia care within primary care; (3) better patient and caregiver experience with care; (4) improved continuity, integration and coordination and improved care; and (5) system efficiencies. The authors conclude that strategic, regional implementation of PCCMCs provides a significant opportunity to support better integrated and coordinated dementia care.

The following paper looks at specialized seniors' clinics which are an integrated network of six outpatient clinics in British Columbia's Fraser Health Authority that utilize interprofessional teams to provide comprehensive geriatric assessments and care planning for frail older adults. As Kadowaki et al. (2014) explain, the clinics provided approximately 19,000 appointments in 2012/13, and clients and primary care physicians were highly satisfied with the model. The authors outline the SSC model and provide reflection on its development, implementation and standardization processes.

The issue concludes with a discussion on using technology to assist with transitional care for persons living with dementia. According to Ritchie et al. (2017) transitions between hospital and community are particularly challenging for vulnerable adults experiencing behavioural and psychological symptoms (BPSD) of dementia. Too often, miscommunication results in triggering a recurrence of disruptive behaviours leading to frustration of staff and families. The described project involved improving transitions using an electronic-based care plan on a 23-bed geriatric dementia unit in a mental health hospital. “My Dementia

Careplan” is an interprofessional care plan that was developed in the electronic medical record (EMR) to enhance communication of information between healthcare providers when patients are being discharged to the community. It is written from the patient’s perspective in collaboration with the family and interprofessional team. It describes strategies to manage behavioural challenges along with standardized tools to objectively monitor progress. This care planning will help to support transition of knowledge between hospital and community.

– The Editors

References

- Hacker Teper, M., C. Godard-Sebillotte and I. Vedel. 2019. Achieving the Goals of Dementia Plans: A Review of Evidence-Informed Implementation Strategies. *Healthcare Policy* 14(4): 10–20 doi:10.12927/hcpol.2019.25860.
- Kadowaki, L., H. Chow, S. Metcalfe and K. Friesen. 2014. Innovative Model of Interprofessional Geriatric Consultation: Specialized Seniors Clinics. *Healthcare Quarterly* 17(3): 55–60. doi:10.12927/hcq.2014.24021.
- Lee, L., L.M. Hillier, K. Lumley-Leger, F. J. Molnar, D. Newton, L. Stirling and K. Milne. 2019. Key Lessons Learned in the Strategic Implementation of the Primary Care Collaborative Memory Clinic Model: A Tale of Two Regions. *Healthcare Policy* 15(1): 53–69. doi:10.12927/hcpol.2019.25938.
- Morton-Chang, F., A.P. Williams, W. Berta and A. Laporte. 2016. Towards a Community-Based Dementia Care Strategy: How do We Get There from Here? *Healthcare Papers* 16(2): 8–32. doi:10.12927/hcpap.2017.25006.
- Nies, H. 2016. The Journey towards Community-Based Dementia Care: The Destination, Roadmap, Guide, Tour Group and The Conditions. *Healthcare Papers* 16(2): 57–63. doi:10.12927/hcpap.2017.25001.
- Puxty, J., R. A. Brander, S. Murphy and V. Byrnes. 2012. Promoting Quality Improvement in Long-Term Care: A Multi-Site Collaboration to Improve Outcomes with Pneumonia, Falls, Bacteriuria and Behavioural Issues in Dementia. *Healthcare Quarterly* 15(2):70–74. doi:10.12927/hcq.2012.22910.
- Ritchie, K., A. Duff-Woskosky and S. Kipping. 2017. Mending the Cracks: A Case Study in Using Technology to Assist with Transitional Care for Persons with Dementia. *Nursing Leadership* 30(3): 54–62. doi:10.12927/cjnl.2018.25385.
- Spenceley, S., S. Caspar and E. Pijl. 2017. Mitigating Moral Distress in Dementia Care: Implications for Leaders in the Residential Care Sector. *Nursing Leadership* 30(4): 45–59. doi:10.12927/cjnl.2017.2544.
- World Health Organization (WHO). 2019. *Dementia*. Accessed December 16, 2019. <<https://www.who.int/news-room/fact-sheets/detail/dementia>>.



Towards a Community-Based Dementia Care Strategy: How do We Get There from Here?



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Abstract

As recent policy reports in Ontario and elsewhere have emphasized, most older persons would prefer to age at home. This desire does not diminish for the growing numbers of persons living with dementia (PLWD). Nevertheless, many PLWD end up in residential long-term care (LTC) or in hospital beds. While LTC is valuable for PLWD with highly progressed cognitive and functional impairment requiring high-intensity care, it can be a costly and avoidable option for those who could remain at home if given early access to a coordinated mix of community-based supports. In this lead paper, we begin by exploring the “state of the art” in community-based care for PLWD, highlighting the importance of early and ongoing intervention. We then offer a brief history of dementia care policy in Ontario as an illustrative case study of the challenges faced by policy makers in all jurisdictions as they aim to re-direct healthcare systems focused on “after-the-fact” curative care towards “before-the-fact” prevention and maintenance in the community. Drawing on results from a “balance of care” study, which we conducted in South West Ontario, we examine how, in the absence of viable community-based care options, PLWD can quickly “default” to institutional care. In the final section, we draw from national and international experience to identify the following three key strategic pillars to guide action towards a community-based dementia care strategy: engage PLWD to the extent possible in decisions around their own care; acknowledge and support informal caregivers in their pivotal roles supporting PLWD and consequently the formal care; and enable “ground-up” change through policies and funding mechanisms designed to ensure early intervention across a continuum of care with the aim of maintaining PLWD and their caregivers as independently as possible, for as long as possible, “closer to home.”

Introduction

As recent policy reports at provincial and national levels have emphasized, most older Canadians would prefer to age in their own homes (Sinha 2012; Walker 2011; Van Hoof et al. 2013). This desire does not diminish for the growing numbers of older persons living with dementia (PLWD). Nevertheless, many PLWD still end up in residential long-term care (LTC) or in hospital alternative level of care (ALC) beds waiting for residential placement (CIHI 2010; Drummond 2012; Walker 2011). In part, this reflects the complex, chronic and progressive nature of dementia often leading to or associated with neurocognitive and physical decline. However, it also reflects the

fact that episodic acute-focused and bed-based healthcare systems are poorly equipped to support persons with chronic health and social needs, safely and appropriately, “closer to home.”

In this paper, we make the case that although the onset of dementia is often portrayed as a catastrophic event, leading almost inevitably to loss of independence and institutionalization, a majority of PLWD can continue to live relatively independently for most or all of their lives if diagnosed at an early stage and can be provided with coordinated access to needed home and community care (H&CC). Such care spans health services such as nursing and physical therapy provided by professionals, as well as

community supports such as homemaking, personal care and transportation provided by care workers and volunteers.

Moreover, improved access to “before-the-fact” community-based care can do much to support and sustain informal caregivers. The international evidence shows that it is family, friends and neighbors that do most of the heavy lifting in the community; they provide an estimated 70% to 90% of the everyday personal, instrumental and emotional care required by older persons to maintain their well-being and independence (Mittleman et al. 2006, 2004; Williams et al. 2016; Williams et al. 2015a). Not only are informal caregivers the main reason why many older persons can continue to age at home, without informal caregivers, formal care systems would not be sustainable (Donner 2015; Sinha 2012).

We are not the first to make this case.

Over the past decade, there have been numerous calls locally, nationally and internationally to meet the needs of older persons, including growing numbers of PLWD and their informal caregivers, closer to home (WHO and ADI, 2012; ASC, 2010). Nevertheless, policy has lagged. As news headlines in national media have recently reminded us, Canada remains one of only two G7 countries – the other being Germany – that have no national dementia care strategy (OMNI Health Care 2015).

In the first section of this paper, we begin by briefly reviewing what we know about dementia and approaches to caring for PLWD and their informal caregivers in community settings.

In the second section, we offer a brief history of dementia care policy in Ontario as an illustrative case study of the challenges faced by policy makers in all jurisdictions as they aim to re-direct healthcare systems focused on “after-the-fact” curative care towards “before-the-fact” prevention and maintenance in the community. Drawing on results from a “balance of care” study, which we conducted in South West Ontario, we

examine how, in the absence of viable community-based care options, PLWD can quickly “default” to institutional care.

In the final section, we consider the way forward. While transformational or “big bang” change seems unlikely, we think that progressive improvements in dementia care still offer value, particularly if enabled and channeled by a guiding strategy. Ontario, like other jurisdictions across Canada and beyond, is now actively considering the essential elements of such a strategy. To that end, we draw from national and international experience to identify three key strategic pillars to guide action: first, engage PLWD early and to the extent possible as active participants in their own care; second, acknowledge and support informal caregivers who play a pivotal role in supporting persons who cannot manage on their own and sustaining formal healthcare systems; and third, enable “ground-up” change through policies and funding mechanisms designed to ensure early intervention across a continuum of care with the aim of maintaining PLWD and their caregivers as independently as possible, for as long as possible, “closer to home.”

Part 1: What We Know About Dementia and Dementia Care

There is a vast and growing literature about dementia and the needs of those affected by it. Contrary to popular belief, dementia is not a normal part of aging; only a minority of older Canadians, estimated at about 15% of those over the age of 65 years, will experience its effects (ASC 2016a). In fact, dementia rates across the developed countries seem to be trending downward, particularly among women and those with higher levels of education (Alzheimer’s Association 2014). Nevertheless, because age is a principal risk factor for dementia, an aging population augurs continued growth in numbers of PLWD (Chertkow 2008; Volicer 2001). Improvements in diagnosis,

medical care and symptom management are contributing to PLWD living longer post-diagnosis and requiring care over more extended periods of time – on average approximately 8.5 years (Keene et al. 2001).

Dementia is complex. It encompasses a broad class of neurocognitive disorders associated with cognitive and physical decline (American Psychiatric Association DSM-V 2013). Dementia is associated with more years of disability than many other chronic illnesses (ASC 2010; WHO and ADI 2012), and it accounts for a higher burden of illness overall (Alzheimer Society of Ontario 2007). Issues with perception, judgement and memory loss can inhibit PLWD's ability to manage routine tasks and personal care on a daily basis, to interpret their environment, to recognize when help is needed and to access formal health and social care in a timely fashion. When neurocognitive changes are combined with age-related declines in vision, hearing and mobility, and/or the lack of an informal caregiver, dementia becomes a “game changer.”

Moreover, because dementia often advances subtly and is concurrent with other chronic conditions, family members and healthcare providers alike can have trouble recognizing early warning signs and symptoms. Missed or delayed diagnosis and poor care management can result in poor quality care, with PLWD often interacting with the healthcare system (e.g., in the emergency room of a hospital) only at a point of crisis in their own health or that of their caregiver (Aminzadeh et al. 2012; Lee et al. 2014, 2010; McAiney et al. 2008; Weber et al. 2011; Woods et al. 2003).

The impact on informal caregivers can be severe (Williams et al. 2015a; MAS 2008; Mittleman et al. 2006, 2004). Although there are many positive aspects related to informal caregiving of PLWD (e.g., reciprocity of care, personal satisfaction), the experience can be difficult, leading to physical, emotional and financial strain and to caregiver fatigue, ill

health and burnout (Fast 2015; Smale and Dupuis 2004a, 2004b, 2004c, 2004d). The literature shows that particularly when intensive and sustained, caregiving can limit social engagement while increasing the risks of physical and mental health problems including stress and depression (Keefe 2011; MAS 2008). Caregivers of PLWD can also experience considerable economic costs related to employment restrictions, out-of-pocket expenses and time spent in caregiving activities (Fast 2015; Keating and Fast 2015).

System costs are also high. Dementia has been identified as “a significant economic burden on the Canadian healthcare system” (MAS 2008: p. 23). Compared with older adults without dementia, PLWD are two to five times more likely to use a range of services, including home care, hospital emergency departments (EDs), in-patient hospital beds, hospital ALC beds and LTC, and they experience more negative clinical outcomes (Aminzadeh et al. 2012; Weber et al. 2011). When in the hospital, PLWD can require ongoing and high-intensity care owing to confusion, anxiety, agitation and delirium (Phelan et al. 2012; Weber et al. 2011). PLWD typically stay longer in the hospital than their peers (Cahill et al. 2012; Timmons et al. 2015), and they are more commonly discharged to residential LTC (Morrison and Siu 2000 in Timmons et al. 2015).

Nevertheless, international evidence and local experience point to a range of community-based supports that can help PLWD and informal caregivers maintain their well-being and independence while minimizing use of costly bed-based care. These include clinical and non-clinical services such as memory clinics, interdisciplinary primary care team approaches, respite care, homemaking, meal programs, early and ongoing case management and care navigation; fulsome dementia curricula, including training and bridging programs for

providers; knowledge exchange platforms, which highlight and communicate the “state of the art”; community support services such as supportive housing, adult day programs and MedicAlert® Safely Home®; and home adaptations such as accessibility and orientation aids, monitoring technology and adequate lighting (Morton-Chang 2015).

In this connection, early diagnosis, intervention and ongoing support are consistently identified as best practices in dementia care, with primary care being the accessible “first contact” to set this process in motion (Aminzadeh et al., 2012; Alzheimer’s Disease International 2011; ASC 2015b; Iliffe et al.

2002; McAiney et al. 2008; Ministry of Health 2012; Prince et al. 2011; Vernooij-Dassen et al. 2005; Woods et al. 2003). Team-based comprehensive interdisciplinary primary care organizations such as Family Medicine Groups in Quebec and Family Health Teams in Ontario and Alberta appear particularly well positioned to provide early and ongoing care and individualized care plans, which adapt to the changing needs of PLWD and caregivers (Bergman and Vedel 2015; Grant 2015).

A complementary community program that collaborates with primary care to connect PLWD and caregivers to a range of community-based services and supports at the point of diagnosis is the Alzheimer Society’s First Link® program. First Link® has been evaluated in Ontario and Saskatchewan as being a successful intervention to enhance health professionals’ understanding of managing dementia and link more people to information and support sooner than without the program (McAiney et al. 2014).

While proactive community-based care is highly important to help maintain the independence of frail and vulnerable older adults, it is not always easily accessible, with access varying considerably within and

across jurisdictions and becoming particularly problematic outside of urban centres (Kuluski et al. 2012a, 2012b; Morton-Chang 2015; Morton 2010).

In Ontario, for example, different community-based programs and providers have different entry points, eligibility requirements, service offerings and user fees (MortonChang 2015; Morton 2010; Peckham 2016). Moreover, while many providers collaborate effectively to coordinate care for older persons with multiple chronic needs and caregivers, there are few formal mechanisms beyond information and referral, to accomplish this, or to follow an individual’s progress as they move between different community-based care providers, or between community, hospitals and LTC (Peckham 2016; Kuluski 2012; Peckham 2014a; Williams et al. 2009a, 2009b; 2016; 2014a, 2014b). Other challenges can include a general lack of awareness among providers and caregivers of dementia-specific services; limited access to key services like respite care that may not be available on evenings and overnight; and lack of ethnically/culturally/linguistically appropriate care (Caplan 2005; Denton et al. 2006; Morton 2010).

Such supply-side challenges can help explain why many PLWD and informal caregivers do not access needed care until they are at the point of crisis (McAiney et al. 2008; MAS 2008; Tootab et al. 2013; Pratt et al. 2006; Smale and Dupuis 2004a, 2004b, 2004c, 2004d). In addition to impacting negatively on the well-being of PLWD themselves, delayed access can limit opportunities for informal caregivers to develop proactive coping strategies, and the ability of formal providers to help them to do so, increasing the likelihood of physical and mental health problems, lost income, isolation, stress and burnout (Fast 2015; Peckham 2016, 2014b; Warrick et al. 2014; Williams et al. 2015a).

Part 2: Where We Are Now

In addition to impacting negatively on the well-being of PLWD and caregivers, challenges in accessing appropriate community-based care can also increase the likelihood of “default” to costly hospital and institutional bed-based care, placing additional pressures on already-stretched healthcare systems. Ontario provides an illustrative case study of these dynamics.

In 2011, Walker analyzed the roots of Ontario’s persistent hospital ALC bed problem; ALC beds are those occupied by individuals, including significant numbers of PLWD, who no longer require costly hospital care but cannot be discharged because of a lack of community-based discharge options. Rather than concluding that hospitalization and referral to LTC are normal and unavoidable consequences of needs, he concluded that older persons, most of whom wish to age at home, too often “default” to hospital EDs and then to in-patient hospital beds because of a lack of proactive community-based care. Moreover, because acute care hospitals are not designed to meet “restorative, supportive and rehabilitation needs” and have been shown to advance functional deterioration and pose risks of “hospital-related infections, falls and other adverse events,” hospitalization can itself increase the likelihood of permanent placement in LTC, “an outcome which could have been avoided” (Walker 2011).

Sinha’s 2012 review of care for older persons, while not focused specifically on dementia, similarly emphasized the need for an integrated seniors’ strategy aimed at building an integrated community-based continuum of care. Because the needs of an aging population are increasingly complex and chronic, this strategy would begin by promoting health and wellness and strengthening access to primary care and community supports. When community care would no longer suffice, it would encourage the evolution of “senior-friendly” hospitals with

timely discharge to home and community, and improve capacity within residential LTC to support short-stay and restorative options, as well as discharge back to the community. Informal caregivers would also be recognized and supported (Sinha 2012).

Donner’s more recent provincially commissioned expert panel highlights the costs and consequences of current fragmented and under-resourced community care systems (Donner 2015). While acknowledging that there are many individual examples of excellent H&CC programs and services in Ontario, she concluded that a general lack of proactive community-based care not only fails “to meet the needs of clients and families” but also misses opportunities to “reduce the use of less appropriate and more expensive healthcare services such as emergency rooms, hospitals and long-term care homes” (Donner 2015: 1). This report again highlights the crucial role of informal caregivers who provide the bulk of the everyday support required by communitydwelling older persons, and who should be included in an expanded “unit of care.”

Of course, such observations are not limited to Ontario. They apply, in varying degrees, to jurisdictions across the industrialized world as they struggle to meet the rise of increasingly complex chronic health and social needs, including dementia, associated with aging populations. For example, the INTERLINKS project, funded by the European Commission and conducted across 13 European Union countries (Austria, Denmark, Finland, France, Germany, Greece, Italy, The Netherlands, Slovakia, Spain, Sweden, UK and Switzerland), clarifies that all countries are now engaged in efforts to span two deeply embedded divides: the first between health-care and social care and the second between formal and informal care (INTERLINKS 2013). Even relatively modest projects to establish interdisciplinary care teams, almost universally considered to be a best practice in

the care of persons with multiple health and social needs including dementia, can confront layers of professional legislation, regulations and funding mechanisms that establish strict hierarchies and limit collaboration, even among regulated healthcare providers (Billings 2013).

The importance of system-level strategies to meet these challenges is by now well recognized internationally (Butler 2016). As noted, most G7 countries – with the exceptions of Canada and Germany – now have a national dementia care strategy.

However, such strategies may be more or less comprehensive, and they can be difficult to achieve and sustain politically, particularly in the face of competing demands from dominant bed-based systems of care. This has clearly been the case in Ontario (MortonChang 2015; Williams et al. 2016).

More than two decades ago, it was already well recognized in Ontario that an aging population and the associated rise of dementia and other chronic needs, if left unaddressed, could result in inappropriate care for individuals and potentially unsustainable pressures on healthcare systems. In 1996, Ontario initiated a broad-based consultation with diverse consumers and providers (MOHLTC 1999) to consider how best to meet the needs of growing numbers of PLWD. In 1999, it introduced a four-year, \$68.4 million Strategy for Alzheimer Disease and Related Dementias, a wide-ranging plan, which proposed a series of initiatives spanning community and institutional settings. These included education for healthcare providers, caregivers and the public (e.g., staff training, physician training, increased public awareness); service enhancements and expansion (e.g., planning for appropriate, safe and secure environments, respite services for caregivers, psychogeriatric consulting resources and intergenerational volunteer initiatives); and research activities and knowledge exchange (e.g., research on

caregiver needs, and the creation of research coalitions) (McAiney 2005).

While other provinces and territories had also begun developing dementia care policies, Ontario's Alzheimer's Strategy was identified by the National Advisory Council on Aging (NACA) as a benchmark for future policy development (NACA 2004). Nevertheless, Ontario's strategy soon came up against new political realities as the Progressive Conservative Government of the day announced that its main response to an aging population would be to build or retrofit 20,000 LTC beds. Although there was little evidence that this number of beds was justified (Coyte et al. 2002; MOHLTC, 2002) and expert advice had argued instead for the creation of new community-based care "spaces" (including home care, supportive housing and day programs), once built, the new beds needed to be filled (Morton-Chang 2015). In 2001, the government capped provincial home care budgets (thus limiting the availability of community care options) and introduced regulations "to ensure existing beds in LTC homes are fully utilized" (Williams et al. 2016).

The succeeding Liberal Government took power in 2003 as the provincial dementia care strategy was winding down. Rather than renewing the strategy, the government provided limited funding for a transition period running to March 2007 during which various "legacy projects," including a virtual repository of knowledge and information gained through the strategy (the Alzheimer Knowledge Exchange) hosted at the Alzheimer Society of Ontario (ASO 2004), were expected to seek alternative funding sources.

In part, a lack of enthusiasm for a dementia-specific strategy reflected legitimate concerns that "disease-specific" policies had the potential to exacerbate the fragmentation of an already "siloed" healthcare system, pitting one disease group against another.¹ However, as it turned out, such concerns took

a back seat to the more intractable politics of community-based versus bed-based care.

In 2007, the Liberal Government introduced a four-year, \$1.1-billion Aging at Home Strategy (AAH) which promised to expand community living options for all older persons (including PLWD) to enable them “to continue leading healthy and independent lives in their own homes.” Included were nonprofessional community-based supports for activities of daily living, such as meal preparation, transportation, shopping, friendly visiting, snow shoveling, adult day programs and caregiver relief and respite (MOHLTC 2010). However innovative and promising, this strategy was soon overtaken by the needs of acute care hospitals that were finding it increasingly difficult to cope with rising numbers of ALC patients, including significant numbers of PLWD, who no longer required hospital care but had no viable community discharge options. Although, as observed by Walker (2011), ALC beds may be seen to result from a lack of before-the-fact community-based care, policy makers were persuaded that after-the-fact solutions to improve hospital “flow through” were preferable (Boyle and Welsh 2011). In 2009–2010, less than a year after the Strategy’s rollout, the province redirected 50% of AAH monies to the discharge of ALC patients; in 2010–2011, 25% of the AAH money was held back by the ministry for its own provincial-level ALC initiatives, with the remaining 75% to be used to address ALC problems at the regional level (Government of Ontario 2010).

This preoccupation with beds also impacted Ontario’s next, albeit more limited, foray into dementia-specific policy. In 2010, the provincial government initiated its Behavioural Supports Ontario (BSO) program to enhance services for older persons with responsive behaviors (e.g., agitation, wandering, physical resistance and aggression) associated with complex and challenging mental health, dementia or other

neurological conditions living in LTC homes or in independent living settings (ASO 2010). Although originally intended to build capacity across the entire continuum (e.g., prevention and early detection for those with cognitive impairments, those at risk of the same, and their caregivers, those in need of community multiple agency support, high-risk individuals in need of LTC specialty services) (Dudgeon and Reed 2010), the implementation of this project mainly focused on people already in LTC beds with relatively limited community focus (Morton-Chang 2015).

We observed the costs and consequences of these policy choices in a “balance of care” (BoC) research project conducted in South West Ontario in 2009 (Morton-Chang 2015). This project, one of a series conducted by our team between 2005 and 2015 in 12 of Ontario’s 14 healthcare regions, brought together an “expert panel” of experienced front-line care managers and decision-makers from across the care continuum (including home care, community supports, hospitals and LTC) to construct ideal community-based care packages required to “divert” LTC waitlisted home care clients at different levels of assessed need back to community settings.

BoC projects conducted in other parts of the Province had estimated divert rates ranging from 10% to 50%, meaning that, in the view of experienced local experts, up to half of individuals waiting for residential LTC could potentially be supported in community “places” rather than in institutional beds (Williams et al. 2016). Higher-range estimates were typically associated with more integrated and cost-effective delivery models such as supportive housing, where needed services could be coordinated around older persons living in the same building.

For example, BoC projects conducted in the North East and North West Local Health Integration Networks (LHINs) concluded

that if scaled up and spread, supported housing models already present in those regions could potentially redirect up to two-thirds of individuals waiting for LTC back to the community (Williams et al. 2010).

In South West Ontario, however, the BoC expert panel estimated a zero divert rate for wait-listed PLWD. Panelists concluded that although, in principle, PLWD and their caregivers could and often were supported in the community to advanced levels of need, there was not, at that time, sufficient community-based capacity to guarantee it on more than an exceptional basis. Panelists noted, for example, that while supportive housing had great potential owing to the flexible, integrated, case-managed care it could provide, most available supportive housing places had not been designed or staffed to meet the needs of persons experiencing cognitive challenges (Morton-Chang 2015). Moreover, even when supportive housing providers could accept PLWD, they could not normally accept them later in the disease progression when more difficult, resource-intensive transitions were required. By contrast, earlier transitions to housing were seen as more manageable, as they would allow PLWD and caregivers to become familiar with staff and setting, while allowing staff to learn about client preferences, establish routines and develop proactive care strategies which balanced client safety and care needs with available resources (Morton-Chang 2015).

The South West project also provided insight into what could be done to support PLWD and caregivers in their own homes. While it is commonly assumed that cognition and difficulties with activities of daily living (ADLs) such as bathing and dressing are key drivers of loss of independence, the home care assessment data revealed – and the expert panelists confirmed – that difficulties with instrumental activities of daily living (IADLs) were just as often the trigger for LTC

placement; this corroborated the findings from previous and subsequent BoC projects across the Province (Kuluski, 2012a, 2012b; Williams et al. 2016, 2010, 2009a). Panelists pointed to the critical importance of everyday community supports for IADLs including transportation (e.g., to access medical appointments, attend Alzheimer day programs, maintain social connections); medication and nutrition monitoring (e.g., including reminders and help with grocery shopping and meal preparation); housekeeping (e.g., especially for those with mobility issues or risk of falls); and respite (e.g., to allow caregivers a break). While not health-care per se, a failure to access these “low-level” community-based supports in a timely manner could lead to “default” to hospital and LTC beds (Kuluski 2012a, 2012b; Morton-Chang 2015; Williams et al. 2010; 2009a).

Expert panelists also emphasized that H&CC packages had to acknowledge and support a broader “unit of care” including PLWD and caregivers. Without such essential caregiver contributions as 24/7 monitoring and coordination of multiple providers in the home, H&CC would not be safe or economically viable.

Part 3: Where We Go From Here

Political theory suggests that “big bang” policy change is unlikely, and that policy development usually occurs in small steps. And, in fact, Canadian policy makers are responding to population aging and the rise of dementia, albeit slowly and often in a piecemeal fashion, relying as much on the relatively weak policy tools of information and persuasion as on the more robust tools of legislation and funding.

At this point, the chances for a unified national dementia strategy in Canada seem modest. In October 2014, the former Conservative Minister of Health, Rona Ambrose, hosted a meeting of provincial and territorial health ministers where a national

plan to help reduce the personal, societal and economic impact of dementia was discussed, although with few concrete commitments (Canadian News Wire 2014). In February 2016, following the election of a Liberal majority government, a private member's Bill promoting a national dementia strategy (C-233: An Act respecting a national strategy for Alzheimer's disease and other dementias) was introduced by an opposition Member of Parliament (MP) with support from a government MP; however, such bills are largely symbolic.

Nevertheless, the Senate Standing Committee on Social Affairs, Science and Technology has now undertaken a study on the issue of dementia in Canadian society; it is currently hearing from witnesses as to what the federal role should be. Witnesses at the hearings, comprising both individuals and organizations, have provided detailed accounts on the societal effects of dementia, with many advocating for the development of a Canadian Alzheimer's Disease and Dementia Partnership (CADDP) (ASC 2015a; Parliament of Canada 2016). The proposed CADDP would bring together dementia experts, governments, researchers, healthcare providers, industry and consumer groups, as well as PLWD and their families to inform, coordinate and facilitate the development and implementation of an integrated, comprehensive national dementia strategy (ASC 2015a).²

As well, there are other actions, short of a full-scale national strategy, that the federal government could take. For example, the federal government could use its spending power, possibly through a renewed health accord, to encourage provincial/territorial action in the area of dementia care. It might also use targeted funding to spur the emergence of panCanadian organizations (such as the former Health Council of Canada) to conduct research, disseminate information

and build consensus around best practices and standards of care (ASTP 2006; Parliament of Canada 2016).

In addition, the federal government has scope to act in areas outside of healthcare. For example, it might consider extending its current enthusiasm for infrastructure renewal by reinvigorating its historical role in social housing, a key area of need for PLWD and others with chronic needs. Examples of dementia-friendly housing models have been elaborated by the Canada Mortgage and Housing Corporation (CMHC) in their recent series "Housing Options for Persons Living with Dementia" (CMHC 2015a, 2015b, 2015c).

Of course, even in the absence of federal action, Canadian provinces and territories are fully capable of developing their own dementia care strategies. As shown in Table 1, a number of Canadian provinces already have, or are in the process of doing so, although these vary considerably. While Table 1 does not provide an exhaustive review – much of the information is derived from a special session of the 2015 Canadian Association of Gerontology (CAG) Conference in which not all provinces/territories were represented – it does offer an instructive snapshot of recurrent themes (CAG 2015).

A first key theme relates to enhanced awareness, information, education and research. In addition to initiatives aimed at connecting older persons, caregivers and providers to existing knowledge, all aim to generate new knowledge, leading hopefully to improved prevention and care.

A second theme speaks to the need to improve and coordinate "person-centred" care. As presented in these provincial initiatives, such care should follow PLWD through the dementia journey, beginning with prevention, early intervention, primary care and home care; moving to acute care

and crisis management; and finally to end-of-life care that respects people's wishes, dignity and comfort.

A third, albeit less consistent, theme concerns family and informal caregivers. In addition to acknowledging caregivers as essential partners in care planning and delivery, caregivers are increasingly seen to merit support in their own right. If not revolutionary, this increasingly common perspective in provincial initiatives and in the international literature highlights an evolution from conventional models of

provider-centred care (where providers determine what patients receive); to “client- or patient-centred” care (where the focus now shifts to what's best from the perspective of the care recipient); to an expanded “unit of care” (including both the care recipient and informal caregiver); and to the creation of supportive neighborhoods and communities (Peckham 2016, 2014a).

Internationally, three countries, England, Japan and Germany, have emerged as frontrunners in promoting such broader visions of dementia care.

Table 1. Dementia strategy responses for six provinces

Province	Initiative	Key foci/priority areas
British Columbia (Zaharia 2015)	2007 Dementia Framework < www.alzheimer.ca/bc/-/media/Files/bc/Advocacy-and-education/Other-files/2007-09-01%20BC%20Dementia%20Service%20Framework.pdf >	<ol style="list-style-type: none"> 1. Collaborative work among stakeholders 2. System gaps in dementia care identified
	2012 Provincial Dementia Action Plan < www.health.gov.bc.ca/library/publications/year/2012/dementia-actionplan.pdf >	<ol style="list-style-type: none"> 1. Support prevention and early intervention 2. Ensure quality person-centred dementia care 3. Strengthen system capacity and accountability
	2015 Three-Year Dementia Action Plan (not available online)	<ol style="list-style-type: none"> 1. Wandering 2. Increase public awareness 3. Dementia training across the system 4. Commitment to patient and healthcare worker safety
	2016 Provincial Guide to Dementia Care in British Columbia: Achievements and Next Steps < http://www.health.gov.bc.ca/library/publications/year/2016/bc-dementiacare-guide.pdf >	<ol style="list-style-type: none"> 1. Public awareness and early recognition 2. Improve community supports for persons with dementia and informal caregivers 3. Improve quality of residential dementia care
Alberta (Schalm 2015)	2002 Alzheimer Disease and other Dementias: Strategic Directions in Healthy Aging and Continuing Care in Alberta < www.health.alberta.ca/documents/Strategic-Alzheimer-Report-2002.pdf >	<ol style="list-style-type: none"> 1. Public awareness 2. Education and training 3. Support for informal caregivers 4. Service delivery across the continuum of care 5. Supportive environments and 6. Ethical issues
	2015 Alberta Dementia Strategy and Action Plan < www.ascha.com/PDF_files/rollout/2015/InfoHandoutDRAFTADSAP18Mar2015.pdf >	<ol style="list-style-type: none"> 1. Acute care and crisis management 2. Caregiver support 3. Dementia journey 4. Primary care 5. Public awareness 6. Research and innovation
Manitoba (Weihs 2015)	2002 Strategy for Alzheimer Disease and Related Dementias in Manitoba < www.alzheimer.mb.ca/election/Strategy%20Backgrounder.pdf >	<ol style="list-style-type: none"> 1. Education 2. Guidelines for diagnosis and treatment 3. Standards across all programs and services 4. Family and individual support 5. Programs and services changes 6. Case management and collaboration 7. Equitable access to diagnostic and support services 8. Human and financial concerns 9. Research and evaluation

Province	Initiative	Key foci/priority areas
Manitoba (Weihls 2015) (continued)	2014 Manitoba's Framework for Alzheimer's Disease & Other Dementias < www.gov.mb.ca/health/alzframework.html >.	<ol style="list-style-type: none"> 1. Developing a health workforce strategy 2. Reviewing and enhancing dementia and cognitive impairment 3. Education in health provider education programs 4. Promoting family/caregiver involvement in care 5. Enhancing ongoing delivery of dementia education for staff 6. Reviewing personal care home standards related to dementia education 7. Developing a coordinated approach to dementia research.
Ontario (Morton-Chang 2015; ASO 2016)	1999–2004 Ontario's Strategy for Alzheimer Disease and Related Dementias < http://brainxchange.ca/Public/Resource-Centre-Topics-A-to-Z/Ontario%E2%80%99s-Strategy-for-Alzheimer-Disease-and-Relat.aspx >	<ol style="list-style-type: none"> 1. Staff education and training 2. Physician training (Mentor Programs) 3. Increasing public awareness, information and education 4. Planning for appropriate, safe and secure environments 5. Respite services for caregivers 6. Research on caregiver needs 7. Advance directives on care choices (Education) 8. Psychogeriatric consulting resources 9. Coordinated specialized diagnosis and support 10. Intergenerational volunteer Initiative
	2004 Three-year Alzheimer Strategy Transition Project (not available online)	<ol style="list-style-type: none"> 1. Web-based repository and sharing platform (Alzheimer Knowledge Exchange) 2. Regional dementia networks 3. Roundtable on future planning for people with Alzheimer's Disease and related dementia 4. Provincial Alzheimer Group (was convened and has since concluded)
	2010 Older Adults Behavioural Support System < http://brainxchange.ca/Public/Files/BSO/Older-Adults-Behavioural-SupportSystem.aspx >	Building on investments from the 1999 strategy, this initiative provides support for older Ontarians whose cognitive impairment is accompanied by responsive behaviours living at home, in acute care facilities or in long-term care homes
	2016 Developing Ontario's Dementia Strategy: A Discussion Paper < https://www.ontario.ca/page/developing-ontarios-dementia-strategydiscussion-paper >	The Ontario Government has committed to developing another provincial dementia strategy with expected implementation in 2017
Québec (Bergman and Vedel 2015)	2009 "Meeting the Challenges of Alzheimer's Disease and Related Disorders" < www.alzheimer.ca/en/montreal/About-us/~media/D6DF412C089F4C1995014784D532BAD7.ashx >	<ol style="list-style-type: none"> 1. Raise awareness, inform and mobilize 2. Provide access to personalized, coordinated assessment and treatment services for PLWD and their informal caregivers 3. Promote quality of life and provide access to home-support services and a choice of high quality alternative living facilities 4. Promote high-quality, therapeutically appropriate end-of-life care that respects people's wishes, dignity and comfort 5. Treat family/informal caregivers as partners who need support 6. Develop and support training programs 7. Mobilize an unprecedented research effort <p>Note: Quebec's Primary Care Report established family medicine groups which are seen as the cornerstone of the Alzheimer strategy</p>
Nova Scotia (Knowles 2015)	2015 "Towards Understanding: A Dementia Strategy for Nova Scotia" < http://novascotia.ca/dhw/dementia/Dementia-Report-2015.pdf > 2015–2018 "Dementia Strategy Action Plan" < http://novascotia.ca/dhw/dementia/Dementia-ActionPlan-2015.pdf >	<ol style="list-style-type: none"> 1. Facilitate early diagnosis, treatment, care and support 2. Enhance health system capacity to provide coordinated care and support that is person-centred and culturally specific 3. Enhance awareness and understanding about dementia

Note: This high-level table has been shaped based on presentation slides at the Canadian Association on Gerontology Supporting Canadians Living with Dementia Symposium 23 October 2015 for five provincial dementia strategies: British Columbia, Alberta, Manitoba, Québec and Nova Scotia. No presentation was made for Ontario at this symposium; however, material for this province has been added by the authors in addition to links for all referenced documents where possible.

England's 2009 dementia care plan, titled *Living Well With Dementia: a national dementia strategy*, captured the attention of former Prime Minister David Cameron, who is said to have had a personal connection to a PLWD. It established a strategic framework for improvements to local services to address health inequalities related to dementia; provide advice, guidance and support for the planning, development and monitoring of services; and provide a guide to the content of high-quality dementia care services (Department of Health 2009). In 2012, the Prime Minister issued a national challenge on dementia care, committing his government to deliver major improvements in dementia care and research by 2015. Three champion groups were set up to drive improvements in health and care; improve dementia research; and create dementia-friendly communities. England's national Dementia Friendly Campaign, backed by over £1.8 billion in 2012–2013, has spurred the emergence of such community-focused actions as the UK Dementia Friendly Initiative, which encourages ordinary people to learn more about dementia and finds ways of supporting PLWD (Alzheimer Society United Kingdom (ASUK) 2016b).

Japan's 2015 New Orange Plan for dementia care, championed by Prime Minister Shinzo Abe himself, identifies seven pillars or principles to guide the creation of dementia-friendly communities, support family caregivers, encourage cooperation and remove institutional barriers within government and between providers, incent intergenerational projects and give people with dementia a greater voice. This plan has stimulated an array of grass-roots innovations, such as dementia training for front-line bank tellers, grocery clerks and garbage collectors who interact with PLWD and their caregivers on a daily basis. It has also spurred the emergence of dementia open houses in private homes where PLWD, informal caregivers and care workers can congregate,

share meals and experiences, socialize, provide mutual support and learn about dementia and best practices; open house hosts have access to professional training and a 24/7 hotline (Hayashi 2015a; Whitehouse 2015). The establishment of professional-free zones where medical care is not provided likewise validates and mobilizes informal social networks, including healthy older persons who can help their peers as well as school children who learn to assist older persons who appear to be lost or in need of assistance (Canadian Research Network for Care in the Community (CRNCC) 2015; Williams et al. 2016).

Germany, as we noted, does not currently have a national dementia care strategy. Nevertheless, it does have a growing country-wide, community-based infrastructure to support PLWD and their caregivers, supported and funded by the national government. By the end of 2016, Germany aims to have in place over 500 "local alliances for persons with dementia" (lokale allianzen für menschen mit demenz), involving municipalities, healthcare and social care authorities, citizens, businesses and educational institutions aimed at developing comprehensive community-based approaches for improving the lives of people with dementia and their families permanently. This approach affirms that local solutions are the way to go, as the municipality is the place where PLWD normally live and where neighbours, decisionmakers employers and other actors in the civil society, can take direct action to influence the design of living conditions (Federal Ministry of Family Affairs 2016; Federal Ministry for Family Affairs, Senior Citizens, Family and Youth 2014).

We believe that these international examples, combined with experiences in Ontario and across Canada, point not only to the importance of developing a robust dementia care policy framework (whether starting from the local level and building up

or vice versa), but also to key principles or pillars to guide the development of such a framework. Here, we are less concerned about resolving jurisdictional issues, as it is clear that all levels of the government need to be involved, but are more concerned about how to improve the lives of PLWD and their caregivers, and, in the process, sustain increasingly stretched healthcare systems. Although focused on dementia care, we suggest that these same principles can improve care for a growing number of persons of every age who face the daily challenges of multiple, ongoing health and social needs.

Pillar One: Put People First

This most important and basic principle is embedded in virtually all dementia care initiatives across Canada and internationally. It affirms both the dignity and worth of PLWD, and also, to echo the motto of the UK dementia strategy, the goal of “living well,” as dementia, at least for the foreseeable future, is not open to cure. Nevertheless, PLWD, and those around them, can and should be able to look forward to fulfilling lives.

As a series of expert reports and commissions in Canada have emphasized, for the majority of older Canadians, including PLWD, living well means living as independently as possible, for as long as possible “closer to home.” In turn, this requires Canadian policy makers, while considering genuine issues of risk and safety, to avoid overprotective responses and to reject the notion that the onset of dementia leads almost inevitably to residential care beds. Instead, they, like their counterparts in countries including Japan, England and Germany, should now aim to find ways to strengthen the physical, social and emotional environments where people normally live.

Nor is this merely a matter of preference; it constitutes good care. A growing body of evidence suggests that aging in familiar

surroundings and routines can enhance the PLWD’s ability to rely on their procedural (unconscious) and emotional memory systems and help compensate for progressive losses. Particularly for PLWD, living in familiar settings may also provide a large measure of comfort and a sense of security and belonging (CMHC, 2015a, 2015b), enhancing quality of life.

Of course, it needs to be recognized that this idea of “person-centred” care goes further than simply providing better care to PLWD as passive care recipients. It also implies that PLWD, to the extent possible, should be active participants in decisions around their own care. At a personal level, even when PLWD progress to a point where they cannot manage routine tasks independently (e.g., finances, cooking, travelling, self-care) most can still express preferences around where and how they live and how care is provided. At the policy level, the Ontario Dementia Advisory Group (ODAG) – a group of PLWD in Ontario, which was formed in 2014 with the purpose of influencing policies, practices and people to ensure that people living with dementia are included in every decision that affects their lives – shows that ways can be found to facilitate meaningful and continuing engagement by PLWD and caregivers in the design of dementia care strategies (ODAG 2016).

Moreover, particularly during dementia’s early stages, PLWD may also wish to continue to help others. As experience in countries such as Japan shows, more capable older persons can assist those less capable as volunteers and peer supporters. Not only does this help to keep people more active, maintain self-worth and live longer in their own community, it can do much to normalize dementia and combat the perception that PLWD are simply a burden on the rest of society (CRNCC 2015).

Of course, even if self-evident, “putting people first,” in principle, can still be hard to achieve in practice, particularly to the extent

that it is seen to imply a decline in provider control and the redistribution of resources away from bed-based towards community-based care. In our case study of Ontario, for example, successive attempts to bolster community-based care for PLWD and older persons with ongoing needs were hollowed out by the competing political imperatives of building institutional beds and solving problems in the acute care sector. Ironically, as our Balance of Care in South West Ontario observed, and as recent expert reports have confirmed, outcomes have been largely perverse. Not only do many older persons, including PLWD, now “default” to costly hospital and residential beds because of a lack of before-the-fact community-based care, hospital ALC rates have shown little improvement in over a decade (Williams et al. 2016).

Pillar Two: Support Informal Caregiving

This second pillar highlights the crucial role of informal caregivers, the family, friends and neighbors who provide an estimated 70–90% of the everyday care required to maintain persons of all ages with ongoing health and social needs safely and appropriately in community settings. As recent expert reports in Ontario and elsewhere have observed, it is the contributions of informal caregivers that allow many older persons, including PLWD, to continue to live at home; without these contributions, formal care systems would not be sustainable (Williams et al. 2016, 2015a, 2015b).

Yet, paralleling the current state of dementia care policy, Canada does not currently have a national caregiver strategy, and caregiver support initiatives at the provincial/territorial levels remain uneven (Peckham, 2016: 140). Although provinces like Nova Scotia provide tangible supports in the form of monthly caregiver allowances and labour code amendments, which extend compassionate care leave to 28 weeks

(Government of Nova Scotia 2015a, 2015b), other provinces like Manitoba concentrate on affirming the informal caregiver role through largely symbolic measures such as its Caregiver Recognition Act (Government of Manitoba 2016).

This compares to dementia care strategies in other jurisdictions internationally where caregivers, families and extended social support networks are now recognized as essential partners in care qualifying for a range of formal supports in their own right. In the UK, for example, the principle of “living well” is extended to people caring for someone with dementia. This includes having access to support services provided by knowledgeable professionals; having access to respite care and time to go out and keep up activities you enjoy; having support to manage your own health; and having support to maintain social relationships and build up peer support networks (Isden 2016). England’s recent Carers Strategy likewise aims to improve caregiver access to a wide range of tangible resources including healthcare and social care but also extends to education, pensions and income support (Department of Health 2014).

In acknowledging and supporting informal caregivers, policy makers need to guard against simply “load shifting” onto individual family members (the majority of whom continue to be women) who may themselves experience a range of physical, emotional and mental health challenges because of caregiving activities. Rather than building informal caregiver capacity and resilience, this could produce the opposite outcome of increased caregiver burden and stress, leading to caregiver burnout and withdrawal and a decline of caregiver capacity (Health Quality Ontario 2016; Williams et al. 2015a, 2015b).

As well, international experience and practice suggests that the idea of caregiving should now be broadened to look beyond

family caregivers, particularly, as traditional nuclear families are in decline across the industrialized nations (McNeil and Hunter 2014). In Canada, for example, the numbers of older persons (those 65 years of age and older) exceeded numbers of younger persons (those under the age of 14) for the first time in 2016, reflecting demographic trends in other countries (McNeil and Hunter 2014) and auguring a progressive erosion of the traditional family caregiver base (Williams et al. 2015a).

Instead, countries like the UK, Germany and Japan are now redefining caregiving as a shared social responsibility and emphasizing the importance of bolstering broader support networks including building “dementia-friendly” communities (ASUK 2016a; Peckham 2016). In such communities, PLWD “are supported to live a high quality of life with meaning, purpose and value” by “policies, services and physical spaces” designed to enable people of all ages “to live in a secure and accessible physical and social environment” (Webster 2016). In the UK and Japan, this includes training and equipping tens of thousands of volunteers – “dementia friends” – to provide essential everyday supports to PLWD, including telephone calls, companionship, peer support and help to attend medical appointments and social activities (ASUK 2016a; CRNCC 2015; Isden 2016).

There are local Canadian examples as well. In Ontario, for instance, the small town of Bobcageon recently initiated a “Blue Umbrella Program,” which brings together multiple stakeholders (e.g., local businesses, professionals, bus drivers, volunteers) to build and strengthen communities by raising awareness about dementia and creating safe places for PLWD to continue to interact in their community (Webster 2016). Age- and dementia-friendly communities, which encourage broader preventative and maintenance efforts and the creation of supportive environments for not only PLWD but also

persons of all ages with multiple chronic needs, seem a logical next step (MortonChang 2015).

Pillar Three: Enable “Ground-Up” Innovation and Change

Which brings us to the key policy question: How best to achieve needed change.

The value of a comprehensive dementia care strategy at national and/or provincial/territorial levels seems clear. Such strategies can establish dementia as a public policy priority at a time when dementia numbers are rising. They can also set clear goals for concerted action, a crucial consideration given that good dementia care for PLWD and caregivers is increasingly seen to span not only a continuum of programs, services and providers within healthcare but also programs, services and providers within diverse fields such as social care, housing, education and income support. As we have seen, dementia care strategies internationally also aim to bolster informal support networks and build stronger neighborhoods.

However, it is less clear that such strategies need to be “top down” or heavily prescriptive. As we have seen, many promising initiatives gain traction at the local community level, where people normally live. Given that communities vary considerably in terms of their needs and capacity, “one size fits all” solutions are unlikely to work. In Ontario, and across Canada, the most rapidly aging communities are in rural and remote areas characterized by sparse formal care infrastructures, and by overall population decline as younger persons (and potential caregivers) pursue education and jobs in cities. Rather than requiring that a pre-specified “basket of services” be present in every community – an essentially “provider-centric” view – as this is unlikely to happen, it might be better to ask how formal and informal resources, including but not limited to healthcare, can be organized around people’s needs where they live.

In the UK, for example, its national dementia care strategy has encouraged local non-governmental organizations (NGO's) such as Enfield Age UK to train dementia care “navigators” in hospitals, as well as dementia care well-being coordinators in communities, to work with caregivers and existing care teams and providers, help access available services and supports and identify and fill care gaps (Enfield Age UK n.d.).

In Japan, the New Orange Plan supports the establishment of an Intensive Support Team in every municipality by 2018; an increase in the number of dementia care community promoters from 175 in 2012 to 700 in 2017; and the mobilization of up to 8 million dementia care “friends” by 2017, including bank staff, grocery clerks, school children and younger older persons (Hayashi 2015b; Wake 2016).

In Germany, its emerging country-wide network of community dementia alliances is mandated to take action in the following four fields: science and research; social responsibility; support for people with dementia and their families; and (re)structuring of support and healthcare systems (Federal Ministry for Family Affairs, Senior Citizens, Family and Youth 2014).

Such approaches do not let senior levels of government off the hook. Rather, they commit them to enabling the development of “ground-up” innovations through the establishment of clear goals, the reduction of bureaucratic hurdles and the infusion of needed resources. In doing so, they also galvanize political support. Instead of starting with a national dementia strategy, Germany is now enabling local communities to build one “from the ground up.”

Conclusions

While focusing on dementia, we do not see it as the only challenge now facing older Canadians, caregivers, communities and health systems. And we certainly do not advocate action that would see limited

resources stripped away from other needs groups, or pit disease-specific organizations one against the other.

However, dementia is a “game changer” to the extent that it complicates other health and social needs and erodes the capacity of individuals to manage on their own.

Moreover, even if rates of dementia are nudging downward and most older persons are living longer and healthier lives, which is where any dementia strategy should start, an aging population means that more people will be touched by dementia, a reality that has prompted leaders nationally and internationally to establish dementia care a policy priority. Moreover, because PLWD are among those most likely to experience the effects of multiple chronic health and social needs, their needs can usefully and appropriately drive the development of more comprehensive and integrated community-based approaches to care for Canadians of all ages who cannot manage on their own. As our work in Ontario suggests, the option of “business as usual” is not a good one: in addition to the negative impact on the well-being and independence of PLWD, the likelihood of caregiver burden and burnout can be expected to increase, with “default” to bed-based care eroding the sustainability of healthcare systems.

Although a Canadian dementia strategy may be desirable, to the extent it applies equally to all Canadians, provinces and territories are fully capable of developing their own strategies, as many provinces have already done, and as Ontario is once again in the process of doing. Nor should provincial strategies preclude federal action, as the federal government can establish national bodies to support knowledge generation and translation, and it can act with considerable freedom in such areas as housing which are key to dementia care.

Moreover, rather than being top-down and prescriptive, we suggest that strategies should aim to enable and set clear goals for

local action against which policy makers at all levels can be held accountable.

We think three overriding goals are essential. The first, “person-centred care,” reflects a growing national and international consensus that care should focus on what PLWD need, and that this in turn means “living well” in familiar settings. The second, “support informal caregivers,” recognizes not only that family, friends and neighbors do most of the heavy lifting in the community, but that they often require help in their own right to “live well” and continue to care. The third, “enable ground-up innovation and change,” emphasizes the need for senior levels of government to create the conditions, and provide tangible support for local innovations, which build capacity within and beyond healthcare to maintain PLWD as independently as possible, for as long as possible, “closer to home.”

In conclusion, we want to extend our thanks to the editors of this journal for giving us the opportunity to contribute to, and hopefully stimulate, ongoing discussion nationally and internationally about the future of dementia care. We look forward to hearing the ideas from an excellent group of commentators.

Notes

1. Interestingly however, another more generic strategy developed during this time frame designed to provide a common policy framework to guide efforts toward effective prevention and management of chronic diseases, with risk factors common to many diseases (Lee, 2006), was also eventually allowed to lapse.
2. Three national strategic objectives have been highlighted by ASC for CADDP: expanded funding and scope of dementia research; evidence-based strategies for dementia prevention and health promotion; and ensuring those who have dementia are living well with their condition (ASC 2015a).

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References

- Enfield Age UK. n.d. Memory Care Navigators Project. Retrieved December 19, 2019. <<https://www.ageuk.org.uk/enfield/our-services/memory-care-navigators-project/>>.
- Alzheimer’s Association. 2014. “Falling Dementia Rates in U.S., Europe Hint at Prevention Benefit: Part 7 of 13.” Alzheimer’s Association International Forum, Copenhagen, Denmark. Retrieved December 19, 2019. <<https://www.alzforum.org/news/conference-coverage/falling-dementia-rates-us-europe-hint-prevention-benefit>>.
- Alzheimer Disease International. 2011. “World Alzheimer Report 2011: The benefits of early diagnosis and intervention.” Retrieved December 19, 2019. <www.alz.co.uk/research/WorldAlzheimerReport2011.pdf>.
- Alzheimer Society of Canada. 2016a. “About Dementia: Dementia numbers in Canada.” Retrieved December 19, 2019. <<https://alzheimer.ca/en/Home/About-dementia/What-is-dementia/Dementia-numbers>>.
- Alzheimer Society of Canada. 2016b. “About Dementia: Brain Health.” Retrieved December 19, 2019. <<https://alzheimer.ca/en/Home/About-dementia/Brain-health>>.
- Alzheimer Society of Canada. 2015a. “Get Involved: The Canadian Alzheimer’s Disease and Dementia Partnership (CADDP).” Retrieved December 19, 2019. <<https://alzheimer.ca/en/sarnialambton/Get-involved/advocacy/national-national-dementia-strategy/caddp>>.
- Alzheimer Society of Canada. 2015b. “Alzheimer’s Disease: The Importance of Early Diagnosis.” Retrieved December 19, 2019. <https://alzheimer.ca/sites/default/files/files/national/core-lit-brochures/importance_early_diagnosis_e.pdf>.

- Alzheimer Society of Canada. 2010. "Rising Tide: The Impact of Dementia on Canadian Society." Retrieved December 19, 2019. <https://alzheimer.ca/sites/default/files/files/national/advocacy/asc_rising_tide_full_report_e.pdf>.
- Alzheimer Society of Manitoba. 2002. "Strategy for Alzheimer Disease and Related Dementias in Manitoba." Call to Action Regarding 2002 Guidelines. Retrieved April 9, 2016. <www.alzheimer.mb.ca/election/Strategy%20Background.pdf>.
- Alzheimer Society of Ontario (ASO). 2004. "Alzheimer Strategy – Next Steps to Shape the Future: A Model for Transition." Retrieved January 9, 2017. <<http://brainxchange.ca/Public/Files/Alzheimer-Strategy/Next-Steps-to-Shape-theFuture.aspx>>.
- Alzheimer Society of Ontario (ASO). 2016. "Get Involved: Ontario Dementia Strategy." Retrieved December 19, 2019. <<https://alzheimer.ca/en/ottawa/Get-involved/Advocacy/Ontario/Ontario-dementia-strategy>>.
- Alzheimer Society of Ontario. 2010. "Ontario Behavioural Support Systems Project. BSO Summary Sheet." Retrieved March 14, 2016. <<http://brainxchange.ca/Public/Files/BSO/Summary.aspx>>.
- Alzheimer's Society United Kingdom (ASUK). 2016a. "Dementia Friendly Communities." Retrieved March 28, 2016. <www.alzheimers.org.uk/dementiafriendlycommunities>.
- Alzheimer's Society United Kingdom (ASUK). 2016b. "Prime Minister's Champion Group." Retrieved March 28, 2016. <www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=3161>.
- Alzheimer Strategy Transition Project (ASTP) Ontario. 2007. "Alzheimer's Disease and Related Dementias: Recommendations for Prevention, Care and Cure Report 3: Health Human Resources Strategy." Retrieved December 19, 2019. <<https://brainxchange.ca/Public/Files/Policy/Health-Human-Resources-Strategy-Report.aspx>>.
- Alzheimer Strategy Transition Project (ASTP) Ontario. 2006. "Roundtable on Future Planning For People Affected by Alzheimer Disease and related dementias: An ADRD planning framework." Retrieved February 12, 2016. <<http://brainxchange.ca/Public/Files/Age-Friendly-Communities/ADRDPlanning-Framework-English.aspx>>.
- Aminzadeh, F., F. Molnar, W.B. Dalziel and D. Ayotte. 2012. "A Review of Barriers and Enablers to Diagnosis and Management of Persons with Dementia in Primary Care." *Canadian Geriatrics Journal* 15(3): 85–94.
- Bergman, H. 2015. "Developing and implementing provincial Alzheimer Strategies: Lessons learned from the Quebec Alzheimer Plan." Supporting Canadians Living with Dementia Symposium, October 23, 2015. Symposium conducted at the annual general conference of the Canadian Association on Gerontology in Calgary, Alberta.
- Bergman, H. and I. Vedel. 2009. "Meeting the Challenge of Alzheimer's Disease and Related Disorders: A Vision Focused on the Individual, Humanism, and Excellence Report of the Committee of Experts for the Development of an Action Plan on Alzheimer's disease and related disorders." Retrieved April 20, 2016. <www.alzheimer.ca/en/montreal/About-us/-/media/D6DF412C089F4C1995014784D532BAD7.ashx>.
- Billings, J. 2013. "The INTERLINKS Framework for Long-Term Care of Older People in Europe." *Journal of Integrated Care* 21(3): 126–38.
- Boyle, T. and M. Welsh. 2011. "Seniors Find Little Care in Provincial Aging Strategy: Ontario's \$1.1 Billion Aging at Home Plan has Left out Thousands of Seniors who are Sick and Frail, but not Sick and Frail Enough." *Toronto Star*. Retrieved March 31, 2016. <www.thestar.com/news/gta/2011/02/18/seniors_find_little_care_in_provincial_aging_strategy.html>.
- BrainXchange. 2016. "Ontario's Strategy for Alzheimer Disease and Related Dementias." Retrieved April 9, 2016. <<http://brainxchange.ca/Public/Resource-Centre-Topics-A-to-Z/Ontario%E2%80%99s-Strategy-for-AlzheimerDisease-and-Relat.aspx>>.
- Butler, D. 2016. "U.S. Expert Endorses National Strategy to Deal with Alzheimer's Disease." *Ottawa Citizen*. Retrieved June 2, 2016. <<http://ottawacitizen.com/news/national/u-s-expert-endorses-nationalstrategy-to-deal-with-alzheimers-disease>>.
- Cahill, S., E. O'Shea and M. Pierce. 2012. "Creating Excellence in Dementia Care: A Research Review for Ireland's National Dementia Strategy." Dublin, IE: School of Social Work and Social Policy, Trinity College Dublin. Retrieved March 13, 2016. <www.issuelab.org/resource/creating_excellence_in_dementia_care_a_research_review_for_irelands_national_dementia_strategy>.
- Canadian Association on Gerontology (CAG). 2015. "Pre-Conference Workshop: Supporting Canadians Living with Dementia (Provincial/Territorial Health Care Innovation Working Group)." Retrieved April 20, 2016. <<http://cag.conference-services.net/programme.asp?conferenceID=3888&language=en-uk>>.

- Canadian Institutes for Health Information (CIHI). 2010. *Analysis in Brief: Caring for Seniors with Alzheimer's Disease and Other Forms of Dementia*. Ottawa, ON: Author. Retrieved January 20, 2016. <www.cihi.ca>.
- Canadian Mortgage and Housing Corporation (CMHC). 1999 Revised 2015a. "Housing Options for Persons Living with Dementia 1." Retrieved April 5, 2016. <www03.cmhc-schl.gc.ca/catalog/productDetail.cfm?c at=17anditm=20andlang=enandsi d=IEz TNtg1NXyoOF0HKWozgyyfDhFsCxu2 ltvCNbwSGTQBpvF5ekUDvVfIRigTZhInandfr =1460581360594>.
- Canadian Mortgage and Housing Corporation (CMHC). 1999 Revised 2015b. "Housing Options for Persons Living with Dementia 2." Retrieved April 5, 2016. <www.cmhc-schl.gc.ca/odpub/pdf/68296.pdf?fr=1444058770247>.
- Canadian Mortgage and Housing Corporation (CMHC). 1999 Revised 2015c. "Housing Options for Persons Living with Dementia 3." Retrieved April 5, 2016. <www.cmhc-schl.gc.ca/odpub/pdf/68298.pdf>.
- Canadian Research Network for Care in the Community (CRNCC). 2015. "Dementia Care Lessons from Japan." CRNCC Newsletter 35(Fall-Winter): 1-10. Retrieved April 20, 2016. <www.ryerson.ca/content/dam/crncc/enews/pdfs/2015/2015-fall-winter-crncc-enews-vol35.pdf>.
- Department of Health. 2009. "Living Well with Dementia: A National Dementia Strategy." Leeds, UK: Government of the United Kingdom. Retrieved March 28, 2016. <www.gov.uk/government/uploads/system/uploads/attachment_data/file/168220/dh_094051.pdf>.
- Department of Health. 2014. "Carers Strategy: Second National Action Plan 2014 - 2016." UK: Government of the United Kingdom. Retrieved March 28, 2016. <www.gov.uk/government/uploads/system/uploads/attachment_data/file/368478/Carers_Strategy_-_Second_National_Action_Plan_2014_2016.pdf>.
- Donner, G. 2015. "Bringing Care Home: Report of the Expert Group on Home and Community Care, March." Toronto, ON: Expert Group on Home and Community Care. Retrieved March 24, 2016. <http://health.gov.on.ca/en/public/programs/ccac/docs/hcc_report.pdf>.
- Drummond, D. 2012. "Public Services for Ontarians: A Path to Sustainability and Excellence". Prepared for the Commission on the Reform of Ontario's Public Services, Ontario Ministry of Finance. Queen's Printer for Ontario. Retrieved April 4 2016. <www.fin.gov.on.ca/en/reformcommission/>.
- Dudgeon, S. and Reed, P. 2010. "Older Adults Behavioural Support System." Retrieved April 4 2016. <http://brainxchange.ca/Public/Files/BSO/OlderAdults-Behavioural-Support-System.aspx>.
- Fast, J. 2015. "Caregiving for Older Adults with Disabilities." December 30, 2016. <http://irpp.org/research-studies/study-no58/>.
- Federal Ministry of Family Affairs (Germany). 2016. "Local Alliances Support the Alliance for Dementia." Retrieved July 6, 2016. <www.lokale-allianzen.de/index.php?id=100>.
- Federal Ministry for Family Affairs, Senior Citizens, Family and Youth (Germany) 2014. "Alliance for People with Dementia: The Fields of Action." Retrieved June 22, 2016. <www.bmg.bund.de/fileadmin/dateien/Englische_Dateien/141107Alliance_for_people_with_dementiaThe_fields_of_action.pdf>.
- Government of Manitoba. 2016. "Healthy Living and Seniors: Seniors and Healthy Aging Secretariat." Retrieved March 28, 2016. <www.gov.mb.ca/shas/cgsupport/cra.html>.
- Government of Nova Scotia. 2015a. "Towards Understanding: A Dementia Strategy for Nova Scotia." Retrieved April 20, 2016. <www.alzheimer.ca/en/montreal/About-us/-/media/D6DF412C089F4C1995014784D532BAD7.ashx>.
- Government of Nova Scotia. 2015b. "Dementia Strategy Action Plan." Retrieved April 20, 2016. <http://novascotia.ca/dhw/dementia/DementiaActionPlan-2015.pdf>.
- Grant, K. 2015. "Ontario's Curious Shift Away from Family Health Teams." *The Globe and Mail*. Retrieved June 22, 2016. <www.theglobeandmail.com/life/health-and-fitness/health/ontarioscurious-shift-away-from-family-health-teams/article22989363/>.
- Hamel, D. 2016. "Developing a Canadian Dementia Strategy: The Time is Now." In *Alzheimers, Homes, OMNI Health Care*. Retrieved June 2, 2016. <http://omniway.ca/developing-a-canadian-dementiastrategy-the-time-is-now/>.
- Hayashi, M. 2015a. "Lessons from Japan: Tackle the Dementia Challenge by Supporting Carers." *Health Service Journal* January 15. Retrieved July 3, 2016. <www.hsj.co.uk/home/innovation-and-efficiency/innovation-network/lessons-from-japan-tackle-the-dementia-challenge-by-supporting-carers/5077940.article#.VLkXPmdRsmQ>.
- Hayashi, M. 2015b. "Dementia Friends in Japan." Presentation at the Dementia Awareness Week Conference 2015, Glasgow, UK, June 1, 2015. Retrieved July 3, 2016. <http://daw.dementiascotland.org/wp-content/uploads/2015/06/Mayumi-HayashiDementia-Friends-.pdf>.

- Health Quality Ontario. 2016. "The Reality of Caring: Distress among the Caregivers of Home Care Patients." Queen's Printer for Ontario. Retrieved July 3, 2016. <www.hqontario.ca/Portals/0/documents/system-performance/realitycaring-report-en.pdf>.
- Iliffe, S., J. Wilcock, T. Austin, K. Walters, G. Rait, S. Turner et al. 2002. "Dementia Diagnosis and Management in Primary Care." *Dementia* 1(1): 11–23.
- INTERLINKS. 2013. "Good Practices in Long Term Care for Older People in Europe." Presented at the European Parliament. The Way Forward: Innovation by Coordination and Integration. Brussels, BE, 28 November. Retrieved 3 July 2016. <<http://interlinks.eurocentre.org/news>>.
- Isden, R. 2016. "Health and Social Care for Older People Living with Dementia in England." Presentation to Joint World Conference on Social Work, Education and Social Development 2016, Seoul, June 29.
- Karp, A., R. Ebrahimi, A. Marengoni and L. Fratiglioni. 2010. "Informal Care and Voluntary Assistance a Systematic Literature Review of Quantitative and Qualitative Aspects of Assistance to Elderly Persons in Sweden, Italy, the United Kingdom and Canada." Prepared for: the Social Council.
- Keating, N. and J. Fast. 2015. "Economics of Family Caregiving to Persons with Dementia" in Supporting Canadians Living with Dementia Symposium October 23, 2015. Symposium Conducted at the Annual General Conference of the Canadian Association on Gerontology in Calgary, AB.
- Keefe, J. 2011. "Supporting Caregivers and Caregiving in an aging Canada. Institute for Research on Public Policy Study no. 23." Retrieved March 28, 2016. <<http://irpp.org/research-studies/study-no23/>>.
- Keefe, J., J. Légaré and Y. Carrieré 2007. "Developing New Strategies to Support Future Caregivers of Older Canadians with Disabilities: Projections of Need and their Policy Implications." *Canadian Public Policy* 33: 65–80.
- Keefe, J. and B. Rajnovich. 2007. "To Pay or Not to Pay: Examining Underlying Principles in the Debate on Financial Support for Family caregivers." *Canadian Journal on Aging* 26(S1): 77–89.
- Keene, J., T. Hope, C.G. Fairburn and R. Jacoby. 2001. "Death and Dementia." *International Journal of Geriatric Psychiatry* (16): 969–74.
- Knowles, R. 2015. "Nova Scotia's Dementia Strategy 2015" in Supporting Canadians Living with Dementia symposium October 23, 2015. Symposium Conducted at the Annual General Conference of the Canadian Association on Gerontology in Calgary, AB.
- Kuluski, K., AP. Williams, W. Berta and A. Laporte. 2012a. "Home Care or Long-Term Care? Setting the Balance of Care in Urban and Rural Northwestern Ontario, Canada." *Health and Social Care in the Community* 20(4): 438–48.
- Kuluski, K., AP. Williams, A. Laporte and W. Berta. 2012b. "The Role of Community-Based Care Capacity in Shaping Risk of Long-Term Care Facility Placement." *Healthcare Policy* 8(1): 92–105.
- Lee, L., L. Hillier, P. Stolee, G. Heckman, M. Gagnon, C. McAiney et al. 2010. "Enhancing Dementia Care- A Primary Care-based Memory Clinic." *Journal of the American Geriatrics Society* 58(11): 2197–204.
- Lee, L., LM. Hillier, G. Heckman, M. Gagnon, M. Borrie, P. Stolee et al. 2014. "Primary CareBased Memory Clinics: Expanding Capacity for Dementia Care." *Canadian Journal on Aging* 33(3): 301–19.
- Lum, J. and A. Ying. 2014. "In Focus Fact Sheet Community Hubs: Right Care, Right Place, Right Time." Toronto, ON: Canadian Research Network for Care in the Community (CRNCC). Retrieved March 28, 2016. <www.ryerson.ca/content/dam/crncc/knowledge/infocus/factsheets/InFocusCommunityHubs.pdf>.
- McAiney, C., L. Hillier, P. Stolee, D. Harvey and J. Michael. 2012. "'Throwing a Lifeline': The Role of First Link™ in Enhancing Support for Individuals with Dementia and their Caregivers." *Neurodegenerative Disease Management* 2(6): 623–38. Retrieved March 28, 2016. <www.alzheimer.ca/-/media/Files/national/For-HCP/for_hcp_McAiney_FL_outcomes_2012_e.pdf>.
- McAiney, C., D. Harvey, and M. Schulz. 2008. "First Link: Strengthening Primary Care Partnerships for Dementia Support." *Canadian Journal of Community Mental Health* 27(2): 1–11.
- McNeil, C. and J. Hunter. 2014. "The Generation Strain: Collective Solutions to Care in an Ageing Society, April 24." London, UK: Institute for Public Policy Research. Retrieved March 30, 2016. <www.ippr.org/publications/the-generationstrain-collective-solutions-to-care-in-an-ageingsociety>.
- Mead LC, JK Eckert, S. Zimmerman, JG. Schumacher. 2005. "Sociocultural Aspects of Transitions from Assisted Living for Residents with Dementia." *Gerontologist* 45 (1): 115–23.
- Medical Advisory Secretariat (MAS). 2008. "Caregiver- and Patient-Directed Interventions for Dementia: An Evidence based Analysis." *Ontario Health Technology Assessment Series* 8(4). Retrieved January 15, 2016. <www.hqontario.ca/english/providers/program/mas/tech/reviews/pdf/rev_aic_dementia_20081002.pdf>.

- Ministry of Health, British Columbia. 2012. "The Provincial Dementia Action Plan for British Columbia: Priorities and Actions for Health System and Service Redesign." Retrieved April 20, 2016. <www.health.gov.bc.ca/library/publications/year/2012/dementia-action-plan.pdf>.
- Ministry of Health and Long-Term Care (MOHLTC), Ontario. 2009. "Caring-About-Caregivers: Caregiving for the Future of Ontario – Long-Range Scenario Planning Supporting Caregiving into 2033." Retrieved March 16, 2016. <www.auditor.on.ca/en/content/annualreports/arreports/en02/304en02.pdf>.
- Ministry of Health and Long-Term Care (MOHLTC), Ontario. 2010. "Archived Backgrounder: Aging at Home Strategy." Government of Ontario Newsroom. Retrieved March 16, 2016. <<https://news.ontario.ca/mohltc/en/2010/08/aging-at-homestrategy.html>>.
- Ministry of Health and Long-Term Care (MOHLTC), Ontario. 2002. "Annual Report of the Provincial Auditor of Ontario: Chapter 3.04–Long-Term Care Facilities Activity, Background." Retrieved March 16, 2016. <www.auditor.on.ca/en/content/annualreports/arreports/en02/304en02.pdf>.
- Mittleman, M. D. Roth, D., Coon, W. Haley. 2004. "Sustained Benefit of Supportive Intervention for Depressive Symptoms in Caregivers of Patients with Alzheimer's Disease." *American Journal of Psychiatry* 161(5): 850–56.
- Mittleman, M., W. Haley, O. Clay, and D. Roth. 2006. "Improving Caregiver Well-Being Delays Nursing Home Placement of Patients with Alzheimer's Disease." *Neurology* 67: 1592–9.
- Moon, G. 1995. "(Re) Placing Research on Health and Health Care." *Health and Place* 1(1): 1–4.
- Morrison RS. and AL. Siu. 2000. "Survival in End-Stage Dementia Following Acute Illness." *JAMA* 284: 47–52.
- Morton, F. 2010. "Dementia Care: Diversity, Access, Coordination Final Report." Prepared on behalf of the Alzheimer Society of Toronto for the Toronto Central Local Health Integration Network Dementia Care Project. Retrieved April 12, 2016. <www.dementiatoronto.org/aboutus/DementiaCareFinalRpt_2010.pdf>.
- Morton-Chang, F. 2015. "Tipping Points to Institutional Care for Persons Living with Dementia: Analyzing the Policy Trajectory in Ontario." Doctoral Dissertation, University of Toronto, ON. Retrieved April 11, 2016. <<http://hdl.handle.net/1807/69351>>.
- National Advisory Council on Aging. 2004. "Alzheimer's Disease and Related Dementias." Minister of Public Works and Government Services Canada. Ottawa, Ontario: Health Canada – Division of Aging and Seniors.
- Nova Scotia Department of Labour and Advanced Education. 2015. "Compassionate Care, Bereavement Leaves Extended." Press release, November 19, 2015. Retrieved November 25, 2015. <<http://novascotia.ca/News/Release/?id=20151119003>>.
- Ontario Dementia Advisory Group (ODAG). 2016. "Ontario Dementia Advisory Group: Our Purpose." Retrieved June 2, 2016. <www.odag.ca/>.
- Ontario Health Coalition. 2015. "The Care We Need: Ontarians Speak Out on the State of Home Care and A Proposal for Reforming Home Care in the Public Interest." Retrieved April 15, 2016. <www.ontariohealthcoalition.ca/wp-content/uploads/homecare-the-care-we-need-report-final.pdf>.
- Organisation for Economic Co-operation and Development (OECD). 2011. "The Impact of Caring on Family Carers." In *Help Wanted? Providing and Paying for Long-Term Care*. Paris, FR: OECD. Retrieved April 11, 2016. <www.oecd.org/els/health-systems/47884865.pdf>.
- Parliament of Canada. 2016. "Parliamentary Business: The Standing Senate Committee on Social Affairs, Science and Technology – Evidence." Retrieved on May 30, 2016. <www.parl.gc.ca/content/sen/committee/421/SOCI/52594-E.HTM>.
- Peckham, A. 2016. "Caring for Caregivers: Establishing Resilience through Social Capital." Doctoral Dissertation, University of Toronto, ON.
- Peckham, A., AP. Williams, and S. Neysmith. 2014a. "Balancing Formal and Informal Care for Older Persons: How Case Managers Respond." *Canadian Journal on Aging* 33(2): 123–36.
- Peckham, A., K. Spalding, J. Watkins, C. BruceBarrett, M. Garsic and AP. Williams. 2014b. "Caring for Caregivers of High Needs Children." *Healthcare Quarterly* 17 (3): 30–35.
- Phelan, E.A., S. Borson, L. Grothaus, S. Balch and E.B. Larson. 2012. "Association of Incident Dementia with Hospitalizations." *Journal of the American Medical Association* 307(2): 165–72.
- Pratt, R., L. Clare, and V. Kirchner. 2006. "'It's Like a Revolving Door Syndrome': Professional Perspectives on Models of Access to Services for People with Early Stage Dementia." *Ageing & Mental Health* 10(1): 55–62.

- Prince, M., R. Bryce and C. Ferri 2011. "World Alzheimer Report 2011: The Benefits of Early Diagnosis and Intervention." Retrieved May 2, 2016. <www.alz.co.uk/research/WorldAlzheimerReport2011.pdf>.
- Provincial Dementia Service Framework Working Group. 2007. "BC Dementia Service Framework." Retrieved on April 20, 2016. <www.alzheimer.ca/bc/-/media/Files/bc/Advocacy-and-education/Other-files/2007-09-01%20BC%20Dementia%20Service%20Framework.pdf>.
- Schalm, C. 2015. "Alberta Dementia Strategy and Action Plan: Alberta Health Continuing Care" in Supporting Canadians Living with Dementia Symposium October 23, 2015. Symposium Conducted at the Annual General Conference of the Canadian Association on Gerontology in Calgary, AB.
- Sivananthan, S.N. and K.M. McGrail. 2016. "Diagnosis and Disruption: Population-Level Analysis: Identifying Points of Care at which Transitions are Highest for People with Dementia and Factors that Contribute to them." *Journal of the American Geriatrics Society* 64: 569–77.
- Sinha, M. 2013. "Analytical paper: Spotlight on Canadians: Results from the General Social Survey – Portrait of Caregivers, 2012." Statistics Canada. Accessed January 8, 2016. <www.statcan.gc.ca/pub/89652-x/89-652-x2013001-eng.pdf>.
- 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 January 20, 2016. <www.health.gov.on.ca/en/common/ministry/publications/reports/seniors_strategy/>.
- Smale, B. and SL Dupuis. 2004a. "Ontario Dementia Caregiver Needs Project: Stage 1: Survey Results, in their own Voices: A Profile of Dementia Caregivers in Ontario." Murray Alzheimer Research and Education Program, University of Waterloo, ON. Retrieved April 2, 2016. <<https://uwaterloo.ca/murray-alzheimerresearch-and-education-program/research/projects/ontario-dementia-caregiver-needs-project>>.
- Smale, B. and SL Dupuis. 2004b. "Ontario Dementia Caregiver Needs Project: Stage 2: The Focus Groups, in their own Voices: Dementia Caregivers Identify the Issues." Murray Alzheimer Research and Education Program, University of Waterloo, ON. Retrieved April 2, 2016. <<https://uwaterloo.ca/murray-alzheimerresearch-and-education-program/research/projects/ontario-dementia-caregiver-needs-project>>.
- Smale, B. and SL Dupuis. 2004c. "Ontario Dementia Caregiver Needs Project: Stage 3: Working Focus Group, in their own voices: Guiding Principles and Strategies for Change Identified by and for Caregivers in Ontario." Murray Alzheimer Research and Education Program, University of Waterloo, ON. Retrieved April 2, 2016. <<https://uwaterloo.ca/murray-alzheimerresearch-and-education-program/research/projects/ontario-dementia-caregiver-needs-project>>.
- Smale, B. and SL Dupuis. 2004d. "Ontario Dementia Caregiver Needs Project: A Literature Review: Caregivers of Persons with Dementia – Roles, Experiences, Supports and Coping." Murray Alzheimer Research and Education Program, University of Waterloo, ON. Retrieved April 2, 2016. <<https://uwaterloo.ca/murray-alzheimer-research-and-education-program/research/projects/ontario-dementia-caregiver-needs-project>>.
- Timmons S, E. Manning, A. Barrett, NM. Brady, V. Browne, E O'Shea et al. 2015. "Dementia in Older People Admitted to Hospital: A Regional Multi-Hospital Observational Study of Prevalence, Associations and Case Recognition." *Age Ageing* 44(6): 993–99. Retrieved January 15, 2016. <www.ncbi.nlm.nih.gov/pmc/articles/PMC4621233/>.
- Tootab, S., J. Hoes, R. Ledgerd, K. Burnell, M. Levine and M. Orrell. 2013. "Causes of Crises and Appropriate Interventions: The Views of People with Dementia, Carers and Healthcare Professionals." *Ageing and Mental Health* 17(3): 328–35.
- Vernooij-Dassen, M.J., E.D. Moniz-Cook, R.T. Woods, J. De Lepeleire, A. Leuscher, O. Zanetti et al. 2005. "Factors Affecting Timely Recognition and Diagnosis of Dementia Across Europe: From Awareness to Stigma." *International Journal of Geriatric Psychiatry* 20 (4): 377–86.
- Wake, J. 2016. "Health and Social Care Policies for Older Persons with Dementia and Japan: Issues and Policy Direction." Presentation to Joint World Conference on Social Work, Education and Social Development 2016, Seoul, South Korea, June 29.
- 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. Ontario." Retrieved March 22, 2016. <www.oanhss.org/oanhssdocs/Issue_Positions/External_Resources/walker_2011.pdf>.
- Warrick, N., A. Peckham, J. Watkins, M. Padjen and AP. Williams. 2014. "Caring for Caregivers of High Needs Older Persons." *Healthcare Quarterly* 17(3): 24–29.

- Webster, D. 2016. "Age-Friendly Communities and Dementia-Friendly Communities: Are We Talking About The Same Thing?" Webinar Presentation Hosted by the Provincial Age-Friendly Community Planning Outreach Initiative Sponsored by the Ontario Seniors' Secretariat. Retrieved March 12, 2016. <<http://files.ctctcdn.com/47769bf7301/15d5944b-91b1-4d669b1e-bc8110ae1bba.pdf>>.
- Weihls, K. 2015. "Manitoba's Framework for Alzheimer's Disease and Other Dementias: CAG Pre-Conference: Provincial Dementia Strategies Lessons Learned" in Supporting Canadians Living with Dementia Symposium October 23, 2015. Symposium Conducted at the Annual General Conference of the Canadian Association on Gerontology in Calgary, AB.
- Whitehouse, P. 2015. "Japan's National Dementia Strategy to Include Intergenerational School Programs for Persons with Dementia, March 6. Beyond the Myth (blog)." Retrieved April 12, 2016. <www.themythofalzheimers.com/blog/index.php/2015/03/06/japan-national-dementia-strategy-to-include-intergenerational-school-programs-for-persons-with-dementia/>.
- Williams, A.P., J. Lum, F. Morton-Chang, K. Kuluski, A. Peckham, N. Warrick et al. 2016. "Integrating Long-Term Care into a Community-Based Continuum: Shifting from "Beds" to "Places" IRPP Study No. 59." Retrieved March 22, 2016. <<http://irpp.org/research-studies/study-no59/>>.
- Williams, AP, A. Peckham, K. Kuluski, J. Lum, N. Warrick, K. Spalding et al. 2015a. "Caring for Caregivers: Challenging the Assumptions." *Healthcare Papers* 15(1): 8–21.
- Williams, AP, A. Peckham, K. Kuluski, J. Lum, F. Morton-Chang, N. Warrick et al. 2015b. "Caring for Caregivers: Bridging the Care Gap." *Healthcare Papers* 15(1): 62–66.
- Williams, AP, J. Watkins and K. Kuluski. 2010. "The North West Balance of Care Project: Final Report." Submitted to the North West Community Care Access Centre. Thunder Bay, ON: North West Local Health Integration Network.
- Williams, A.P., D. Challis, R. Deber, J. Watkins, K. Kuluski, JM. Lum and S. Daub, 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. Retrieved March 22, 2016. <www.longwoods.com/content/20694>.
- Williams, A.P., R. Deber, JM. Lum, R. Montgomery, A. Peckham, K. Kuluski et al. 2009b. "Mapping the State of the Art: Integrating Care for Vulnerable Older Populations". Prepared for the Ministry of Health and Long-term Care and the Canadian Institutes of Health Research." Toronto, ON: University of Toronto and Ryerson University. Retrieved March 22, 2016. <www.ryerson.ca/content/dam/crncc/knowledge/relatedreports/integratedcare/MappingtheStateoftheArt.pdf>.
- Woods, RT., E. Moniz-Cook, S. Iliffe, P. Champion, M. Vernooij-Dassen, O. Zanetti et al. 2003. "Dementia: Issues in Early Recognition and Intervention in Primary Care." *Journal of the Royal Society of Medicine* (96): 320–24. Retrieved March 22, 2016. <<http://jrs.sagepub.com/content/96/7/320.full.pdf>>.
- World Health Organization and Alzheimer's Disease International (WHO and ADI). 2012. "Dementia: A Public Health Priority." Retrieved March 11, 2016. <www.who.int/mental_health/publications/dementia_report_2012/en/index.html>.
- Zaharia, M. 2015. "Provincial Dementia Strategy: Lessons Learned [in British Columbia]" in Supporting Canadians Living with Dementia symposium October 23, 2015. Symposium conducted at the annual general conference of the Canadian Association on Gerontology in Calgary, AB.



The Journey Towards Community-Based Dementia Care: The Destination, Roadmap, Guide, Tour Group and the Conditions



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Abstract

In their paper, Morton-Chang et al. (2016) discuss how aging societies are struggling and trying to cope with the rapidly increasing numbers of persons living with dementia (PLWD). In that sense, the Canadian case is not unique. On the contrary, it is very similar to other developing countries. Therefore, it is worthwhile to reflect from another country's perspective on this unprecedented societal development.

In this paper, I will consider the challenge of dealing with increasing numbers of PLWD from the European and, in particular, Dutch perspectives. Whereas, MortonChang et al. pose the question: "How do we get there from here?" I will address the issues of what the "there" should be and how we get there from my European/Dutch perspective. I will provide my view on how the roadmap can be drawn, who needs to be on the tour, who might be the guide and what conditions need to be in place to arrive at the desired destination.



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The Destination

Before I discuss the destination – the “there,” in terms of Morton-Chang et al. (2016) – I will first briefly depict my “here,” The Netherlands. Geographically, The Netherlands is a small country, with a population of 17 million, of whom ~260,000 people suffer from dementia (RIVM 2016). The Dutch spend ~5.3% of their health budget on dementia (RIVM 2014). As in other countries, there are some signs that the prevalence is decreasing, probably because of improved prevention of vascular disease and higher levels of education (Larson et al. 2013; Matthews et al. 2013). Because of the sheer aging of the population, however, predictions are that in 2050, the number of PLWD will be ~500,000 in The Netherlands (Alzheimer Nederland 2013). Or, to give an impression of how it will affect society, in every street, there will be, on average, two PLWD. No doubt, dementia will affect the Dutch society to a large extent, as it will affect the Canadian society.

Acknowledging that there will be no cure for dementia in the short term, society has to deal with this reality. It needs to take up the hazardous journey into developing communities that can accommodate PLWD. One argument for this journey is guided by normative principles: it is a human right that PLWD find a place in society and can participate without any discrimination, irrespective of disease or disability, as stated in the UN Convention on the Rights of Persons with Disabilities (UN 2006). Communities, therefore, should be accessible to all citizens, irrespective of the kinds of disabilities or impairments. Therefore, according to these principles, we need to develop dementia-friendly communities, that will be beneficial to other groups of people with disabilities as well.

The second argument is an economic one. Calculated over a person’s life, dementia is – after learning disabilities – the second most

expensive disease or disability (RIVM 2014). The OECD (2015) recently estimated the worldwide cost of dementia was US \$645 billion in 2010. This is more than the GDP of Switzerland. As the number of PLWD is expected to double the next 30 years, expenses will increase enormously, in high-income countries, but even more in middle- and low-income countries (OECD 2015).

The third, and maybe the most appealing argument, is the enormous challenge to support PLWD and their relatives to live a life with dignity and that it is worthwhile to live. On average, they live eight years with their disease, i.e., approximately, one-tenth of their lives. These should be years with as high as possible quality of life. The same holds for their relatives, neighbors and their neighborhoods in which they live. The pressure on informal carers is large: European data suggest that in the early stages of Alzheimer’s disease, more than half of informal carers spend more than 28 hours per week providing care. As Alzheimer’s disease progresses, the burden increases, with half of the carers spending more than 70 hours per week providing care (Glendinning et al. 2009). So, the quality of life is surely a good case for working on communities that can deal with dementia.

Thus, whatever argument is taken first, the destination is clear: we need a dementia-friendly society, with dementia-friendly communities.

The Roadmap

If a dementia-friendly community is the joint destination, what should be the roadmap? As outlined above, dementia has huge consequences for society. In my view, it is not merely a healthcare issue. Not surprisingly, a traditionally economy-oriented organization such as the OECD has recently extensively addressed the issue on how to deal with dementia in society at large (OECD 2015). Along with other more

healthcare-oriented policies, the OECD calls for a wide variety of measures to be taken in and by society: healthy aging strategies for PLWD, safer communities, more acceptance, awareness raising, dementia education at schools, training of people who get in contact with PLWD, promoting independence and self-determination through user-directed support and care coordination, support of relatives and friends who take up care tasks, peer-to-peer support networks, safe and appropriate environments including alternatives to institutional care for living with dementia in dignity, guidance and financial support to help people to make their homes suitable for living with dementia and the use of effective technologies. One can hardly disagree!

Dementia care standard

The issue is how to take this further. In The Netherlands, we have developed some strategies, which may also work for other countries. One is the instrument of the so-called Care Standards. A Care Standard is a document that describes what the important ingredients are for optimum dementia care and support in a region, based on the most state-of-the-art (evidence based) multidisciplinary knowledge and guidelines for a particular disease or category of health-related problems. It is developed by all relevant national stakeholders and experts (Nies et al. in press). The national Care Standard is translated to the regional and local communities by care programs. The Dutch Care Standard for Dementia resembles the NICE guideline on *Dementia, Disability and Frailty in Old Age* (NICE 2015). It specifies what should be organized in functional terms without exactly saying *who* is responsible for what.

The present standard, however, is pretty much health-, long-term- and social care-oriented. It more or less follows the process in the disease of the PLWD. It describes how to organize early recognition and prevention,

diagnostics, case management (or care coordination), treatment, counselling and support, delivery of care and services, and organization of integrated services/care. The regional translation and implementation is a responsibility of dementia care networks. These are networks of professional organizations and/ or professionals (e.g., general practitioners) in dementia care, as well as representatives of local or regional Alzheimer's associations, representing the voices of the users. To make dementia care work at the regional level, the Dutch Government has issued a large implementation program to encourage the development of regional collaborative networks (Nies et al. 2009), and will do so again from 2017 on. Between regions, differences can exist in how dementia care is organized and how far it is implemented (Nies et al. in press).

However, the present approach is not yet a success in all respects. The present Care Standard is signed by a great number of stakeholders, but not by healthcare insurers and municipalities, two important categories of stakeholders. The national council of municipalities did not sign the Standard because of the political autonomy of local governments. The healthcare insurers were reluctant because of financial implications. At the time the standard was approved, it was not an obligation to get them on board and committed. The standard as a quality instrument was at that time merely seen as a professional standard, but tested from a user perspective. A final limitation is that the current standard is yet a *care* standard, not a *community* standard.

Dementia-friendly communities

A second strategy is that of "dementia-friendly municipalities." As in other countries, at present, a number of municipalities are profiling themselves as such. The Dutch Alzheimer Association supports this development by encouraging municipalities to join the aforementioned care networks, to

commission and to develop dementia-friendly services (Alzheimer Nederland 2012). The movement towards dementia-friendly communities (municipalities, neighborhoods, companies, citizens) is at its beginning stage. There are quite a number of good examples, for instance, in encouraging arts work among PLWD, teaching on how to interact with PLWD at schools, enabling police officers to be more aware of dementia, providing information to citizens, organizing informal carers' support and so on.

Innovation

A third strategy is innovation. A number of services that fit in the concept of "dementia friendly" are well-developed and grounded on scientific evidence. For instance, the dementia meeting centres are – as the name suggests – a place where the PLWD meet. A small team of professionals and volunteers provides support and a social environment to a group of mildly to moderately impaired PLWD in a lowthreshold setting. Meeting centres integrate different types of support and offer a wide range of activities. Informal carers are invited to join for information meetings and discussion groups. The centres are also open for assistance in practical, emotional and social problems (Dröes et al. 2004, 2006). At this moment, ~150 meeting centres exist.

Another type of service, and to some extent similar, are the Alzheimer Cafés (Jones 2010; Jones and Miesen 2011; Miesen and Jones 2004). These cafés provide, usually on a monthly basis, opportunities for meeting and sharing information for PLWD, their informal carers and professionals. The meetings are often accompanied by music performances and themes on dementia are discussed and usually inspired by presentations of one or more experts. The Alzheimer Cafés are widely spread across the country and are often run by volunteers or professionals, or professionals in their leisure time.

Further, the so-called green care farms fit within the model of dementia-friendly communities. These are often a form of collaboration between healthcare and social care and agriculture. People with dementia or learning disabilities; those with psychosocial, psychiatric or (formerly) addiction issues, and those with burn-out issues and other problems that make it difficult for them to participate in society, are working under guidance at a farm for a given number of days a week. Hereby, people engage in meaningful activities and meet other people. Participants sometimes also have the option of staying overnight. The mixture of target groups is diverse, and sometimes, the farms only focus on people of one of these groups (De Bruin et al. 2010a, 2010b). The number of care farms has mushroomed from 214 in 2000 to 1,088 in 2009 (no recent data available) (Federatie Landbouw en Zorg n.d.). At present, the continuation of these green care farms has become critical in some cases because of recent changes and cutbacks in public long-term care funding.

The Guide, the Tour Group and the Conditions

These examples demonstrate that optimum dementia care and dementia-friendly communities can be encouraged and guided by governments; for instance, by establishing an instrument like the Care Standard, by using a label such as "dementia-friendly community" or by issuing a significant implementation program. In our – Dutch – view, it is a system-responsibility of our government to ensure healthcare for all citizens. However, its needs to be taken up by service users and their representatives, citizens (including volunteers), service providers, professionals and authorities. They need to be actively involved in designing these communities. They constitute the "tour group" that is heading for the jointly agreed destination. And if the tour doesn't

take place, our government can be held accountable for not upholding its system-responsibility.

The examples also show that creative entrepreneurship and initiatives of citizens are helpful. The green care farms, to some extent, developed because of the difficult times in agriculture and a number of farmers had to find new ways to continue their business. On the other hand, new paradigms of participation, inclusion and normalization were adopted by the dementia care providers. Pioneers are to explore new pathways!

Thirdly, the examples show, that supportive conditions need to be in place. It is not always big money that makes the difference, but some money is necessary. Skillful people are also needed to develop and run the right services, which are attuned to the needs of PLWD. Moreover, infrastructure is necessary: building homes suitable for PLWD, running buses to transport people and constructing local information structures.

The challenge

The journey from “here” to “there” is a challenge. The destination is clear: a supportive society that is receptive to PLWD and enables them to live as full a life as possible. But what do we mean by saying this? “A life in good health” could be the obvious answer. However, “health” has become a concept that is heavily medicalized. The definition of the World Health Organization (WHO 1948) – “a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity” – declares the majority of people, particularly older people with multiple conditions, as unhealthy. This easily contributes to over-medicalization. Huber et al. (2011: p. 235) introduced the concept of “positive health,” which is the “ability to adapt and self-manage in the face of social, physical and emotional challenges.” Resilience and selfmanagement are key

to experiencing quality of life, well-being and dignity, although impairments, frailty and/or multiple conditions exist, which is the case in PLWD. This concept of “positive health” implies living a normal life for as much as possible. It also implies a paradigm shift away from the traditional disease-oriented healthcare, which is often dominant in care for PLWD. PLWD are more than their disease, although their conditions are limited. Huber et al. (2016) identified the following six main dimensions within the concept of “positive health”: bodily functions, mental functions and perception; the spiritual/existential dimension; quality of life; social and societal participation; and daily functioning. These dimensions are made up of in sum 32 aspects.

It was established that citizens and patients value all these dimensions, but the values of professional carers differ from those of citizens and patients. However, according to Huber et al.’s (2016) research, policy makers, healthcare insurers and researchers deviate most from the values of citizens and patients.

The real challenge will be to support positive health for PLWD. The on-average eight years are too long to live a life that is “unhealthy” and dominated by the disease. Optimizing life alongside the six dimensions by supporting self-management and resilience is the real challenge; sometimes by counseling, nursing and treatment, but most of the time by supporting what makes life worthwhile. And often that can be done by providing support to the social and physical environment. And, in the end, people constitute their own lives, for good or for bad.

From a community point of view, conditions need to be created to enable positive health for PLWD. This community journey needs a well-designed roadmap. Many barriers exist that we ourselves have created,

such as legislation, funding, organizations, professions, which create their own boundaries, whereas the PLWD deserve fully integrated support. This calls for a guide who knows how to navigate around these barriers and to cross the boundaries. It also requires a tour group that is destined to reach the “there” and to establish supportive conditions and investments, in terms of money and infrastructure. Each local itinerary and each journey can be different and should be different, be it in Canada or in The Netherlands. But there needs to be a common view: supporting people with dementia and their dearest to make life worthwhile and dignified!

References

- Alzheimer Nederland/Vilans. 2012. *Stappenplan Dementie Gemeenten*. (in Dutch; translation: Alzheimer’s Association of the Netherlands/Vilans. 2012. Roadmap Dementia Municipalities). Retrieved January 17, 2017. <[www.invoorzorg.nl/docs/ivz/informatiecentrum/DV_Stappenplan_dementie_gemeenten_juni_2012\[1\].pdf](http://www.invoorzorg.nl/docs/ivz/informatiecentrum/DV_Stappenplan_dementie_gemeenten_juni_2012[1].pdf)>.
- Alzheimer Nederland/Vilans. 2013. *Zorgstandaard Dementie*. Utrecht, NL: Alzheimer Nederland, Vilans. (in Dutch; translation: Alzheimer’s Association of The Netherlands/Vilans. 2013. Care Standard Dementia).
- De Bruin, S.R., S.J. Oosting, H. Tobi, Y.H. Blauw, J.M.G.A. Schols et al. 2010a. “Day Care at Green Care Farms: A Novel Way to Stimulate Dietary Intake of Community-Dwelling Older People with Dementia?” *Journal of Nutrition, Health & Aging* 14(5): 352–57. doi:10.1007/s12603-009-0223-6.
- De Bruin, S.R., S.J. Oosting, J.M.P. Enders-Slegers, A.J. Van der Zijpp and J.M.G.A. Schols. 2010b. “The Concept of Green Care Farms for Demented Elderly: An Integrative Framework.” *Dementia: The International Journal of Social Research and Practice* 9(1): 79–128.
- Dröes, R.M., F.J.M. Meiland, M. Schmitz and W. van Tilburg. 2004. “Effect of Combined Support for People with Dementia and Carers versus Regular Day Care on Behaviour and Mood of Persons with Dementia: Results from a Multi-Centre Implementation Study.” *International Journal of Geriatric Psychiatry* 19: 1–12.
- Dröes, R.M., F.J.M. Meiland, M.J. Schmitz and W. van Tilburg. 2006. “Effect of the Meeting Centre’s Support Program in Informal Carers of People with Dementia: Results from a Multi-Centre Study.” *Aging & Mental Health* 10(2): 112–24.
- Federatie Landbouw en Zorg, n.d. *Landbouw en zorg groeit* (in Dutch; translation: Federation Agriculture and Care. Agriculture and care grows). Retrieved October 14, 2016. <www.landbouwzorg.nl/index.php?pagid=55&chb=72>.
- Glendinning, C., F. Tjadens, H. Arksey, M. Morée, N. Moran and H. Nies. 2009. “Care Provision within Families and its Socio-Economic Impact on Care Providers.” York, UK: University of York Social Policy Research Unit.
- Huber, M., J.A. Knotnerus, L. Green, H. van der Horst, A.R. Jadad, D. Kromhout et al. 2011. “How Should we Define Health?” *BMJ* 343(4163): 235–37.
- Huber, M., M. van Vliet, M. Giezenberg, B. Winkens, Y. Heerkens, P.C. Dagnelie et al. 2016. “Towards a ‘Patient-Centred’ Operationalisation of the New Dynamic Concept of Health: A Mixed Methods Study.” *BMJ Open* 5: e010091. doi:10.1136/bmjopen-2015-010091.
- Jones, E. 2010. “The Alzheimer Café: Why it Works.” Sunninghill, UK: The Wide Spectrum.
- Jones, G.M.M. and B.M.L. Miesen. 2011. “Dementia Care: Involving People in Alzheimer Cafés.” *Nursing and Residential Care* 13(9): 442–45.
- Larson, E.B., K. Yaffe and K.M. Langa. 2013. “New Insights into the Dementia Epidemic.” *New England Journal of Medicine* 369: 2275–77.
- Matthews, F.E., A. Arthur, L.A. Barnes, J. Bond, C. Jagger, L. Robinson et al. 2013. “A Two-Decade Comparison of Prevalence of Dementia in Individuals Aged 65 years and Older from Three Geographical Areas of England: Results of the Cognitive Function and Ageing Study I and II.” *Lancet* 382(9902): 1405–12.
- Miesen, B. and G. Jones. 2004. “The Alzheimer Café Concept: A Response to the Trauma, Drama and Tragedy of Dementia.” In Jones, G.M.M. and B.M.L. Miesen, eds., *Caregiving in Dementia*, Vol. 3. London, UK: Brunner-Routledge.
- Morton-Chang, F., A.P. Williams, W. Berta and A. Laporte. 2016. “Towards a CommunityBased Dementia Care Strategy: How Do We Get There from Here?” *Healthcare Papers* 16(2): 8–32. doi:10.12927/hcpap.2017.25006.

NICE. 2015. Dementia, Disability and Frailty in Later Life – Mid-Life Approaches to Delay or Prevent Onset. NICE guidelines [NG16]. Retrieved January 7, 2016. <www.nice.org.uk/guidance/ng16>.

Nies, H., J. Meerveld, and R. Denis. 2009. "Dementia Care: Linear Links and Networks." *Healthcare Papers* 10(1): 34–43.

Nies, H., M. Minkman and C. van Maar. In Press. "Integrated Care for People Suffering from Frailty, Dementia and Multi-Morbidity." In Amelung, V.E., V. Stein, N. Goodwin, R. Balicer, E. Nolte and E. Suter. eds., *Handbook of Integrated Care*. London, UK: Springer-Verlag.

Organisation for Economic Co-operation and Development (OECD). 2015. *Addressing Dementia: The OECD Response*. Paris, FR: OECD Health Policy Studies, OECD Publishing.

RIVM (National Institute for Public Health and the Environment). 2014. "Nationaal Kompas Volksgezondheid." Retrieved October 11, 2016. <www.nationaalkompas.nl/gezondheid-en-ziekte/ziekten-en-aandoeningen/welke-ziekten-zijn-het-duurst/>.

RIVM (National Institute for Public Health and the Environment). "Volksgezondheidszorg.info." Retrieved October 11, 2016. <www.volksgezondheidszorg.info/onderwerp/dementie/cijfers-context/incidentie-en-prevalentie>.

United Nations. 2006. "Convention on the Rights of Persons with Disabilities." Retrieved October 11, 2016. <www.un.org/disabilities/convention/conventionfull.shtml>.

World Health Organization (WHO). 1948. *WHO Definition of Health*. Retrieved December 30, 2016. <<http://www.who.int/about/definition/en/print.html>>.



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Achieving the Goals of Dementia Plans: A Review of Evidence-Informed Implementation Strategies



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achieving-the-goals-of-dementia-plans-a-review-of-evidence-informed-implementation-strategies](https://www.longwoods.com/content/25860/healthcare-policy/achieving-the-goals-of-dementia-plans-a-review-of-evidence-informed-implementation-strategies)>.*



Abstract

A 2019 report by the Canadian Academy of Health Sciences identified the importance of evidence-informed implementation strategies in reforming dementia care. Such implementation strategies may be relevant to changing clinical practice in the wake of Canada's impending federal dementia plan (initiated by Bill C-233). As this federal dementia plan is elaborated, there may be value in looking ahead to some of the implementation challenges likely to be faced "on the ground" in healthcare settings. We thus conducted a rapid review of provincial and national dementia plans from high-income countries and reviewed studies on implementation strategies to dementia care. We advance seven key implementation strategies that may be useful for future dementia care reform.

The Alzheimer Society of Canada (2010) reports that by 2038 over 1.1 million Canadians will have dementia. This represents 2.8% of the total Canadian population, with 9% of Canadians over age 60 and 50% of Canadians over age 90 having dementia (Alzheimer Society of Canada 2010).

Ultimately, this prevalence of dementia will lead to a cumulative economic burden of \$293 billion per year by 2040 (Alzheimer Society of Canada 2018). In response to rising global dementia rates, the World Health Organization (WHO 2012) has identified dementia as a global health priority. In Canada, this priority has been addressed provincially: beginning with Ontario in 1999 (MOHLTC 1999), provinces have gradually developed plans to address the overwhelming scale, impact and cost of dementia. While provincial stewardship in this arena is logical (Flood and Choudhry 2002), calls for a federal dementia strategy that is complementary to provincial stewardship – involving investment in research, increasing awareness of dementia risk factors and supporting and inspiring local clinicians to improve care practices for dementia – persist (Alzheimer Society of Canada 2018).

Canada's recent passage of Bill C-233, an Act respecting a national strategy for Alzheimer's disease and other dementias, suggests that a federal dementia plan may soon be established. Bill C-233 identified five priorities for dementia care reform: (1) developing national objectives, (2) encouraging investment in research, (3) coordinating with international bodies (e.g., WHO), (4) assisting provinces with the development and dissemination of diagnostic treatment guidelines and best practices for dementia care management; and (5) making recommendations for standards of care. A National Dementia Conference (PHAC 2018) and a report conducted by the Canadian Academy of Health Sciences (CAHS 2019) were organized in response to Bill C-233. Both the conference and report allowed for diverse stakeholders to share perspectives on dementia care and support, research and public education. They also suggested that implementing a dementia strategy is easier said than done. Accordingly, the CAHS recommended that evidence-informed implementation strategies be considered to achieve stated goals of dementia care reform (CAHS 2019). To respond to this final recommendation – and to support the

clinic-level objectives identified by Bill C-233 and the National Dementia Conference – a synthesis of existing implementation strategies specifically relevant to dementia care is needed.

In this article, our aims are (1) to highlight why implementation strategies are essential components downstream of any dementia plan, (2) to examine the implementation strategies referenced in dementia plans of peer high-income countries and provinces; and (3) to review and propose evidence-informed implementation strategies that national and provincial governments in Canada may use as they further reform dementia care at the clinical level. To do so, we conducted a rapid review as defined by Tricco et al. (2016), examining provincial and national dementia plans from around the world. In addition, we reviewed studies on implementation strategies that are specific to dementia care reform. Note that while a dementia plan should ideally be broad, including supportive housing, community programs, caregiver support, dementia-friendly cities, transportation and anti-stigma campaigns, this paper will specifically focus on the healthcare delivery system for dementia care.

Why Implementation Strategies Matter

The inclusion of implementation strategies in dementia care reform is important for countries to reap the benefits – improved care and reduced cost – of dementia plans (Milstein and Shortell 2012). Studies have shown that the dissemination of healthcare initiatives is challenging. For example, Damschroder et al. (2009) report that only one-third of healthcare improvement initiatives successfully transition from adoption to sustained implementation across organizations. Even if implementation strategies to change clinical practice are only enacted after high-level policy is negotiated, understanding implementation

challenges likely to be faced by healthcare professionals is relevant to the negotiation of funding mechanisms and resource allocation by federal and provincial governments.

Whereas many implementation strategies are applicable to any healthcare policy, specific implementation strategies matter for dementia because of the complex nature of dementia diagnosis, care and affected population. First, dementia is notoriously underdiagnosed in primary care, with rates between one-half (Bradford et al. 2009) and two-thirds (Valcour et al. 2000). The challenges of primary care physicians to diagnose dementia stem from a lack of confidence (Foley et al. 2017) and/or uncertainty about whether the diagnosis of an incurable disease such as dementia will improve the care or quality of life of a patient (Borson and Chodosh 2014). Second, optimal dementia care requires a wide range of personnel and services, which change as the needs of dementia patients evolve (Borson and Chodosh 2014). Third, patients with dementia suffer from high degrees of comorbidity, with one-third of patients experiencing five or more additional chronic conditions (Mondor et al. 2017). Acute exacerbations of these co-existing diseases often make dementia care too rare of a priority. Finally, optimal dementia care requires engaging both the patient and their caregiver(s), which is specific to dementia care (Borson and Chodosh 2014).

Shedding Light on the Lack of Implementation Strategies in Published National and Provincial Plans for Dementia

National and provincial plans for dementia have been published in 29 countries and eight Canadian provinces, according to *Alzheimer's Disease International* (2018). We analyzed the 24 strategies that were written in either English or French (16 countries plus all eight Canadian provinces).

These reports generally share a common form: the reports define dementia and describe its prevalence and impact, underscore the purpose for a national or provincial dementia strategy and outline strategic priorities for dementia reform. These priorities typically include (1) increasing awareness and understanding of dementia, (2) promoting timely diagnosis through workforce development; and (3) improving dementia management and care. Of the 24 national and provincial plans for dementia examined, *only 12* addressed the implementation strategies for the programs. The plans either introduce implementation

strategies throughout the documents (i.e., tying individual strategies to specific objectives) or through explicit “stand-alone” chapters on implementation strategies, typically located towards the conclusion of the documents (Table 1).

More critically, even among the national and provincial plans for dementia that include sections on implementation strategies, very few plans actually articulate strategies for the diffusion or implementation of dementia care reform. They tend to state objectives but not how such objectives will be achieved or measured (e.g., “educating more people earlier about the risks of

Table 1. A list of reviewed national and provincial dementia plans, and how they address implementation strategies

Region	Implementation	Integrated throughout plan	Stand-alone section
Country			
Australia	✓	•	
Finland			
France	✓	•	
Greece	✓	•	
Indonesia	✓	•	
Ireland	✓		•
Israel			
Italy			
Korea	✓	•	
Luxembourg			
Malta	✓		•
Netherlands			
Norway			
Switzerland			
United Kingdom	✓	•	
United States	✓	•	

Table 1. continued

Region	Implementation	Integrated throughout plan	Stand-alone section
Canadian Province			
Alberta			
British Columbia			
Manitoba	✓	•	
Newfoundland & Labrador			
Nova Scotia			
Ontario			
Quebec	✓		•
Saskatchewan	✓	•	

developing dementia”). The few implementation strategies that have been articulated remain vague. Strategies like “investing in research” (United Kingdom) (United Kingdom Department of Health 2009), “diversifying pedagogical approaches” (France) (Ministère des Affaires sociales, de la Santé et des Droits des femmes 2014) and “involving individuals living with dementia and their caregivers” (Switzerland and Malta) (Office fédéral de la santé publique 2013; Scerri 2014) form inadequate foundations upon which governments can orchestrate targeted and consequential steps towards achieving dementia plan goals.

A Review of Successful Implementation Strategies in Dementia Care

The literature suggests that any implementation of dementia reform, like any innovation, should target both individual adopters (healthcare professionals and informal caregivers) and whole organizations (Greenhalgh et al. 2004). Individual adopters benefit from pragmatic guidelines that target the confidence and expertise of

individuals, address their concerns and encourage them to engage with dementia reform over an extended period.

Implementation strategies should also be conceived at the organizational level, where integrating reforms with the current organizational context, identifying and valourizing a “champion” of dementia reform and providing additional resources and incentives may facilitate improved dementia care.

Successful Strategies at the Individual Level: Putting People First

Disseminating pragmatic guidelines and training through active, concise and varied formats

Traditional didactic and passive strategies (lecture-style meetings, printed materials and guidelines) are usually ineffective strategies for increasing healthcare professionals’ knowledge of dementia and their confidence in managing patients (Aminzadeh et al. 2012; Burgio et al. 2001; Gifford et al. 1999). Healthcare professionals

benefit most from *problem-based* and *solution-focused* dementia training (Yaffe et al. 2008). Whatever the intervention, strategies that focus on pragmatic benefit and usability should be developed (Aminzadeh et al. 2012). Guidelines must recognize the importance of the patient–caregiver dyad, which is specific to dementia (CAHS 2019). For example, caregivers benefit from specialized training including practice opportunities, personalized feedback and collaboration with practitioners (Chesney et al. 2011; Mazmanian and Davis 2002; Soumerai 1998). Guidelines to healthcare professionals and informal caregivers should be communicated in succinct and synchronized trainings to minimize “guideline fatigue” (Aminzadeh et al. 2012). These guidelines should also include recent recommendations from the Fourth Canadian Consensus Conference on the Diagnosis and Treatment of Dementia (Gauthier et al. 2012). Finally, guidelines should be encompassing of the comorbidity associated with dementia that often compounds physicians’ difficulty with diagnosing and providing care for dementia and patients’ difficulty with living with the disease while managing other chronic conditions (Borson and Chodosh 2014; Mondor et al. 2017).

Promoting confidence and expertise

Implementation strategies must be designed to target the confidence of healthcare professionals who feel ill-equipped to diagnose and care for dementia in Canada (Aminzadeh et al. 2012). Confident healthcare professionals are more likely to take a keen interest in dementia and dementia care reform and to diagnose dementia in a timely way (Aminzadeh et al. 2012; Moore and Cahill 2012). Confidence and expertise may be self-initiated, but governments can also furnish this capacity by providing funding and resources to train additional staff, such

as geriatric nurses, who can collaborate and mentor closely with other clinicians (Aminzadeh et al. 2012).

Addressing concerns of potential adopters

Similarly, many healthcare professionals approach dementia diagnosis and care from a nihilist perspective (Pentzek et al. 2009). Family physicians are concerned about whether a diagnosis will improve the quality of life of a patient (Borson and Chodosh 2014) and whether dementia care interventions will result in improved care (Black and Fauske 2007; Netting and Williams 1999; Seddon and Robinson 2001). Studies show that when healthcare professionals maintain negative attitudes towards dementia interventions, the interventions are less likely to be adopted (Khanassov et al. 2014). A final unique barrier remains the reluctance of some family physicians to be trained in dementia care by non-physicians (Cameron et al. 2010).

Encouraging adopters to engage with the intervention over an extended period

Interventions take time to implement, and practices take time to change. This is especially true in dementia care, which mobilizes multiple health and social service organizations. Accordingly, benefits of dementia diagnosis and management take time to emerge. Persistence with interventions is thus particularly important in the context of dementia care. When healthcare professionals engage with new dementia programs for longer durations, their adherence to, and confidence in, the interventions increases (Cherry et al. 2004; Gladman et al. 2007; McCrae and Banerjee 2011; Netting and Williams 1999; Van Eijken et al. 2008). Eventually, as outcomes become perceivable, healthcare professionals feel increased self-worth and accomplishment (Grinberg et al. 2008).

Successful Strategies at the Organizational Level: Teamwork and Resources

Integration with current context

Dementia interventions that are implemented in ways that are compatible with the current healthcare structure are more likely to be well-received by healthcare professionals (Khanassov et al. 2014). This can be challenging, since dementia care is often time-consuming, especially for solo practitioners (Hinton et al. 2007). Team-based care, with a clear division of labour, is needed. For example, nurses (referred to as *infirmières pivots*, “pivot nurses”) are particularly suited to conduct cognitive screening, assessment and functional evaluation (Bergman 2009).

Identifying and valourizing a “champion” of dementia reform

As is usually the case for any policy or program implementation, a critical predictor for the successful implementation of a strategy is the presence of a physician or nurse who serves as a “clear champion” for dementia reform (Gifford et al. 1999). This champion, who recognizes the potential benefits of new recommendations, including timely diagnosis of dementia and interdisciplinary management, takes an active role in convincing other colleagues to use the guidelines (Gifford et al. 1999). If the champion is knowledgeable in dementia management, they may also provide support and guidance to peers. Championing dementia reform can be individual- or team-based.

Resources, incentives and culture

Governments must also fund and support dementia-specific resources beyond the clinic: home-based care, community services, transportation, long-term care and assistive devices. Healthcare professionals

should be trained to know which of these options or services are available in the region, how efficient and organized these resources are and how to refer patients to them (Yaffe et al. 2008). Governments should also consider personal incentives (such as remuneration and other motivations) and cultural differences (unique perceptions of dementia and caregiving, especially in rural, Northern or immigrant communities) when developing strategies for implementation (Braun and Browne 1998; Khanassov et al. 2014; Martindale-Adams et al. 2017).

Limitations

This rapid review serves as a brief overview of the current state of dementia plans, vis-à-vis implementation strategies, across Canada and other high-income countries. However, our analysis is limited. First, untranslated dementia plans (written in languages other than English or French), or those not available in the public domain, were not examined. Also, this review was limited to national and provincial plans. Grey literature (including future policy enforcement documentation) was not examined. Accordingly, we may have missed more applied guidelines (including implementation strategies) in subsequent years.

Summing Up: Implementation Strategies for Dementia

Even if implementation strategies are not included in national and provincial dementia plans, they will ultimately be relevant to transforming dementia care practice “on the ground.” This article advances several dementia-specific implementation strategies that can be leveraged to improve the diagnosis and management of dementia. These strategies should be considered as future dementia plans are translated from policy to action.

References

- Alzheimer Society of Canada. 2010. "Rising Tide: The Impact of Dementia on Canadian Society." Retrieved April 30, 2018. <https://alzheimer.ca/sites/default/files/files/national/advocacy/asc_rising_tide_full_report_e.pdf>.
- Alzheimer Society of Canada. 2018. "Alzheimer Society of Canada Calls for 'Alzheimer's Disease and Dementia Partnership.'" Retrieved May 3, 2018. <<http://alzheimer.ca/en/Home/News-and-Events/feature-stories/alzheimers-disease-dementia-partnership>>.
- Alzheimer's Disease International. 2018. "Dementia Plans." Retrieved March 29, 2018. <<https://www.alz.co.uk/dementia-plans>>.
- Aminzadeh, F., F.J. Molnar, W.B. Dalziel and D. Ayotte. 2012. "A Review of Barriers and Enablers to Diagnosis and Management of Persons with Dementia in Primary Care." *Canadian Geriatrics Journal* 15(3): 85. doi: 10.5770/cgj.15.42.
- Bergman, H. 2009. "Meeting the Challenge of Alzheimer's Disease and Related Disorders. A Vision Focused on the Individual, Humanism, and Excellence." Report on the Committee of Experts for the Development of an Action Plan on Alzheimer's Disease and Related Disorders.
- Black, K. and J. Fauske. 2007. "Exploring Influences on Community-Based Case Managers' Advance Care Planning Practices: Facilitators or Barriers?" *Home Health Care Services Quarterly* 26(2): 41–58. doi: 10.1300/J027v26n02_03.
- Borson, S. and J. Chodosh. 2014. "Developing Dementia-Capable Health Care Systems: A 12-Step Program." *Clinics in Geriatric Medicine* 30(3): 395–420. doi: 10.1016/j.cger.2014.05.001.
- Bradford, A., M.E. Kunik, P. Schulz, S.P. Williams and H. Singh. 2009. "Missed and Delayed Diagnosis of Dementia in Primary Care: Prevalence and Contributing Factors." *Alzheimer Disease and Associated Disorders* 23(4): 306–14. doi: 10.1097/WAD.0b013e3181a6bebc.
- Braun, K.L. and C.V. Browne. 1998. "Perceptions of Dementia, Caregiving, and Help Seeking among Asian and Pacific Islander Americans." *Health & Social Work* 23(4): 262–74. doi: 10.1093/hs/w/23.4.262.
- Burgio, L., K.L. Lichstein, L. Nichols, S. Czaja, D. Gallagher-Thompson, M. Bourgeois et al. 2001. "Judging Outcomes in Psychosocial Interventions for Dementia Caregivers: The Problem of Treatment Implementation." *The Gerontologist* 41(4): 481–89. doi: 10.1093/geront/41.4.481.
- Cameron, M.J., M. Horst, L.W. Lawhorne and P.A. Lichtenberg. 2010. "Evaluation of Academic Detailing for Primary Care Physician Dementia Education." *American Journal of Alzheimer's Disease & Other Dementias* 25(4): 333–39. doi: 10.1177/1533317510363469.
- Canadian Academy of Health Sciences (CAHS). 2019. "Improving the Quality of Life and Care of Persons Living with Dementia and Their Caregivers." *The Expert Panel on Dementia Care in Canada*, CAHS.
- Cherry, D.L., B.G. Vickrey, L. Schwankovsky, E. Heck, M. Plauchm and R. Yep. 2004. "Interventions to Improve Quality of Care: The Kaiser Permanente-Alzheimer's Association Dementia Care Project." *American Journal of Managed Care* 10(8): 553–60.
- Chesney, T.R., B.E. Alvarado and A. Garcia. 2011. "A Mild Dementia Knowledge Transfer Program to Improve Knowledge and Confidence in Primary Care." *Journal of the American Geriatrics Society* 59(5): 942–44. doi: 10.1111/j.1532-5415.2011.03384.x
- 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." *Implementation Science* 4(1): 50. doi: 10.1186/1748-5908-4-50.
- Flood, C.M. and S. Choudhry. 2002. "Strengthening the Foundations: Modernizing the Canada Health Act." *Discussion Paper No. 13, Royal Commission on the Future of Health Care in Canada*. ISBN 0-662-32783-7.
- Foley, T., S. Boyle, A. Jennings and W.H. Smithson. 2017. "'We're Certainly Not in Our Comfort Zone': A Qualitative Study of GPs' Dementia-Care Educational Needs." *BMC Family Practice* 18(1): 66. doi: 10.1186/s12875-017-0639-8.
- Gauthier, S., C. Patterson, H. Chertkow, M. Gordon, N. Hermann, K. Rockwod et al. 2012. "Recommendations of the 4th Canadian Consensus Conference on the Diagnosis and Treatment of Dementia (CCCDTD4)." *Canadian Geriatrics Journal* 15(49): 120–26. doi: 10.5770/cgj.15.49.
- Gifford, D.R., R.G. Holloway, M.R. Frankel, C.L. Albright, R. Meyerson, R.C. Griggs et al. 1999. "Improving Adherence to Dementia Guidelines Through Education and Opinion Leaders: A Randomized, Controlled Trial." *Annals of Internal Medicine* 131(4): 237–46. doi: 10.1186/s12875-017-0639-8.

- Gladman, J., R. Jones, K. Radford, E. Walker and I. Rothera. 2007. "Person-Centred Dementia Services Are Feasible, but Can They Be Sustained?" *Age and Ageing* 36(2): 171–76. doi: 10.1093/ageing/af1161.
- Greenhalgh, T., G. Robert, F. Macfarlane, P. Bate and O. Kyriakidou. 2004. "Diffusion of Innovations in Service Organizations: Systematic Review and Recommendations." *The Milbank Quarterly* 82(4): 581–629. doi: 10.1111/j.0887-378X.2004.00325.x.
- Grinberg, A., J. Lagunoff, D. Phillips, B. Stern, M. Goodman and T. Chow. 2008. "Multidisciplinary Design and Implementation of a Day Program Specialized for the Frontotemporal Dementias." *American Journal of Alzheimer's Disease & Other Dementias* 22(6): 499–506. doi: 10.1177/1533317507308780.
- Hinton, L., C.E. Franz, G. Reddy, Y. Flores, R.L. Kravitz and J.C. Barker. 2007. "Practice Constraints, Behavioural Problems, and Dementia Care: Primary Care Physicians' Perspectives." *Journal of General Internal Medicine* 22(11): 1487–92. doi: 10.1007/s11606-007-0317-y.
- Khanassov, V., I. Vedel and P. Pluye. 2014. "Case Management for Dementia in Primary Health Care: A Systematic Mixed Studies Review Based on the Diffusion of Innovation Model." *Clinical Interventions in Aging* 9: 915. doi: 10.2147/ CIA.S64723.
- Martindale-Adams, J., T. Tah, B. Finke, C. LaCounte, B.J. Higgins and L.O. Nichols. 2017. "Implementation of the REACH Model of Dementia Caregiver Support in American Indian and Alaska Native Communities." *Translational Behavioral Medicine* 7(3): 427–34. doi: 10.1007/s13142-017-0505-1.
- Mazmanian, P.E. and D.A. Davis. 2002. "Continuing Medical Education and the Physician as a Learner: Guide to the Evidence." *JAMA* 288(9): 1057–60. doi: 10.1001/jama.288.9.1057.
- McCrae, N. and S. Banerjee. 2011. "Modernizing Mental Health Services for Older People: A Case Study." *International Psychogeriatrics* 23(1): 10–19. doi: 10.1017/S1041610210001407.
- Milstein, A. and S. Shortell. 2012. "Innovations in Care Delivery to Slow Growth of US Health Spending." *JAMA* 308(14): 1439–40. doi: 10.1001/jama.2012.12659.
- Ministère des Affaires sociales, de la Santé et des Droits des femmes. 2014. "Plan Maladies Neuro-Dégénératives." Retrieved April 17, 2018. <https://www.cnsa.fr/documentation/plan_maladies_neuro_degeneratives2014.pdf>.
- Ministry of Health and Long-Term Care (MOHLTC). 1999. "Ontario's Strategy for Alzheimer Disease and Related Dementias. Government of Ontario." Retrieved April 17, 2018. <<http://brainxchange.ca/Public/Resource-Centre-Topics-A-to-Z/Ontario%E2%80%99s-Strategy-for-Alzheimer-Disease-and-Relat.aspx>>.
- Mondor, L., C.J. Maxwell, D.B. Hogan, S.E. Bronskill, A. Grunier, N.E. Lane et al. 2017. "Multimorbidity and Healthcare Utilization among Home Care Clients with Dementia in Ontario, Canada: A Retrospective Analysis of a Population-Based Cohort." *PLoS Medicine* 14(3): e1002249. doi: 10.1371/journal.pmed.1002249.
- Moore, V. and S. Cahill. 2012. "Diagnosis and Disclosure of Dementia – A Comparative Qualitative Study of Irish and Swedish General Practitioners." *Aging & Mental Health* 17(1): 77–84. doi: 10.1080/13607863.2012.692763.
- Netting, F. E. and F.G. Williams. 1999. "Implementing a Case Management Program Designed to Enhance Primary Care Physician Practice with Older Persons." *Journal of Applied Gerontology* 18(1): 25–45. doi: 10.1080/13607863.2012.692763.
- Office fédéral de la santé publique. 2013. "Stratégie nationale en matière de démence 2014–2017. Champs d'action." Retrieved April 17, 2018. <<https://www.bag.admin.ch/bag/fr/home/strategie-und-politik/nationale-gesundheitsstrategien/nationale-demenzstrategie.html>>.
- Pentzek, M., A. Wollny, B. Wiese, F. Jessen, F. Haller, W. Maier et al. 2009. "Apart from Nihilism and Stigma: What Influences General Practitioners' Accuracy in Identifying Incident Dementia?" *The American Journal of Geriatric Psychiatry* 17(11): 965–75. doi: 10.1097/JGP.0b013e3181b2075e.
- Public Health Agency of Canada (PHAC). 2018. "Conference Report: National Dementia Conference. Inspiring and Informing a National Dementia Strategy for Canada. Government of Canada." Retrieved February 1, 2019. <<https://www.canada.ca/content/dam/phac-aspc/documents/services/publications/diseases-conditions/national-dementia-conference-report/national-dementia-conference-report-eng.PDF>>.
- Scerri, C. 2014. "National Dementia Strategy: Malta 2015–2023. Valleria: Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing." <<https://activeageing.gov.mt/en/Documents/National%20Dementia%20Strategy%20-%20Public%20Consultation.pdf>>.
- Seddon, D. and C.A. Robinson. 2001. "Carers of Older People with Dementia: Assessment and the Carers Act." *Health & Social Care in the Community* 9(3): 151–58. doi: 10.1046/j.1365-2524.2001.00291.x.

- Soumerai, S.B. 1998. "Principles and Uses of Academic Detailing to Improve the Management of Psychiatric Disorders." *The International Journal of Psychiatry in Medicine* 28(1): 81–96. doi: 10.2190/BTCA-Q06P-MGCC-Q0L5.
- Tricco, A.C., W. Zarin, J. Antony, B. Hutton, D. Moher, D. Sherifali et al. 2016. "An International Survey and Modified Delphi Approach Revealed Numerous Rapid Review Methods." *Journal of Clinical Epidemiology* 70: 61–67. doi: 10.1016/j.clinepi.2015.08.012.
- United Kingdom Department of Health. 2009. "Living Well with Dementia: A National Dementia Strategy. United Kingdom Department of Health." Retrieved April 17, 2018. <https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/168220/dh_094051.pdf>.
- Van Eijken, M., R. Melis, M. Wensing, M.O. Rikkert and T. Van Achterberg. 2008. "Feasibility of a New Community-Based Geriatric Intervention Programme: An Exploration of Experiences of GPs, Nurses, Geriatricians, Patients and Caregivers." *Disability and Rehabilitation* 30(9): 696–708. doi: 10.1080/09638280701400508.
- Valcour, V.G., K.H. Masaki, J.D. Curb and P.L. Blanchette. 2000. "The Detection of Dementia in the Primary Care Setting." *Archives of Internal Medicine* 160(19): 2964–68. doi: 10.1001/archinte.160.19.2964.
- World Health Organization (WHO). 2012. "Dementia: A Public Health Priority." Retrieved March 29, 2018. <<https://extranet.who.int/agefriendlyworld/wp-content/uploads/2014/06/WHO-Dementia-English.pdf>>.
- Yaffe, M.J., P. Orzeck and L. Barylak. 2008. "Family Physicians' Perspectives on Care of Dementia Patients and Family Caregivers." *Canadian Family Physician* 54(7): 1008–15.



Mitigating Moral Distress in Dementia Care: Implications for Leaders in the Residential Care Sector



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Abstract

In 2012, the World Health Organization estimated that the number of people living with dementia worldwide was approximately 35.6 million; they projected a doubling of this number by 2030, and tripling by 2050. Although the majority of people living with a dementia live in the community, residential facility care by nursing providers is a common part of the dementia journey in most countries. Previously published research confirms that caring for people living with dementia in such facilities often creates moral distress for nursing care providers. In this paper, the authors share additional findings from a two-year, two-phase, mixed methods study of moral distress as experienced by nursing caregivers of residents with dementia

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in residential care settings in a Western Canadian province. The findings relate to strategies to reduce moral distress in this caregiving group, with a particular focus on the role of supportive and responsive leadership. Important implications for practice and for leadership in the residential care sector are presented.

Introduction

In 2012, the World Health Organization estimated that the number of people living with dementia worldwide was approximately 35.6 million; they projected a doubling of this number by 2030, and tripling by 2050 (WHO 2012). Although the majority of people living with dementia live in the community, residential facility care by nursing providers is a common part of the dementia journey in most countries.

Indeed, literature from around the world confirms that of those people requiring supportive living environments such as long-term care (LTC) or assisted living (AL), nearly half are living with some form of dementia (Global Observatory for Ageing and Dementia Care 2013). In one study in a Canadian province, Strain et al. (2011) reported that 58% of AL residents lived with a diagnosis of dementia, as did 71% of residents in LTC. Research has also shown that caring for persons with dementia can be emotionally, physically and ethically challenging on a daily basis (Bolmsjö et al. 2006) and that turnover in nursing staff in these settings tends to be high (McGilton et al. 2013b; Utley et al. 2011).

Findings for this paper were derived from a mixed methods study of moral distress among nearly 400 nursing staff caring for people with dementia in LTC and AL facilities (collectively referred to as residential care facilities or RCFs) in one Western Canadian province. Nathaniel (2004) defined moral distress as the pain or anguish affecting the mind, body or relationships in response to a situation in which the person is aware of a moral problem, acknowledges

moral responsibility, and makes a moral judgment about the correct action; yet, as a result of real or perceived constraints, cannot do what is thought to be right. In this paper, we report findings that specifically relate to the mitigation of moral distress in dementia care, and most particularly on the role of leadership in such efforts.

Background

Much of the background for this paper resides in our own previously published findings. Therefore, a brief overview of those original findings is warranted here (although the reader is directed to these publications for full details) (Pijl-Zieber et al. 2016; Spenceley et al. 2017).

In this two-year, mixed method study, we found high levels of moral distress in all levels of nursing care staff (registered nurses, licensed practical nurses and unregulated healthcare aides) providing care to people living with dementia. The top five causes of severe and frequent moral distress are in Table 1. Canadian research has revealed that unregulated workers such as healthcare aides (HCAs) (also called nurses' aides, nursing attendants or personal support workers) provide 75–80% of direct care to LTC residents (Estabrooks et al. 2015). We found that invariably, the severity and frequency of moral distress increased with proximity to the provision of bedside care, with HCAs reporting the highest levels of moral distress (Table 2). We also found that all providers of all designations reported consequences of feeling morally distressed. Indeed, at least weekly, approximately 49% of participants reported feeling frustrated, 44% reported

feeling physically exhausted, 42% reported feeling emotionally drained, 39% reported feeling powerless and 33% reported engaging in coping behaviours that were not healthy (Spenceley et al. 2017). In relation to job satisfaction, we learned that despite approximately 40% of the sample reporting that moral distress reduced their job satisfaction by either a large or extremely large amount, and over 25% of the sample indicating that moral distress contributed to them wanting to quit their job in either a large or extremely large amount, approximately 85% of the sample indicated that they did not intend to quit their job in the next year (Pijl-Zieber et al. 2016). Qualitative findings also painted a

compelling picture of a nursing workforce feeling stuck in conflicting expectations around care in a resource-strapped environment, in a context that privileged tasks over touch. These findings also revealed feelings of unheard outrage and powerlessness in nursing providers who reported seeing repetitive failures around accountability for the care delivered by colleagues, and failures of leadership to advocate, listen, follow up and manage performance issues (Spenceley et al. 2017). Within the context of these findings, we found ourselves repeatedly circling back to the notion of leadership in residential care settings, particularly as a factor to consider in the mitigation of moral distress.

Table 1. Top five situations that caused the most severe and frequent moral distress

Situation	Severity		Frequency	
	Mean (SD)*	% Who experience large or very large amount	Mean (SD) [§]	% Who experience daily or weekly
Seeing the care of residents with dementia suffer because there are not enough staff to do the work	3.84 (1.39)	71.9	2.61 (1.28)	58.2
Having to rush the care of residents with dementia because of lack of time – even though I know it might upset them	3.44 (1.61)	59.6	2.44 (1.41)	53.9
Seeing the care suffer for residents with dementia because families do not provide basic necessities such as clothing and other supplies	3.38 (1.48)	53.8	2.04 (1.28)	35.1
Seeing a low quality of life for residents with dementia because there are not enough activities	3.30 (1.62)	52.7	2.56 (1.43)	59.4
Having to provide care to aggressive residents with dementia without the supports I need to feel safe	2.89 (1.95)	49.7	1.66 (1.46)	33.0

SD = standard deviation. *Scale 0–5, §Scale 0–4.

Literature Review

In the existing literature, there have been numerous calls for leadership development in RCFs resulting from the rising demand for residential care services and the “staggering” turnover in staff (Utley et al. 2011: 212), the heavily regulated environment, the predominantly non-professional workforce (Davis 2016) and the importance of

competent leadership for monitoring, maintaining and improving the quality of care in RCFs (McGilton et al. 2013a). Further, it has been observed that there is a growing, and often “hidden complexity” to care in these settings: the vast majority of residents have dementia, resources are scarce, environments are often not physically well set up for the population needing

Table 2. Frequency of causes of moral distress by role designation (RN, LPN, HCA)

Situation	Role	<i>n</i>	% Weekly or daily	Mean	<i>SD</i>	Test statistic	<i>df</i>	Post hoc test [§]
Telling the resident with dementia things that are not true so he/she won't get upset	RN	72	41.6	2.15	1.329	18.589	2	RN < HCA**
	LPN	53	60.4	2.58	1.379			
	HCA	249	69.5	2.90	1.253			
	Total	374		2.71	1.315			
Having to make a resident with dementia wait for care because another resident needs me just as much, at the same time	RN	71	32.4	1.59	1.430	42.200	2	RN < HCA** RN < LPN*
	LPN	53	52.8	2.42	1.379			
	HCA	250	69.2	2.85	1.305			
	Total	374		2.55	1.422			
Having to rush the care of residents with dementia because of lack of time – even though I know it might upset them	RN	72	31.9	1.68	1.402	25.863	2	RN < HCA* RN < LPN*
	LPN	53	49.1	2.45	1.353			
	HCA	250	61.6	2.65	1.357			
	Total	375		2.44	1.413			
Having to provide care that I think is against the wishes of the resident with dementia	RN	72	8.4	.92	1.097	10.631	2	RN < HCA* RN < LPN*
	LPN	52	23.0	1.50	1.321			
	HCA	246	29.2	1.49	1.363			
	Total	370		1.38	1.326			
Having to provide care to aggressive residents with dementia without the supports I need to feel safe	RN	72	18.0	1.13	1.288	13.476	2	RN < HCA**
	LPN	52	28.9	1.65	1.399			
	HCA	247	38.9	1.84	1.496			
	Total	371		1.68	1.468			
Having to work without the supports I need to prevent residents with dementia from hurting other residents	RN	72	19.4	1.19	1.307	6.395	2	RN < HCA*
	LPN	52	28.9	1.52	1.407			
	HCA	247	31.6	1.67	1.443			
	Total	371		1.56	1.421			
Seeing the care suffer for residents with dementia because families do not provide basic necessities	RN	72	19.4	1.46	1.198	20.886	2	RN < HCA*
	LPN	53	26.4	1.91	1.148			
	HCA	249	41.4	2.24	1.282			
	Total	374		2.04	1.282			

df = degrees of freedom; HCA = healthcare aide; LPN = licensed practical nurse; RN = registered nurse; *SD* = standard deviation.

§ Post hoc tests with Bonferroni correction reveal which designations had the more frequent causes of moral distress.

* ≤ 0.05;

** ≤ 0.001

care, and care providers often report being torn between the espoused and the enacted philosophies of care (Cammer et al. 2014: 1013). Among the contextual factors identified as critical to helping staff navigate this growing complexity, Cammer and colleagues (2014) noted the importance of

empowering leadership and supportive mentoring.

Studies exploring the connection between moral distress and leadership in RCFs are very rare. In one such study, de Veer and colleagues (2012) explored individual and job characteristics associated with moral

distress in nursing staff in nursing homes, elder care homes, home care and acute care hospitals in the Netherlands. Situations found to be associated with the most moral distress included being caught between the expectations of family, the physician and the wishes of the person in terms of desired care and working with staffing levels perceived as unsafe. It is also notable that the highest mean level of moral distress was found in nursing home staff (de Veer et al. 2012). As part of their study, two aspects of leadership were explored: supportive leadership (employee-oriented, considerate, approachable and friendly) and instrumental leadership (focusing on tasks, setting boundaries, targets and standards). It is interesting to note that instrumental leadership was found, more often, to trigger moral distress, whereas a more supportive leadership style tended to buffer the intensity of moral distress. Further, de Veer and colleagues (2012) noted that nursing staff could benefit from being able to talk to and reflect with other nurses about the problems they face, and encouraged managers to empower staff by creating opportunities for staff to talk with each other and with management about their views and experiences.

In this paper, we will first describe the design and methods of a two-year, mixed methods exploratory study of moral distress experienced by nursing care providers. Next, we will share the findings from that study that were specifically related to potential mitigation strategies for moral distress, with a particular focus on the role of leadership. It is our purpose to offer insights into the role of leadership in relation to its importance in helping to address the morally distressing challenges faced by those providing nursing care to some of the most vulnerable citizens in Canadian society. Finally, we will offer a

discussion of the implications of our findings for leadership in residential care environments.

The Study

Setting and sample

The study was conducted in one health authority of a Western Canadian province, serving the healthcare needs of approximately 298,000 people. The region has two main population centers with populations of 95,000 and 62,000, situated within a largely rural geography in the southern part of the province. The study was conducted in RCFs including LTC and AL facilities. LTC facilities are homes for the most medically complex, and these residents are cared for by a mix of regulated and unregulated nursing staff. AL facilities house older people with moderately complex health needs, who are cared for in a home-like setting, with scheduled support by home care nurses and unregulated nursing providers (Strain et al. 2011). We also included AL sites that provided care to individuals with dementia or other mental illnesses who required a secured environment. The study encompassed 30 different care facilities across both rural and urban settings.

The nursing staff we sampled in this study included registered nurses (RNs), licensed practical nurses (LPNs) and HCAs (Table 3). Approximately two-thirds of the sample was constituted by HCAs, reflecting their prevalence in the residential care workforce in Canada. Indeed, it is estimated that HCAs constitute approximately 75–80% of the long-term care workforce (Roulston 2008). Although comparable proportionate data are unavailable related to AL settings, it would be reasonable to assume that unregulated nursing staff provide an even higher proportion of direct care in AL settings – given that

Table 3. Demographics of sample

Characteristic	n*	%
Gender of nursing staff		
Female	356	92.5
Male	29	7.5
Professional designation of nursing staff		
RN	72	18.9
LPN	53	13.9
HCA	255	67.1
Years of experience in dementia care		
Less than 10 years	233	60.7
10–20 years	111	28.9
More than 20 years	40	10.4
Total	389	100

*Totals may not match in each category because of missing data.

staffing levels are lower and a smaller proportion of the staff is constituted by regulated nursing providers in these settings (Maxwell et al. 2015).

Methods

We conducted a mixed methods, exploratory sequential study in two phases to explore the nature, causes, prevalence and intensity of moral distress as experienced by nursing staff providing dementia care in RCFs. First, we used a qualitative exploratory descriptive approach with staff in six RCFs and three home care sites (central offices for home care RNs serving one or more care facilities). Purposeful sampling of nursing caregivers at these sites who were interested in participating was undertaken, such that we obtained participants across all three designations, different genders and with varying years of experience providing dementia care. Trained research assistants collected qualitative data through semi-structured interviews of 60–90 min in length with 18 nursing care providers; it was at this point that we noted no new information emerging. The interviews began with a discussion of the

meaning of moral distress, followed by prompting questions asking participants to recall specific events or times when they were providing care to a resident with dementia and they experienced moral distress, how they felt during and after an experience, what effects they experienced that they could attribute to moral distress and what helped, or could help, to reduce moral distress. Thematic analysis of qualitative data and review of the existing literature informed the development of the Moral Distress in Dementia Care Survey (MDDCS; instrument available from the researchers). The MDDCS was piloted in seven sites with a 62% response rate ($n = 68$). Data from the pilot helped us assess the validity and reliability of the MDDCS and informed minor changes to the survey prior to its final distribution to the remaining 23 sites, where it was completed by approximately 400 nursing care providers (Pijl-Zieber et al. 2016; Spenceley et al. 2015).

Data analysis

In phase one, transcribed interview data were subjected to a descriptive, data-near

qualitative thematic analysis (Clarke and Braun 2014). Categories of response were identified in the data, including sources of moral distress, consequences for care providers and potential mitigating strategies. Thematic coding within each of these categories was undertaken. Three rounds of team discussion resulted in a final list of themes in each category of response, and the resulting list of themes and their definitions were verified in individual follow-up discussions with each interviewed participant. Subsequently, the team developed survey items that reflected these themes, staying as close as possible to the language used by participants. This rigorous qualitative analysis and participant validation helped to ensure content validity; further confidence in the instrument was also gained by having two nursing experts in the field assess the first version of the instrument for clarity, comprehensiveness and appropriateness to the setting.

In phase two, quantitative data were gathered from participants using the MDDCS in the areas of sources of moral distress, its consequences, as well as potential mitigating strategies. Research assistants entered the data from the completed surveys and the research team as a whole analyzed the data using statistical software (Statistical Package of the Social Sciences (SPSS), v. 21.

The overall Cronbach's alpha for the MDDCS tool was found to be 0.95. Intraclass correlation coefficients revealed a high Cronbach's alpha for frequency of moral distress (0.938), severity of moral distress (0.924), effects (0.928) and mitigating factors (0.825). A full discussion of findings is published elsewhere (Pijl-Zieber et al. 2016).

Ethical considerations and approval

Ethical approval for the study was obtained through two university research ethics boards in the province. All participants gave written, informed consent prior to interviews, and full information was provided as part of the survey instrument, with completion being accepted as implied consent.

Findings: Mitigating Moral Distress

Qualitative findings: Phase one

Several themes emerged in each of the three data categories (sources of moral distress, consequences for care providers and mitigating strategies) in phase one. Please see the qualitative thematic overview provided in Table 4. Of particular relevance for our purposes in this paper are the themes that emerged related to mitigation strategies for moral distress; these are reported in greater depth here.

Table 4. Major themes

Category	Theme
Sources of moral distress	Managing dementia behaviors (e.g., conflict regarding the need for medication; providing care to aggressive residents without supports)
	Lack of resources (e.g., lack of staff; time; activities; education about dementia care)
	Inconsistent care expectations (e.g., inconsistent care planning; delayed care; inconsistent follow-up on with staff who do not meet expectations; inconsistent staffing patterns)
	Seeing residents treated disrespectfully (e.g., like children; doing the fast thing instead of the right thing)
	Family issues/reactions (e.g., disagreements between staff and families regarding aspects of care; bearing brunt of family anger)
Impacts of moral distress	Emotional reactions (e.g., powerlessness; guilt; anger; frustration sadness; anxiety)
	Physical reactions (e.g., physical exhaustion; body pain)
	Relationship effects (e.g., taking out frustration on own family members; withdrawing from residents)
	Quitting (e.g., wanting to or planning to quit working at the RCF)
	Sick time (e.g., taking sick time to cope with moral distress)
Factors to reduce moral distress	Increased administrative/leadership support (e.g., having leadership that understands the work and who connect with staff; leaders that listen and follow up on issues)
	Increased education (e.g., on dementia care)
	Peer support (e.g., venting with other staff; sharing humour)
	More resources for care (e.g., more manageable resident assignments and case loads; more staff)
	Attention to self-care (e.g., laughter, exercise, positive thinking)

Five themes emerged from thematic analysis around those things that may ease moral distress: more resources for care, increased leadership support and followup, increased opportunities for peer support, increased training/education for staff around dementia care, and attention to physical self-care.

Resources for care

This theme was broadly represented in the data, with numerous variations on these words:

... because they try to get by with as little people to do the job as they can. You just have to bite the bullet and pay

to have more people. Because sometimes not enough staffing is, it's so bad ... and it's hard. It's so emotionally taxing, and physically taxing to take care ... they just really need to make sure that they have appropriate amount of staff ... my number one for sure. (HCA participant)

Further, participants were clear that they counted on their leaders to have their fingers on the pulse of what was going on in the workplace, understand the work and keep their eye on things by "more closely monitoring their people, and people in their facilities and if they need better staffing." (LPN participant)

Leadership support

The support of leadership was perceived when care leaders in positions of power took the time to connect with, and listen to the concerns of staff:

Not all managers are accessible. Or you know, willing ... there's a power thing. But if you connect at the right time with the right person, the right manager, the right powers that be, you feel better. Because at least you are sharing ideas or you are suggesting well, why don't we try this? Or could we try this? ... because then it kind of pumps you up again, and you think "okay, we could do something here." (RN participant)

This was perceived as supportive even if the leader could not address the concern raised:

I'll go and talk to my boss even if she doesn't do anything about it. At least I got it off my chest ... I'm not worrying about it every day. She knows about it. She has to deal with it, because it's not my job ... (LPN participant)

Staff also reported that it reduced their moral distress when managers stepped in to assist with resident care, as noted by an LPN participant:

[it helps to have a manager helping with ...] each different floor ... [taking] a certain number of residents ... deal with all their needs so that you're not dealing with almost a whole facility worth of residents. So kind of dividing things up a little more to make it easier to make sure everybody has what they need ...

Peer support

The power of connecting in positive ways with co-workers was another resonant

theme in the data. The opportunity to share feelings, experiences, ideas and sometimes a laugh were described as powerful ways to reduce moral distress:

One of the best things about our office is we're a great group of nurses. So I think that that helps us sometimes, because we do like vent, and talk to each other and there's a lot of support there from co-workers. We do support each other and so that's really nice and I do appreciate that a lot. (RN participant)

... we sit around the table and sometimes we vent. Sometimes we throw around ideas, sometimes we throw out there certain issues that are going on. Just kind of getting it out ... talking about it with your peers that are there. They witness it, they see it. (LPN participant)

I think that my coworkers really help for sure ... and there's always kind of a lightheartedness and goofiness about the coworkers ... Everyone that I've worked with in this setting, is kind of a little bit quirky or has like a weird sense of humor and ... you just need to bring kind of a lightheartedness ... (HCA participant)

Education

This theme emerged particularly in relation to the work of HCAs, who perform the bulk of direct care in RCFs, and have the least education. In particular, the notion was shared that HCAs were being placed in situations for which they were not well prepared, as was the belief that more "hands on" training was needed:

And I think that more hands on ... practicum type settings ... those would be a lot better ... I just think that a lot of people don't really get

trained for what they are coming in for. Like when people are coming out of the college and just finishing their HCA program they really have no idea what the actual job is like. I feel like there is a really big disconnect between the books and the real job. (HCA participant)

... maybe some more training [is needed for HCAs] on how to deal with the residents that are a little more aggressive ... someone needs to talk to them and ask them what their reasons are for not wanting to help these residents and work with them to show them that the care does need to be done and how to go about it properly, and that sort of thing. (LPN participant)

Self-care

Finally, although less widespread in the data, a theme emerged related to the value of self-care strategies in mitigating moral distress.

I run a lot on my own at home. So that's probably like my meditation time where I'll probably be a bit

wound up until I go home and take the dogs out for a run. Come home, have a shower, and I'll be ready for tomorrow again. (LPN participant)

I go to the weight room and really that's how I deal with things. Sometimes I just go and lift weights. And that's a pretty good release for me. Or running ... exercise I find is the best release. (HCA participant)

Quantitative data: Phase two

From the survey data in phase two, we discovered the strategies that were reported to have the greatest impact on moral distress for participants. Strategies to reduce moral distress by a large or extremely large amount, as suggested by over half of the sample, are summarized in Table 5. Of particular note, the top three strategies selected by more than three-quarters of the participants were: "Having enough staff to provide good care for residents" (87.9% of participants); "Sharing laughter and humour with colleagues" (82.4%) and "Having a manager who will listen to my concerns, look into them and get back to me with possible solutions" (78.2%).

Table 5. Strategies to reduce moral distress

Strategy	% "Large amount"	% "Extremely large amount"	% Total
Having enough staff to provide good care for residents	22.2	65.7	87.9
Sharing laughter and humour with colleagues	32.8	49.6	82.4
Having a manager who will listen to my concerns, look into them, and get back to me with possible solutions	34.4	43.8	78.2
More education and training of staff about how to better care for people with dementia	29.6	41.3	70.9
Co-workers that you can talk to and vent to	39.5	29.2	68.7
Better management policies and procedures for reporting and disciplining poor staff performance	28.9	38.5	67.4
A manager that listens to your difficulties and frustrations, even if not able to do anything about them	29.7	22.9	52.6

The experience of moral distress was amplified with increasing proximity to the bedside. Thus, HCAs were most likely to experience frequent and severe moral distress. LPNs experienced moral distress, but not to the same degree as HCAs. RNs experienced the lowest rates of and least severe moral distress, compared to LPNs and HCAs. These differences were statistically significant. For example, “Having to make a resident with dementia wait for care because another resident needs me just as much, at the same time” was a source of high levels of moral distress for HCAs (73.8%, mean = 3.25), to a lesser extent for LPNs (70.0%, mean = 2.82) and to a much lesser extent, RNs (39.4%, mean = 1.89). These differences by role designation were statistically significant ($p < 0.01$).

Discussion

Overwhelmingly, participants in this study told us that not having enough staff to provide what they believed to be good care to residents was a frequent situation, and associated with very high levels of moral distress. This finding has surfaced repeatedly in relation to moral distress and in many different healthcare settings. McAndrew and Garcia (2011) surveyed critical care nurses about their experiences with moral distress and found that circumstances such as inadequate staffing and inadequately prepared/trained staff were associated with moral distress. Cummings (2010) noted that nurses in acute care settings experienced moral distress when they went unheard in decisions around staffing, workflow and patient care structures and processes – noting that these decisions were often made by people without clinical knowledge, who often made ostensibly cost-reducing decisions that actually ended up being a “detriment to the bottom line” (p. 39). The current study informs us that these findings are applicable to residential care settings as well.

Participants in our study also indicated that they felt powerless, with little to no ability to enact change in their work environments that could improve the quality of care. This finding is consistent with those in other healthcare sectors. Cummings (2010) noted that moral distress was an everyday occurrence for many nurses and was caused in many instances by care decisions beyond the nurse’s control that caused patient suffering despite the nurse’s efforts to advocate for the patient. Edmonson (2015) also discussed the problem of moral distress in acute care environments, and cited the most common causes of moral distress as feeling trapped in providing futile and/ or poor quality care, and feeling unsuccessful in advocacy for patients and families. Edmonson (2015) further cited a gap in the literature related to what he saw as an essential step in addressing the issue of moral distress – developing supportive and responsive leaders who could nurture moral courage in healthcare environments. This gap is an important one that highlights the work needed to be done around enabling a culture of empowerment in the workplace and the role of leadership in creating opportunities for staff to become involved in developing strategies to mitigate moral distress.

The notion that supportive and responsive leadership could provide an effective means by which to mitigate moral distress is strongly supported by our findings.

Participants indicated that having managers listen to concerns and follow up with possible solutions, or simply listen even in the absence of the ability to address the concern, were actions that would help them mitigate feelings of moral distress. This is consistent with the research of McAndrew and Garcia (2011), who found that, in addition to perceived collaborative relationships with other staff and physicians, and having adequate resources to provide good care, moral distress was mitigated when staff felt supported by a visible and responsive

leader with high standards. In addition, Lachman (2016) noted that morally resilient nurse leaders influence those they lead and can nurture resilience in specific ways by: creating opportunities for interprofessional dialogue about morally complex cases; formulating policies to support and require staff to share their concerns in such cases; and creating an ethical work environment where leaders model consistency in words and actions that support staff to navigate complex moral issues. Cummings (2010) further noted the importance of nurse leaders listening and acknowledging the causes of moral distress, providing safe outlets for staff to express their feelings and providing opportunities for ethical reflection and input into making positive change in the practice environment.

Finally, as researchers, it is always exciting when a finding emerges that is unexpected or novel. For us, this was the significant proportion of participants (82%) who indicated that “Sharing laughter and humour with colleagues” would be an effective strategy to help mitigate their experience of moral distress. We believe this finding is associated with two factors: care providers’ desire to have positive and enjoyable relationships with colleagues and their need to release stress and tension through the therapeutic use of laughter and humour. It is well documented that laughter and humour can provide a safe and effective means by which to reduce the negative effects of stress and improve health and well-being (Lefcourt et al. 2012; Romero et al. 2006). In addition, previous research has also demonstrated that the quality of workplace relationships in LTC facilities has a direct and meaningful influence on care staffs’ ability to provide high-quality, individualized care (Caspar and O’Rourke 2008).

There are limitations to this study. For example, we found limitations in the tool as a measurement device, i.e., a high degree of multi-collinearity, particularly in the first

scale of the instrument. We assessed this limitation as likely an outcome of constructing the items in the first scale to reflect, as completely as possible, the situations nursing care providers told us caused moral distress. These situations are inherently complex and have overlapping elements, which may limit conclusions that can be drawn “per situation” but accurately capture (in our view) the complex construct of moral distress in this context. Also, this study is descriptive and geographically limited. However, despite these limitations, we believe that the findings provide valuable lessons and contain important practice implications for leaders in the residential care sector.

Conclusion

In our experience, it is an all-too-common mindset that “nothing can be done” about workload and staffing levels in this sector. Perhaps to a degree this is the case in all sectors of care; indeed, perhaps this is also a cause of moral distress in those who are charged with making the resource allocation decisions. However, it appears to us that too often, this care sector is more likely to go unheard in the debates around resource allocation. We speculate that one factor contributing to this situation is the relative lack of status accorded to HCAs – the majority of the residential care workforce. In a sector that cares for some of society’s most vulnerable, complex and frail citizens, we believe it must be a priority for leaders, decision-makers and policy makers to listen to the voices of those providing care, and advocate persistently for adequate resources to make it possible for staff to consistently provide good quality care to this growing segment of our population.

The findings of this study also give us confidence in asserting the value of supportive and responsive leadership in confronting and addressing moral distress in the residential care sector. Our findings indicate that leadership focused on creating a culture

where all providers of care feel empowered, connected to one another and heard when they have concerns, is a significant part of addressing moral distress, and that this is true regardless of sector, and regardless of status in the care provider hierarchy. We also assert that the development of innovative initiatives aimed at increasing the experience of joy, laughter, connection and teamwork among care team members in residential care facilities may prove to be an additional effective means by which to mitigate the negative effects of moral distress in these settings. Finally, from the perspective of this study, perhaps the most important message is that the voices and perspectives of those providing care need to be consulted and authentically engaged as leaders seek strategies to address the issue of moral distress.

References

- Bolmsjö, I., A. Edberg and L. Sandman. 2006. "Everyday Ethical Problems in Dementia Care: A Teleological Model." *Nursing Ethics* 13(4): 340–59. doi:10.1191/0969733006ne890oa.
- Cammer, A., D. Morgan, N. Stewart, K. McGilton, J. Rycroft-Malone, S. Dopson and C. Estabrooks. 2014. "The Hidden Complexity of Long-Term Care: How Context Mediates Knowledge Translation and Use of Best Practices." *Gerontologist* 54(6): 1013–23. doi:geront/gnt068.
- Caspar, S. and N. O'Rourke. 2008. "The Influence of Care Provider Access to Structural Empowerment on Individualized Care in Long-Term-Care Facilities." *Journals of Gerontology Series B: Psychological Sciences & Social Sciences* 63(4): S255–65.
- Clarke, V. and V. Braun 2014. "Thematic Analysis." In A. C. Michalos (Ed.) *Encyclopedia of Quality of Life and Well-Being Research*. New York, NY: Springer.
- Cummings, C.L. 2010. "Moral Distress and the Nursing Experience." *Nurse Leader* 8(6): 37–39. doi:10.1016/j.mnl.2010.03.014.
- Davis, J.A. 2016. "The Need for Leadership Training in Long-Term Care Settings." *Leadership in Health Services* 29(4): 354–57. doi:10.1108/LHS-08-2016-0035.
- de Veer, A. J. E., A. L. Francke, A. Struijs and D. L. Willems. 2012. "Determinants of Moral Distress in Daily Nursing Practice: A Cross Sectional Correlational Questionnaire Survey." *International Journal of Nursing Studies* 50(1): 100–08. doi:10.1016/j.ijnurstu.2012.08.017.
- Edmonson, C. 2015. "Strengthening Moral Courage Among Nurse Leaders." *Online Journal of Issues in Nursing* 20(2): 9. doi:10.3912/OJIN.Vol20No02PPT01.
- Estabrooks, C.A., J.E. Squires, H.L. Carleton, G.G. Cummings and P.G. Norton. 2015. "Who is Looking After Mom and Dad? Unregulated Workers in Canadian Long-Term Care Homes." *Canadian Journal on Aging* 34(1): 47–59. doi:10.1017/S0714980814000506.
- Global Observatory for Ageing and Dementia Care. 2013. *World Alzheimer Report 2013: Journey of Caring—An analysis of Long-Term Care for Dementia*. London, UK: Alzheimer's Disease International.
- Lachman, V.D. 2016. "Ethics, Law, and Policy. Moral Resilience: Managing and Preventing Moral Distress and Moral Residue." *MEDSURG Nursing* 25(2): 121–24.
- Lefcourt, H.M. and R.A. Martin. 2012. *Humor and Life Stress: Antidote to Adversity*. New York, NY: Springer.
- Maxwell, C.J., J.E. Amuah, D.B. Hogan, M. Cepoiu-Martin, A. Gruneir, S.B. Patten et al. 2015. "Elevated Hospitalization Risk of Assisted Living Residents with Dementia in Alberta, Canada." *Journal of the American Medical Directors Association* 16(7): 568–77. doi:10.1016/j.jamda.2015.01.079.
- McAndrew, N.S., J.S. Leske and A. Garcia. 2011. "Influence of Moral Distress on the Professional Practice Environment During Prognostic Conflict in Critical Care". *Journal of Trauma Nursing* 18(4): 221–30. doi:10.1097/JTN.0b013e31823a4a12.
- McGilton, K.S., J. Profetto-McGrath and A. Robinson. 2013a. "Implementing the Supportive Supervision Intervention for Registered Nurses in a Long-Term Care Home: A Feasibility Study". *Worldviews on Evidence-Based Nursing* 10(4): 238–47. doi:10.1111/wvn.12004.
- McGilton, K.S., A. Tourangeau, C. Kavcic and W.P. Wodchis. 2013b. "Determinants of Regulated Nurses' Intention to Stay in Long-Term Care Homes." *Journal of Nursing Management* 21(5): 771–81. doi:10.1111/jonm.12130.

Nathaniel, A.K. 2004. "A Grounded Theory of Moral Reckoning in Nursing." *Grounded Theory Review* 4(1): 45–58.

Pijl-Zieber, E.M., O. Awosoga, S. Spenceley, B. Hagen, B. Hall and J. Lapins. 2016. "Caring in the Wake of the Rising Tide: Moral Distress in Residential Nursing Care of People Living with Dementia." *Dementia*. doi:10.1177/1471301216645214.

Romero, E.J. and K.W. Cruthirds. 2006. "The Use of Humor in the Workplace." *Academy of Management Perspectives* 20(2): 58–69. doi:10.5465/AMP.2006.20591005.

Roulston, S. 2008. *Labour Market Study: Recruitment and Retention of Health Care Aides in Long Term Care*. Edmonton, AB: Alberta Continuing Care Association. Retrieved January 20, 2018. <http://www.ab-cca.ca/uploads/files/PDF/HCA_Labour_Market_Study_Package.pdf>.

Spenceley, S., B. Hagen, B. Hall, O. Awosoga, C. Witcher and R. Ikuta. 2015. *Moral Distress in the Care of Persons with Dementia in Residential Care Settings in Southern Alberta: Project Final Report*. Retrieved January 15, 2018. <<http://www.moraldistress.ca/about-the-study/study-1-archive/>>

Spenceley, S., C.S. Witcher, B. Hagen, B. Hall and A. Kardolus-Wilson. 2017. "Sources of Moral Distress for Nursing Staff Providing Care to Residents with Dementia." *Dementia* 16(7): 815–34. doi:10.1177/1471301215618108.

Strain, L.A., C.J. Maxwell, D. Wanless and E. Gilbert. 2011. "Designated Assisted Living (DAL) and Long Term Care (LTC)." in *Alberta: Selected Highlights from the Alberta Continuing Care Epidemiological Studies (ACCES)* (174 pages). Edmonton, AB: ACCES Research Group, University of Alberta.

Utley, R., R. Anderson and J. Atwell. 2011. "Implementing Transformational Leadership in Long-Term Care." *Geriatric Nursing* 32(3): 212–19. doi:10.1016/j.gerinurse.2011.02.001.

World Health Organization (WHO). 2012. *Dementia: A Public Health Priority*. Retrieved January 21, 2018. <http://www.who.int/mental_health/publications/dementia_report_2012/en/>.

Longwoods Publishing Corporation

Announcement



It is with great pleasure that Longwoods Publishing Corporation announces that Jason M. Sutherland, Professor, Centre for Health Services and Policy Research, University of British Columbia, has accepted the appointment as Editor-in-Chief of our journal, *Healthcare Policy*.

Prof. Sutherland succeeds Prof. Jennifer Zelmer who has led the journal for more than 10 years, building its reputation and strengthening its readership.

We encourage you to communicate to Prof. Zelmer, President and CEO at The Canadian Foundation for Healthcare Improvement, your thanks and gratitude for her successes with the journal.

Please also join Longwoods in welcoming Jason to the role of Editor-in-Chief. We look forward to his leadership and implementing his renewed vision for the journal.

Thank you,

MATTHEW HART, CEO, LONGWOODS PUBLISHING



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Promoting Quality Improvement in Long-Term Care: A Multi-Site Collaboration to Improve Outcomes with Pneumonia, Falls, Bacteriuria and Behavioural Issues in Dementia



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Abstract

The Bridges to Care for Long-Term Care research project aimed to facilitate improvements in outcomes for long-term care residents through the provision of knowledge-to-practice and quality improvement resources by trained facilitators. Point-of-care staff reported improved communication and collaboration, improved use of scope of practice and implementation of best practice knowledge. Overall, participating long-term care homes demonstrated an enhanced capacity for common care issues of the elderly (pneumonia, falls, bacteriuria and behavioural and psychological symptoms of dementia) and the ability to effectively engage in quality improvement processes with efficient and effective use of healthcare resources.

The long-term care (LTC) sector is a crucial component of our healthcare system and has distinct challenges. Physicians and LTC health professionals are increasingly challenged in responding to higher-acuity and more advanced disease processes. An additional concern is how to best minimize the occurrence of common safety issues and risks, such as nosocomial infections (Wagner and Rust 2008). Research has revealed that the context of LTC homes in Ontario may include stagnant approaches to care, a lack of teaching resources, sub-optimal quality of resident life and a lack of positive nursing role models (Gates et al. 2009).

A review of the literature combining the major headings of LTC, nursing homes and quality improvement (QI) revealed 140 scholarly publications. The search was refined to focus on research that had targeted issues such as professional roles, general methodologies for QI in LTC and reducing the potentially avoidable use of emergency rooms and acute care hospitals. Despite variability in topic areas and methodologies for implementation, there were common themes that influenced the design and implementation of the Bridges to Care initiative:

- There is an opportunity and willingness for process and practice improvement within LTC (Ouslander et al. 2009).
- The uptake of comprehensive evidence-based tools and multiple risk-based processes may be problematic (ColonEmeric et al. 2006; Ouslander et al. 2009).
- Change must be supported and endorsed at all levels of care within facilities (Capezuti et al. 2007).
- LTC staff and practitioners need additional supports in both initiating and incorporating new QI strategies into their normal work processes for sustainable change (Davies and Cripacc 2008).

The Centre for Studies in Aging and Health (CSAH) at Providence Care provided project leadership. This project was designed to foster improved care within LTC through facilitated introduction of evidence-based resources within a resident-centred collaborative care model linked to a QI framework. The project research question was, what is the effectiveness of a QI model for knowledge-to-practice resource delivery on collaborative practice, staff satisfaction, knowledge translation and resident outcomes?

Ethics Approval

The Queen’s University Research Ethics Board, Providence Care Research Review Committee, Kingston, Ontario, and Research Ethics Boards of Lakehead University, Thunder Bay, and the University of Ottawa approved the project.

Methods

The research project was divided into five broad phases: (1) the recruitment of LTC homes, (2) the preparation of knowledge-to-practice resources (preliminary phase), (3) the learning collaborative (first workshop), (4) the initiation of the change process (action) and (5) the sharing of results (second workshop). Six LTC homes were recruited within three LHINs: South East, Champlain and North West, Ontario. Each site identified its internal QI team: a point-of-care staff caregiver (non-regulated), a regulated staff member and a manager. Each site also identified external facilitators to its QI initiative. Funds were supplied for appointment of a local resource consultant to facilitate the improvement initiative at the LTC home level and to liaise and coordinate interactions between local teams and CSAH.

The QI projects were defined for each home, and plans evolved to create resource tool kits for each topic (**preliminary phase**; topics included pneumonia, falls, bacteriuria and behavioural and psychological symptoms of dementia [BPSD]). Resource tool kits included recommended assessment and decision support tools, best practice guidelines, evidence summaries, fact sheets and electronic informational links to other resources. The tool kits were created in both electronic and hard copy formats, with selected resources translated into French, with this need determined by the homes that would use them.

The **first workshop** was held in Kingston over two days in November 2009, and all invited LTC home teams participated. The focus was to share information and training

Table 1. Quality indicators as selected by long-term care homes for individual projects

Pneumonia
Hospitalization rates of residents with pneumonia
Time from identification to treatment of pneumonia
Staff and family satisfaction surveys
Behaviours and psychological symptoms of dementia
Quality and content of communication and collaboration among staff around behaviours associated with dementia
Staff and family satisfaction surveys
Frequency of occurrence and type of undesired behaviours associated with dementia
Falls
Compliance with a post-falls assessment tool and implementation of physiotherapy assessment and treatment after a fall
Falls rate over a three-month period, from January to March 2010

in best practices for the core topic areas and in QI methodologies, and to begin a process of a creating a learning collaborative network for the project.

Over a three-month period (**action phase**), LTC home teams applied the QI strategies designed for their topics. Each team refined aim statements for their QI projects, outcome targets, processes to achieve these outcomes and metrics to monitor progress to targets (Table 1). They applied rapid-cycle improvement methodology using the Plan-Do-Study-Act cycle. Feedback and discussion occurred between participating LTC homes, facilitators, resource consultants and the CSAH team through monthly videoconferences, webcasts and teleconferences.

The **second workshop** was held in March 2010 in Kingston, with representatives from all participating LTC homes. Homes demonstrated QI in action by presenting highlights, challenges and successes for their individual projects.

Results

The Collaborative Practice Assessment Tool (CPAT) is a standardized and validated tool

Table 2. Average Collaborative Practice Assessment Tool scores

	Workshop 1 (n = 35)	Workshop 2 (n = 21)	Difference	p Value
Goals, mission	5.7	6.1	+0.4	.020*
Relations	6.0	6.3	+0.3	.343
Leadership	5.7	6.0	+0.3	.185
Roles and responsibility	5.4	5.2	-0.2	.154
Communication	5.7	5.8	+0.1	.516
Community linkages	5.4	5.6	+0.2	.554
Decision-making	5.1	5.1	0.0	.964
Patient involvement	6.3	6.2	-0.1	.564

*Statistically significant at $p < .05$ level.

Table 3. Average scores from the Bridges to Care workshop evaluation

	First Workshop (n = 27)	Second Workshop (n = 18)	p Value
Goals, mission	6.1	+0.4	.020*
Relations	6.3	+0.3	.343
Leadership	6.0	+0.3	.185
Roles and responsibility	5.2	-0.2	.154
Communication	5.8	+0.1	.516
Community linkages	5.6	+0.2	.554
Decision-making	5.1	0.0	.964
Patient involvement	6.2	-0.1	.564

BPSD = behavioural and psychological symptoms of dementia.

*Statistically significant at $p < .05$ level.

(Schroder et al. 2010) that measures levels of collaboration between members of a healthcare team. The CPAT results showed increases in six of the eight domains of collaborative practice, with a statistically significant increase in the area of “goals, mission and meaningful purpose” (Table 2).

For all four topics combined, there were overall improvements for all three domains of knowledge: general knowledge, ability to identify and application to practice (Table 3). However, when each topic area was considered separately, differences were noted. Statistically significant increases were seen in all three domains for pneumonia, for two domains (knowledge and application to practice) for falls and a single domain (application to practice) for bacteriuria. Although there were trends to improvement

in BPSD, they did not reach statistical significance. Project participants reported significantly better knowledge of the QI process, as would be expected, but no increased confidence. There was also a significant increase in participants’ likelihood of recommending LTC to others as a place of work, and significance ($p = .061$) in their own increased workplace satisfaction.

Five of six participating LTC homes reported on the process and outcomes at the second workshop (Table 4). One LTC home was unable to report due to a number of staff changes, resulting in a disruption of the original QI team. Each of the five reporting LTC homes met or exceeded its QI target. All LTC homes reported ongoing sustainable activities.

Table 4. QI strategies and outcomes

Site Area of QI Focus	Aim Statement	Process	Outcome at Three Months
Pneumonia	Reduce hospitalization with pneumonia by 30% within three months	Implement Alberta Care Plan and Assessment Tool Educate registered staff, PSWs, family, residents and staff	No hospitalizations with pneumonia despite five diagnosed cases
BPSD	Educate 100% in use of three question template	Educate staff and implement use of three question template at daily reports	Stream-lined communication at daily reports Increased staff satisfaction Established secondary QI initiative at mealtime
BPSD	Improve atmosphere in dining room at meal times	Turn off the radio during mealtimes Repaint the dining room Nutrition and dementia information/ staff training delivered to resident care and dining room staff Eliminate stress factors such as drug trolley	Improvement in dining room atmosphere by 75% Improved awareness of resident-specific needs by 60% Reduction of stress level in dining room by 75%
Falls	Reduce number of harmful falls in one year	Introduce PFAT Improve post-fall documentation and care plan	100% completion of PFAT at 3/12 months PT assessment and treatment linked to PFAT
Falls	Reduce number of harmful falls by 6% in three months	Implement PFAT and PFOT with post-fall medication and PT assessment	100% completion of PFAT and PFOT at 3/12 months 55% reduction of harmful falls

BPSD = behavioural and psychological symptoms of dementia; PFAT = post-fall assessment tool; PFOT = post-fall observation tool; PSW = personal support worker; PT = physiotherapy; QI = quality improvement.

Qualitative data from focus groups supported that the roles and responsibilities of team members as adopted in the QI change processes were effective in ensuring success. There were three key themes from the LTC home teams:

1. The fact that they worked in “real teams on real issues,” as opposed to using “fictitious” case studies, was very pertinent to their ability to apply their knowledge in their own working environments.
2. Project processes enabled a safe environment where there was a “meeting of equals” to share ideas and design team-built strategies in a spirit of mutual respect.

3. Group facilitators were highly credible, and physician engagement augmented the team’s ability to move forward in their local QI processes.

Finally, staff satisfaction surveys were completed by two of the LTC home teams. The results showed that most staff members on each of the teams were highly satisfied with knowledge of their team’s projects, the usefulness of the tools they chose and the implementation of those tools, and the levels of education and communication surrounding changes made as part of the project. Open-ended comments from staff showed a belief that the changes made led to improved communication and early identification and treatment of patients with particular need.

Discussion

At the end of three months, all participating LTC homes reported significant improvements in sustainable collaborative resident-centred care processes within the focus of their QI initiatives. These improvements were associated with improved resident care outcomes in terms of reductions in hospitalization with pneumonia, serious falls and troublesome behaviours associated with dementia.

These benefits are first attributable to the homes being strongly engaged in the development of their QI learning and applications from onset. They identified their own projects, their own teams, many of their own resources and the way and means of implementing best practices that would work within their own environments. They also identified and refined the measures and targets to determine their own successes. They worked with their teams on real issues and expressed feelings of ownership concerning their project.

Benefits are also attributable to the provision of combining facilitated knowledge-to-practice and QI processes through the use of internal champions, resource consultants and external facilitators. Home participants repeatedly stated that this personal contact and support were key to their success in moving resources from a “shiny tool kit gathering dust on a shelf” to successful changes in collaborative care practices. A number of complementary improvements in both collaborative care processes and the working environment were demonstrated:

- Increased knowledge, attitudes and skills of the participating individuals were confirmed in common care issues of the elderly in LTC and in QI processes.
- All homes reported that participants were empowered to use their new skills and to act as both a resource and support to other staff members in improved collaborative care practices. The unregulated staff reported feelings of empowerment and being active contributors to the QI processes.
- There was evidence of an increased inter-professional approach to resident care in terms of clarification of scopes of practice and in both team and improved inter-organizational communication and collaboration. Respective roles and scopes of practice of champions within the process appear to have been enhanced beyond the team members’ usual respective areas of influence.
- Improved health and safety outcomes for residents resulted within the three QI topic areas. This was likely a result of both access to and the expanded use of evidence-based, residentcentred, collaborative practice resources offered through the project. Participants accessed these resources through a variety of formats, including a web-based repository.
- There was evidence of efficient and effective use of both onsite and external health human resources through the transfer of evidence into relevant care plans that optimize clinical decision-making and care delivery skills of a variety of health-care providers.
- Sites that collected data reported that staff, family and resident satisfaction improved concerning the quality of care within LTC. This included an increased appreciation by staff that LTC homes are desirable places in which to work.

The Bridges to Care initiative was conceptualized and designed as a pilot project; this limits some of the generalizability of the results. The small sample of LTC homes limits the analysis and generalizability of the findings, although three distinct geographical communities were included. In addition to this, the relative contributions of the various components of the process have not been examined as independent variables. Future research might examine the relationships between the different components and levels of support provided and the outcomes examined through this initiative.

Conclusions

The participating LTC homes were positively influenced in the education and training of staff, with commitments for sustainability and spread within their sites and throughout their regions. All participating LTC homes reported success in achieving their primary QI outcomes.

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References

- Capezuti, E., J. Taylor, H. Brown, H.S. Strothers III and J.G. Ouslander. 2007. "Challenges to Implementing an APN-Facilitated Falls Management Program in Long-Term Care." *Applied Nursing Research* 20: 2–9.
- Colon-Emeric, C., A. Schneck, J. Gorospe, J. McArdle, L. Dobson, C.A. DePorter et al. 2006. "Translating Evidence-Based Falls Prevention into Clinical Practice in Nursing Facilities: Results and Lessons Learned from a Quality Improvement Collaborative." *Journal of the American Geriatrics Society* 54(9): 1414–19.
- Davies, S.A. and C.G. Cripacc. 2008. "Supporting Quality Improvement in Care Homes for Older People: The Contribution of Primary Care Nurses." *Journal of Nursing Management* 16: 115–20.
- Gates, K., E.J. Santos, M. Nguyen, I. Granovskaya, A. Servidio and M. Turzanski. 2009. "Gerontology Education Initiatives in the Health Sciences: Seeking Advice from Students and Seniors in Focus Group Conversations." *Perspectives* 33(3): 6–13.
- Ouslander, J.G., M. Perloe, J.H. Givens, L. Kluge, T.A. Rutland and G. Lamb. 2009. "Reducing Potentially Avoidable Hospitalizations of Nursing Home Residents: Results of a Pilot Quality Improvement Project." *Journal of the American Medical Director's Association* 10: 644–52.
- Schroder, C., J. Medves, M. Paterson, V. Byrnes, C. Chapman, A. O'Riordan et al. 2010. "Development and Pilot Testing of the Collaborative Practice Assessment Tool (CPAT)." *Journal of Interprofessional Care* 25(3): 189–95.
- Wagner, L.M. and T.B. Rust. 2008. "Safety in Long-Term Care Settings: Broadening the Patient Safety Agenda to Include Safety in Long-Term Care." *Healthcare Quarterly* 11(Special Issue): 31–34.



Key Lessons Learned in the Strategic Implementation of the Primary Care Collaborative Memory Clinic Model: A Tale of Two Regions



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Abstract

Primary care collaborative memory clinics (PCCMCs) address existing challenges in dementia care by building capacity to meet the needs of persons living with dementia within primary care. This paper describes the strategic implementation of the PCCMC care model in two regions within Ontario. Evaluation of this initiative included the completion of individual interviews ($N = 32$) with key informants to identify impacts associated with the PCCMCs and tracking of all referrals and assessments completed in the first nine months of clinic implementation. The qualitative analysis of interview transcripts generated five major themes: (1) earlier identification of dementia and intervention; (2) increased capacity for dementia care within primary care; (3) better patient and caregiver experience with care; (4) improved continuity, integration and coordination and improved care; and (5) system efficiencies. Across both regions, 925 patients were referred to PCCMCs, of which 631 (68%) had been assessed during the evaluation period. Strategic, regional implementation of PCCMCs provides a significant opportunity to support better integrated and coordinated dementia care.

Introduction

To address the well-documented challenges associated with managing dementia in primary care (Aminzadeh et al. 2012; Bradford et al. 2009; Pimlott et al. 2009), the primary care collaborative memory clinic (PCCMC) care model was created to increase capacity within primary care to assess and manage persons with memory concerns (Lee et al. 2010, 2017a). PCCMCs are family physician-led interprofessional teams that provide comprehensive evidence-informed assessments and person-centred care management plans for persons living with dementia and other memory disorders and for their family members. PCCMCs support referring family physicians to provide quality dementia care through a shared-care collaborative approach. The goal of this program is to build capacity and skills for primary care practitioners to better manage memory disorders within the family practice setting, efficiently streamlining

appropriate referrals to specialist care for cases that are the most complex. Partnerships with local community services such as the Alzheimer Society ensure timely patient and caregiver access to education, support services and system navigation. More information about this care model is presented elsewhere (Lee et al. 2010, 2014b, 2017a).

The first PCCMC was created and implemented in 2006 in the Centre for Family Medicine Family Health Team, in Kitchener, Ontario, Canada, and following its success, an accredited training program was developed to support the establishment of new clinics in other primary care settings (Lee et al. 2013; McLeod et al. 2016). Currently, there are over 100 PCCMCs across Ontario (Lee et al. 2017a). The establishment of new clinics has primarily been based on the desire of individual practice settings to meet the dementia care needs of their unique patient populations with limited planning

for coordination and integration with other local geriatric services for older adults. In some areas, this has resulted in the clinics working in isolation, rather than in concert, with other geriatric services.

Two regions in Ontario were interested in implementing the PCCMC care model using a strategic, systematic implementation plan, thereby facilitating region-wide planning and collaboration among various existing agencies and specialized services for older adults. In Ontario, local health integration networks (LHINs) are regional health authorities responsible for healthcare service planning and funding; the two regions involved in this project were the Central East LHIN (CELHIN) and the Champlain LHIN. The purpose of this paper is to describe the strategic implementation of the PCCMC model of care within these two regions in Ontario, describing their rationale for adopting a systematic approach to establishing clinics in their region and key lessons learned in the regional implementation of the clinics.

Strategic Implementation in Two Regions

Champlain LHIN

The Champlain LHIN is located in eastern Ontario, Canada, bordering Quebec, covering five sub-regions in and surrounding the nation's capital, Ottawa. Demographic and health service information for this region is presented in Table 1. The process of developing and implementing the clinics is summarized in Table 2. Both tables are available at longwoods.com/content/25938.

In 2012, the increasing number of persons in the Champlain region living with dementia was a key issue driving the region's interest in improving dementia care in primary care. Key organizations involved in dementia care (Champlain Dementia Network, the Regional Geriatric Program of Eastern Ontario [RGPEO], Geriatric Medicine and Alzheimer

Societies of Ottawa and Renfrew County and Cornwall and District) began planning a regional approach to identifying sustainable, collaborative and capacity-building dementia care models in primary care. There was an interest in moving more specialist care as provided by geriatricians into the community while recognizing the lack of community infrastructure to support specialist care. The PCCMC model was identified as potentially meeting this need.

A planning and implementation team was created to guide this initiative. The RGPEO invested in an advanced practice nurse role to facilitate this process. Planning was informed by a review of the literature, review of the primary care landscape and leveraging lessons learned from existing dementia initiatives. Strategies to inform this process included discussions with practice administrators to determine the potential fit of the PCCMC model, a site visit to observe the Centre for Family Medicine memory clinic team in practice and presentations on the PCCMC model to invested primary care practices and key regional stakeholders. A funding proposal was submitted to the Champlain LHIN outlining a number of initiatives to support dementia care across the continuum. Three complementary capacity-building models, including the PCCMC model, were selected to meet the unique needs and resources available to the different primary care delivery structures in the region.

The Champlain LHIN provided three consecutive one-time/one-year funding envelopes to support the training of 15 PCCMCs in the region as well as ongoing funding for dedicated staff from the Alzheimer Society to participate in all PCCMCs (Table 2). The RGPEO committed, in kind, the services of an advanced practice nurse to lead the planning and coordination of the clinics and support capacity-building needs across clinics. An awareness-raising campaign was launched to inform primary

care settings in the region about the potential opportunity to establish a PCCMC. A formal readiness assessment process was established to ensure that the PCCMC model was a good fit for interested practices. Fifteen sites were selected across the region representing urban and rural, academic and non-academic and Francophone and Anglophone practices. Because 13 of the 15 clinic settings were in team-based primary care structures (Family Health Teams and Community Health Centres), these clinics were able to recruit their own interprofessional team of health-care providers (HCPs) to construct their PCCMC team, including nurse practitioners, registered nurses/practical nurses, pharmacists, social workers, health promoters and dietitians. Two of the PCCMC settings were Family Health Organizations; thus, in-kind partnerships with local community, hospital services and the RGPEO provided the social work, pharmacist and additional nursing resources required to complete their team. In-kind support from local Alzheimer Society staff was provided to all 15 PCCMC teams. To support the goal of implementing 15 PCCMCs in the region over three years, a plan was put in place to target the training of five clinic teams per year starting in February 2014, and by April 2016, all 15 clinics were established with 137 HCPs who had completed training. All of the clinics accepted referrals from within their practice settings, in total supporting 152 family physicians with a combined patient base of 167,923 (Table 2).

To provide ongoing regional support to the PCCMCs, the advanced practice nurse works with teams to identify and address concerns that arise with clinic implementation, develops processes to facilitate geriatrician support, identifies processes for integration with Specialized Geriatric Services to facilitate seamless transitions for patients and supports learning needs through coordination of continuing education events. Over time, the number of geriatricians

providing support to PCCMCs in this region has increased from four to seven. Because the role of specialists within this care model represented a new way of working with family physicians, a collaborative framework was developed to highlight strategies to foster specialist integration into the clinic team and to optimize specialist collaboration and support for the memory clinic team, with the ultimate goal of optimizing the care of patients and families.

Central East LHIN

The CELHIN includes urban and rural areas in central east Ontario. Demographic and health service information for this region is presented in Table 1. The system of care for older adults living with frailty is coordinated and implemented through the Seniors Care Network, a network of health service programs and organizations that collaborate to deliver Specialized Geriatric Services in this region.

“Grass-roots level” interest was initiated by several physicians who approached the Seniors Care Network to explore opportunities for implementation of PCCMCs in this region. Leveraging existing resources and expertise in dementia care in the region, a planning group was formed consisting of representatives from the local Alzheimer Society chapter, Seniors Care Network and various Specialized Geriatric Service providers.

Funding was provided by the LHIN for the memory clinic training program, which was attended by not only the health professionals who would be working in the memory clinics, as is usually the case, but also health professionals in all of the relevant dementia care-related services in the region. The training was proposed as an educational opportunity and served to facilitate “buy-in” for the introduction of PCCMCs from all relevant community programs by fostering a common understanding of the scope and role of PCCMCs. This common understanding

helped to overcome the initial resistance to the introduction of this new service, which was primarily related to lack of understanding of the capacity and complementary role of PCCMCs within the continuum of care for seniors.

As all of the PCCMCs were being established in practice settings without access to the required interprofessional HCPs, a shared interprofessional “mobile team” was created to support the PCCMCs. In-kind contributions of space and staff were made by the Alzheimer Society and PCCMC family practice settings. The mobile team consists of two registered practical nurses, additionally trained in mental health, addictions and dementia as Behavioural Supports Ontario (BSO) program staff; two social workers; and two occupational therapists. (BSO is a province-wide program aimed at providing care for older adults exhibiting, or who are at risk of exhibiting, responsive behaviour [e.g., aggression, wandering, physical resistance, agitation] related to cognitive impairment due to mental health problems, addictions, dementia or other neurological conditions [Gutmanis et al. 2015].) Many of these HCPs were recruited from existing local community geriatric services, which helped to integrate all relevant dementia care programs into the PCCMC care model. These included the Alzheimer Society First Link program (McAiney et al. 2012), the BSO program and local Geriatric Assessment and Intervention Network teams (Seniors Care Network 2015). Integration of team members from these programs facilitated access to various community services and improved communication and coordination of care through PCCMCs. To help foster relationships between interprofessional HCPs and physicians who had not previously worked together with an interprofessional team, and to support the logistical requirements of mobile clinical work, which included home visits, the PCCMC program manager role was created. This program manager supports

implementation across participating primary care practices and connects via a formalized committee structure to specialized geriatric services to collaborate in planning, coordination and regional quality improvement initiatives, aligning local and regional services.

In total, 70 individuals completed the memory clinic training program in March 2016, 33 representing primary care and 37 representing the Specialized Geriatric Service programs coordinated by the Seniors Care Network and Alzheimer Society staff. Following completion of the training program, four new PCCMCs were created. Three of the clinics are supported by the mobile team, and one clinic created its own interprofessional team supplemented with HCPs from the Seniors Care Network’s local Geriatric Assessment and Intervention Network team. All four clinics have an assigned geriatrician to provide consultative support; these geriatricians attended the memory clinic training program. Two of the clinics accept referrals for patients rostered within their practice settings, whereas the other two additionally accept referrals from outside of their practice setting. In total, these clinics support a very large number of medical practices in the regions (Table 2).

Evaluation Methods

Up to 16 months following the establishment of their PCCMCs (10–12 months in the CELHIN; 12–16 months in the Champlain LHIN), all team members, initiative leads and partners were invited to participate in individual telephone interviews to gather their perceptions regarding how dementia care in the region has changed as a result of the PCCMCs (e.g., What do you think are key impacts of the memory clinics on the system of care for persons with dementia in your region? In what ways has the care for persons with dementia in the region improved with the development of the memory clinics?).

Table 3. Primary and secondary outcomes by referral status

Tracked data	Percentage (#)	
	Central East LHIN (N = 4 clinics)	Champlain LHIN (N = 15 clinics)
Total number of referrals	409	516
Number of urgent referrals*	11 (2.7%)	23 (4.5%)
Number of patients assessed*	273 (66.6%)	358 (69.4%)
Number of patients awaiting assessment*	111 (127.1%)	98 (19.0%)
Wait time for assessment** (months), mean, standard deviation	1.1 (1.3)	1.2 (1.4)
Referrals for specialist consultation***	30 (11.0%)	48 (13.4%)

* Percentage is based on the total number of referrals in each region.
 ** Calculated as the difference between the date of referral and date of assessment.
 *** Percentage is based on the total number of patients assessed in each region.

A total of 32 interviews were completed (CELHIN, N = 13; Champlain LHIN, N = 19). Across both regions, interviews were completed with physicians (N = 11), allied health professionals (N = 12) and initiative leaders/partners (N = 9). Interviews ranged in length from 14 to 51 minutes (average = 27 minutes).

Interviews were completed by one author (L.M.H.) to ensure consistency, digitally recorded and transcribed. Within each region, saturation was achieved (little or no new information was gathered from the latest interviews). Transcripts were analyzed using a qualitative naturalistic inquiry approach to develop an understanding of impacts at both patient and health system levels (Lincoln and Guba 1985). Transcripts were analyzed by one author (L.M.H.) and then reviewed by a research assistant to confirm reliability in the emerging themes; this process required several iterations to achieve greater clarity in the final themes generated.

Team members from each clinic tracked all referrals and assessments completed in the first nine months of clinic implementation, collecting information on number of referrals, urgency status (urgent, non-urgent), number of patients assessed, number awaiting assessment and number of assessed patients who were referred to specialists for

further consultation. Wait time for assessment was calculated as the difference between the date of referral and date of assessment. A key outcome indicator for this initiative is the number of established clinics that continued to operate nine months following launch.

This study was approved by the Hamilton Integrated Research Ethics Board, McMaster University.

Results

In the Champlain LHIN, 14 of 15 clinics continue to operate in the longer term (some up to four years). One clinic chose to suspend acceptance of new referrals, though they continue to see patients already assessed for follow-up; a number of reasons influenced this decision, including the low number of referrals, a younger demographic within the practice setting and quick access to specialist consultation. In the CELHIN, all four established clinics continued to operate in the longer term (two years).

Across both regions, 925 patients were referred to PCCMCs, of which 631 (68%) were assessed and 209 (23%) were awaiting assessment (Table 3). Across both regions, the average wait time for assessment was one month (1.2 months; SD = 1.4 months); 87% (N = 548) of the patients were assessed

within three months of referrals, whereas 38% ($N = 242$) were assessed within a month of referral. Across both regions, 12% of the patients assessed were subsequently referred for specialist consultation.

Regarding impacts associated with the PCCMCs, the qualitative analysis of interview transcripts generated five major themes: (1) earlier identification and intervention; (2) increased capacity for dementia care in primary care; (3) better patient and caregiver experience with care; (4) improved continuity, integration and coordination and care; and (5) system efficiencies. These themes were common across both regions. Table 4, available at longwoods.com/content/25938, presents a description of these themes with illustrative quotes.

Discussion

The PCCMC implementation experiences in the CELHIN and the Champlain LHIN highlight the value of a strategic system-wide approach to implementation, which allowed for the integration of the model within the system of existing services for older adults across sectors, ensuring alignment with regional strategic plans and visions for seniors' healthcare. The process built on, complemented and enhanced the strengths of the region's current service offerings and contexts and expedited assessments, while also avoiding competition and duplication with existing established services. For example, in the CELHIN, the planning committee provides a practical forum for identifying the best service to be the lead, or primary, service provider for particular patients based on unique patient needs. The different services build on the work of each other so that if a patient is transferred between services, they avoid repeating assessments completed by the previous service.

Strategic implementation also allowed each region to capitalize and make efficient use of existing staff, programs and strategies for seniors and dementia care. These

improved efficiencies have the potential to result in cost savings to the system. Across both regions, a number of factors supported improved integration of dementia care services. In the Champlain LHIN, assigning several geriatricians to support PCCMCs fostered a strong sense of specialist support of this initiative and positive relationships between primary care and specialist care, establishing the foundation for true collaboration. In the CELHIN, the creation of a mobile team with team members drawn from various existing regional programs served to improve integration and coordination of care with other services. Participation of the PCCMCs in the regional operations committee has strengthened and entrenched this service within the system of Specialized Geriatric Services. In both the Champlain LHIN and the CELHIN, the role of the clinic coordinator was critical to the successful strategic implementation of PCCMCs. Integration of HCPs from the existing geriatric services in both LHINs also proved to further support and develop the clinical capacity of the PCCMC. A growing body of literature on integrated care provides evidence that collaboration between health-care professionals can be enhanced through development of a structure for team work, sharing of team resources and organizational supports (administration, facilities) and mechanisms for communication and coordination (San Martin-Rodriguez et al. 2005). Interprofessional team-based care, with ongoing care coordination, communication and information sharing among all care providers, is the mainstay of person-centred care (American Geriatrics Society Expert Panel on Person-Centered Care 2016) and has been identified as essential for integrated care (Gonzalez-Ortiz et al. 2018). Community-based integrated systems of care for older adults have demonstrated improved quality, coordination and continuity of care and health outcomes for older adults (Bernabei et al. 1998; Johri et al. 2003; McAdam 2008). Engagement of local services

in service planning and implementation is important to the success of new health innovations. In this instance, the bringing together of key players from various community programs (Alzheimer Society, BSO, Specialized Geriatric Services) supported by clinic coordinators contributed to better system navigation, integration and care coordination. Consistent with the findings of other studies (Lee et al. 2014a), collaboration and communication across multiple organizations and programs in the Champlain LHIN and the CELHIN facilitated improved access to community services and better, more seamless transitions between services for patients and caregivers. Effective implementation of new health innovations to affect system change has been demonstrated to require consideration of facilitating factors at micro (individual), meso (organizational) and macro (community and system) levels and how these levels interact and collaborate to affect change (Chaudoir et al. 2013; Durlak and DuPre 2008; Wandersman et al. 2008). The findings from this study demonstrated that both regions were able to affect change at all levels to improve dementia care. Consistent with the literature on effective practice change, the memory clinic training program has demonstrated its ability to facilitate practice improvements through multiple and best teaching practices (Lee et al. 2013, 2014c) and drawing on principles of effective program planning (Caffarella 2002; Kern et al. 2009). These training strategies have included case-based learning, feedback and practice and mentorship opportunities (Bell 2002; Bero et al. 1998); access to guideline-based interventions (Colon-Emeric et al. 2004); and access to expert resources and ongoing support (Stolee et al. 2015). Facilitating factors within practice settings that have enabled practice change and memory clinic implementation have included selection of highly motivated team members (Mazmanian and Davis 2002), access to enabling resources such as clinical support

tools (Bloom 2005; Mazmanian et al. 2009) and clinic flow templates (Berwick 2003), organization and management support (Bradley et al. 2003; Broad 2005; Stolee et al. 2005), and support and commitment from identified champions, physicians and interprofessional team members (Resnick et al. 2004). At a system level, clinic implementation in both regions was facilitated by cross-sector and service collaborative partnerships; these types of partnerships have been identified as important to the effectiveness of interventions that affect health system changes (Mitchell et al. 2015; Mitchell and Shortell 2000; Nicholson et al. 2013) and particularly important to the development of a comprehensive system of care for dementia (Hogan et al. 2008; Patterson et al. 2001).

Communities of practice (CoP), groups of individuals with shared interests, represent a significant opportunity for healthcare improvements (Endsley et al. 2005; Ranmuthugala et al. 2011; Wenger et al. 2002) and can break down silos of care. Regional implementation supported the development of CoP by having local teams train and attend “Booster Days” together, which are annual refresher days that provide an opportunity for PCCMC clinicians to network and learn from one another, further supporting cross-service and cross-sector collaboration (Lee et al. 2017b). Relationships between clinic coordinators and local teams as well as the PCCMC model being endorsed as part of a regional dementia strategy served to foster the CoP connectedness. As mentioned above, strategic regional implementation can facilitate greater opportunities for integration and alignment with existing regional programs particularly when establishing clinics on a large scale. This is important for sustainability and further development, efficient use of limited system resources and potential inclusion of PCCMCs in other health system initiatives, such as coordinated intake systems for specialized geriatric services, as was the case

in at least two regions in the province.

In both regions, the majority of patients (>67%) referred to the PCCMCs were assessed during the evaluation period. Although the number of patients awaiting assessment in Champlain at the end of the evaluation period likely had wait times for assessment consistent with those who were assessed, wait times for awaiting assessment ($N = 111$ for assessment across four clinics) in the CELHIN were likely longer. This reflects a steady increase in referrals over time as the capacity of the memory clinics to assess and manage memory concerns became better understood and as some referrals to specialists were redirected to the memory clinic. On occasion, some of the clinics would hold an extra clinic per month to manage the increasing wait list and reduce wait time to assessment.

Across both regions, the rate of referrals to specialists (12%) is consistent with ideal models of chronic disease management where the majority of care for chronic conditions is managed within primary care (Scott 2008) and only the most complex of cases are referred for specialist management; this 12% referral rate represents a substantive reduction from the estimated rate of referral of up to 82% to geriatric specialists for memory concerns in typical family practice (Pimlott et al. 2006). Given this rate of referral to specialists, it could be estimated that the PCCMCs across both regions have the potential to avert 758 referrals (82% of 925 referrals to PCCMC) that would otherwise have been made to specialists. Anecdotal evidence, collected in the key informant interviews (Table 4), has also suggested system efficiencies related to reduced emergency department visits due to early identification and intervention and proactive approaches to care that prevent crises that can lead to use of acute care and institutionalization. While outcomes related to improved patient care, reduced rates of referrals to specialists and potentially

reduced emergency department visits are consistent with those of PCCMCs across the province (Lee et al. 2010, 2017a), the strategic implementation processes in the Champlain LHIN and the CELHIN appeared to contribute to other outcomes such as improved integration and coordination with services and sectors across the regions.

While specialists integrated into the PCCMC care model in these regions have been geriatricians, there is growing recognition that geriatric psychiatrists and cognitive neurologists have unique and important roles to play in dementia care. An initiative is currently underway to establish and evaluate a triad of specialist support for memory clinics (geriatricians, geriatric psychiatrists and cognitive neurologists); this will provide greater opportunities for integration and coordination with specialist services and for capacity building among the PCCMCs.

A number of key lessons were learned in the regional implementation of PCCMCs. Across regions, there was strong organizational buy-in for the PCCMC model and readiness for change, particularly as measured in the Champlain LHIN, both of which have been identified as key factors impacting successful implementation of new innovations (Dijkstra et al. 2006; Scott et al. 2003). Both regions also had well-established Specialized Geriatric Services for older adults, and implementation of PCCMCs provided a greater recognition among these services of the capacity that exists in primary care for quality dementia care. Designated PCCMC coordinators in each region were important to facilitating, strengthening and sustaining the PCCMC initiative. This vital role was credited with driving and overseeing all stages of planning, development and ongoing implementation; serving as the PCCMC “point person” to whom all inquiries could be directed; and reinforcing system efficiencies with continuous quality improvement efforts aimed at refining, evolving and growing the PCCMC initiative. Access to

standardized training and continuing education was viewed as critical to implementing the PCCMC model, and in the CELHIN, inclusion of professionals working in other services served to increase understanding of the role of primary care in dementia care, which in turn increased buy-in for the model and supported collaborative efforts across sectors. Moreover, inclusion of specialists in the training served to solidify support for the model, as they better understood the role of the PCCMC within the system of dementia care in the region and increased their understanding of the learning needs of the PCCMC teams, further contributing to collaboration between primary care and specialists.

Implementation of the PCCMCs within both regions was not without challenges. Space needs and administrative support for the clinics were underestimated. Policies and procedures for privacy and clinical documentation needed to be developed for mobile interprofessional teams to practice in locations where they were not employees. In both regions, team members who were not employees of the organization hosting the memory clinic were required to sign confidentiality agreements to access and document in the electronic medical record. In many instances, these team members had to learn multiple documentation systems as these were not consistent across all clinic settings. Within two practice settings in the Champlain LHIN, a memorandum of understanding regarding the roles of non-employees working within the clinics was developed and is signed on an annual basis. In the Champlain LHIN, further development of the collaboration between the specialist and primary care will continue to evolve in supporting an upstream approach to early detection and intervention. The issue of sustainability of the clinics has been an ongoing challenge that includes not only the need for a sustainable operational

funding model but also the training and recruitment of new PCCMC team members to manage clinic expansion and staff turnover.

From a funding perspective, a regional approach to implementation can assure accountability for achieving deliverables pertinent to the delivery of dementia care, support equitable access to health services, enable economies of scale when considering training costs and foster coordination among clinics and integration with existing specialist services through the allocation of dedicated clinical resource personnel. A strategic approach to implementing PCCMCs organizes services at a system level and can promote sustainability, which is particularly relevant as Ontario engages in building a cohesive dementia care strategy.

The usual system of care for dementia has been criticized for its limited integration and coordination between various medical, social and community services (Bruce and Paterson 2000; Samsi and Manthorpe 2014; Tan et al. 2014). Efforts to improve care coordination have typically been aimed at the patient level with the use of individual case management models (Bass et al. 2015; Khanassov and Vedel 2016), with less attention paid to coordination and integration across health sectors. The PCCMC care model aims to address these limitations by implementing interprofessional team-based care management that is rooted in primary care but linked to specialist care and services. The PCCMCs continue to evolve with the structured integration of geriatric medicine, geriatric psychiatry and cognitive neurology to further develop collaborative working relationships and improve care capacity and integration.

There are a number of limitations to the evaluation of memory clinic implementation. Interviews were conducted with clinic team members and leaders; the perspectives of practice setting management and health

system leaders are not known. Interview questions focused on the identification of practice improvements and impacts associated with the clinics, which may have biased the findings. Measurement of outcomes and impacts were primarily based on anecdotal evidence. Further research is needed to better delineate the health system and efficiencies afforded by the PCCMCs, namely, the impact of early identification and intervention by the PCCMCs on utilization and cost of health services, specifically emergency department visits, hospital admissions and long-term care placements, and how better integrated and coordinated care can impact health service utilization and health outcomes. More research, with rigorous methodologies, such as case-controlled, time-series methods, and multiple case-study designs, is needed to further our understanding in this area.

Conclusion

This paper offers insight into a coordinated and systematic approach to implementing the PCCMC model region-wide. Strategic, regional implementation of PCCMCs provides a significant opportunity to support better integrated and coordinated dementia care across services and sectors. In two regions in Ontario, regional implementation has fostered a higher level of collaboration between PCCMCs, Specialized Geriatric Services and community services, and thereby led to a stronger CoP than would otherwise be possible. Lessons learned from this initiative can inform the implementation of other primary-care-based initiatives for complex chronic conditions of older adults.

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References

- American Geriatrics Society Expert Panel on Person-Centered Care. 2016. "Person-Centered Care: A Definition and Essential Elements." *Journal of the American Geriatrics Society* 64(1): 15–18. doi:10.1111/jgs.13866.
- Aminzadeh, F., F.J. Molnar, W.B. Dalziel and D. Ayotte. 2012. "A Review of Barriers and Enablers to Diagnosis and Management of Persons with Dementia in Primary Care." *Canadian Geriatrics Journal* 15(3): 85–94. doi:10.5770/cgj.15.42.
- Bass, D.M., K.S. Judge, K. Maslow, N.L. Wilson, R.O. Morgan, C.A. McCarthy et al. 2015. "Impact of the Care Coordination Program 'Partners in Dementia Care' on Veterans' Hospital Admissions and Emergency Department Visits." *Alzheimer's & Dementia: Translational Research and Clinical Interventions* 1(1): 13–22. doi:10.1016/j.trci.2015.03.003.
- Bell, C.R. 2002. *Managers as Mentors: Building Partnerships for Learning*. San Francisco, California: Berrett-Koehler Publishers, Inc.
- Bernabei, F., F. Landi, G. Gambassi, A. Sgardari, G. Zuccala, V. Mor et al. 1998. "Randomized Trial of Impact of Model of Integrated Care and Case Management for Older People Living in the Community." *British Medical Journal* 316(7174): 1348–51. doi:10.1136/bmj.316.7141.1348.
- Bero, L.A., R. Grilli, J.M. Grimshaw, E. Harvey, A.D. Oxman and M.A. Thomson. 1998. "Closing the Gap between Research and Practice: An Overview of Systematic Reviews of Interventions to Promote the Implementation of Research Findings. The Cochrane Effective Practice and Organization of Care Review Group." *British Medical Journal* 317(7156): 465–68. doi:10.1136/bmj.317.7156.465.
- Berwick, D.M. 2003. "Disseminating Innovations in Health Care." *Journal of the American Medical Association* 289(15): 1969–75. doi:10.1001/jama.289.15.1969.
- Bloom, B.S. 2005. "Effects of Continuing Medical Education on Improving Physician Clinical Care and Patient Health: A Review of Systematic Reviews." *International Journal of Technology Assessment in Health Care* 21(3): 380–85. doi:10.1017/S026646230505049X.

- Bradford, A., M.E. Kunik, P. Schulz, S.P. Williams and H. Singh. 2009. "Missed and Delayed Diagnosis of Dementia in Primary Care. Prevalence and Contributing Factors." *Alzheimer Disease and Associated Disorders* 23(4): 306–14. doi:10.1097/WAD.0b013e3181a6bebc.
- Bradley, E.H., E.S. Holmboe, J.A. Matterna, S.A. Roumanis, M.J. Radford and H.M. Krumholz. 2003. "The Roles of Senior Management in Quality Improvement Efforts: What Are the Key Components?" *Journal of Healthcare Management* 48(1): 15–29. doi:10.1097/00115514-200301000-00005.
- Broad, M.L. 2005. *Beyond Transfer of Training: Engaging Systems to Improve Performance*. San Francisco, CA: Pfeiffer.
- Bruce, D.G. and A. Paterson. 2000. "Barriers to Community Support for the Dementia Carer: A Qualitative Study." *International Journal of Geriatric Psychiatry* 15(5): 451–57. doi:10.1002/(SICI)1099-1166(200005)15:5<451.
- Caffarella, R.S. 2002. *Planning Programs for Adult Learners. A Practical Guide for Educators, Trainers, and Staff Developers*. New York, NY: Jossey-Bass.
- Canadian Consensus Conference on Dementia. 2007. *Third Canadian Consensus Conference on Diagnosis and Treatment of Dementia*. 146 Approved Recommendations. Retrieved April 6, 2018 <http://www.cccdt.ca/pdfs/Final_Recommendations_CCCDTD_2007.pdf>.
- Central East Local Health Integrated Network (CELHIN). 2015. *Integrated Health Service Plan 2016–2019*. Retrieved April 6, 2018. <<http://www.centraleastlin.on.ca/priorities/ihsp/IHSP%202016-2019.aspx>>.
- Champlain Local Health Integrated Network (CLHIN). 2014. *Population Characteristics for Champlain Health Link Areas*. Retrieved April 6, 2018. <<http://www.champlainlin.on.ca/Accountability/Integration/Health%20Links.aspx>>.
- Champlain Local Health Integration Network (CLHIN). 2016. *2016–2019 Integrated Health Service Plan*. Retrieved April 6, 2018. <<http://www.champlainlin.on.ca/GoalsandAchievements/OurStratPlan.aspx>>.
- Chaudoir, S.R., A.G. Dugan and C.H. Barr. 2013. "Measuring Factors Affecting Implementation of Health Innovations: A Systematic Review of Structural, Organizational, Provider, Patient, and Innovation Level Measures." *Implementation Science* 8: 22. doi:10.1186/1748-5908-8-22.
- Colon-Emeric, C.S., L. Casebeer, K. Saag, J. Allison, D. Levine, T.T. Suh et al. 2004. "Barriers to Providing Osteoporosis Care in Skilled Nursing Facilities: Perceptions of Medical Directors and Directors of Nursing." *Journal of the American Medical Directors Association* 5(6): 361–66. doi:10.1097/01.JAM.0000141950.34986.EE.
- Dijkstra, R., M. Wensing, R. Thomas, R. Akkermans, J. Braspenning, J. Grimshaw et al. 2006. "The Relationship between Organisational Characteristics and the Effects of Clinical Guidelines on Medical Performance in Hospitals, A Meta-Analysis." *BMC Health Services Research* 6: 53. doi:10.1186/1472-6963-6-53.
- Durlak, J.A. and E.P. DuPre. 2008. "Implementation Matters: A Review of Research on the Influence of Implementation on Program Outcomes and the Factors Affecting Implementation." *American Journal of Community Psychology* 41(3-4): 327–50. doi:10.1007/s10464-008-9165-0.
- Endsley, S., M. Kirkegarrd and A. Linares. 2005. "Working Together: Communities of Practice in Family Medicine." *Family Practice Management* 12 (1): 28–32.
- Gonzalez-Ortiz, L.G., S. Calciolari, N. Goodwin and V. Stein. 2018. "The Core Dimensions of Integrated Care: A Literature Review to Support the Development of a Comprehensive Framework for Implementing Integrated Care." *International Journal of Integrated Care* 18(3): 10. doi:10.5334/ijic.4198.
- Gutmanis, I., M. Synder, D. Harvey, L.M. Hillier and J.K. LeClair. 2015. "Health Care Design for Responsive Behaviour. The Behavioural Supports Ontario Experience: Lesson Learned and Keys to Success." *Canadian Journal of Community Mental Health* 34(1): 45–63. doi:10.7870/cjcmh-2015-001.
- Hogan, D.B., P. Bailey, S. Black, A. Carswell, H. Chertkow, B. Clarke et al. 2008. "Diagnosis and Treatment of Dementia: 5. Nonpharmacologic and Pharmacologic Therapy for Mild to Moderate Dementia." *Canadian Medical Association Journal* 179(10): 1019–26. doi:10.1503/cmaj.081103.
- Johri, M., F. Beland and H. Bergman. 2003. "International Experiments in Integrated Care for the Elderly: A Synthesis of the Evidence." *International Journal of Geriatric Psychiatry* 18(3):222–35. doi:10.1002/gps.819.
- Kern, D.E., P.A. Thomas and M.T. Hughes. 2009. *Curriculum Development for Medical Education – A Six-Step Approach*. Baltimore, MD: The John Hopkins University Press.

- Khanassov, V. and I. Vedel. 2016. "Family Physician-Case Manager Collaboration and Needs of Patients with Dementia and Their Caregivers: A Systematic Mixed Studies Review." *Annals of Family Medicine* 14(2): 166–77. doi:10.1370/afm.1898.
- Lee, L., L.M. Hillier, P. Stolee, G. Heckman, M. Gagnon, C. McAiney et al. 2010. "Enhancing Dementia Care: A Primary Care-Based Memory Clinic." *Journal of the American Geriatrics Society* 58(11): 2197–204. doi:10.1111/j.1532-5415.2010.03130.x.
- Lee, L., L.M. Hillier and D. Harvey. 2014a. "Integrating Community Services into Primary Care: Improving the Quality of Dementia Care." *Neurodegenerative Disease Management* 4(11): 11–21. doi:10.2217/nmt.13.72.
- Lee, L., L.M. Hillier, G.A. Heckman, M. Gagnon, M.J. Borrie, P. Stolee et al. 2014b. "Primary Care Based Memory Clinics: Expanding Capacity for Dementia Care." *Canadian Journal on Aging* 33(3): 307–19. doi:10.1017/S0714980814000233.
- Lee, L., L.M. Hillier and W.W. Weston. 2014c. "Ensuring the Success of Interprofessional Teams: Key Lessons Learned in Memory Clinics." *Canadian Journal on Aging* 33(1): 49–59. doi:10.1017/S0714980813000652.
- Lee, L., L.M. Hillier, F. Molnar and M.J. Borrie. 2017a. "Primary Care Collaborative Memory Clinics: Building Capacity for Optimized Dementia Care." *Healthcare Quarterly* 19(4): 55–62.
- Lee, L., L.M. Hillier and W.W. Weston. 2017b. "Booster Days': An Educational Initiative to Develop a Community of Practice of Primary Care Collaborative, Memory Clinics." *Gerontology and Geriatrics Education* 5: 1–16. doi:10.1080/02701960.2017.1373350.
- Lee, L., W.W. Weston and L.M. Hillier. 2013. "Developing Memory Clinics in Primary Care: An Evidence-Based Interprofessional Program of Continuing Professional Development." *Journal of Continuing Education in the Health Professions* 33(1): 24–32. doi:10.1002/chp.21163.
- Lincoln, Y.S. and E.G. Guba. 1985. *Naturalistic Inquiry*. Newbury Park, CA: Sage Publications.
- Mazmanian, P.E. and D.A. Davis. 2002. "Continuing Medical Education and the Physician as a Learner: Guide to the Evidence." *Journal of the American Medical Association* 288(9): 1057–60. doi:10.1001/jama.288.9.1057.
- Mazmanian, P.E., D.A. Davis and R. Galbraith. 2009. "Continuing Medical Education Effect on Clinical Outcomes: Effectiveness of Continuing Medical Education: American College of Chest Physicians Evidence-Based Educational Guidelines." *Chest* 135(Suppl. 3): 49S–55S. doi:10.1378/chest.08-2518.
- McAdam, M. 2008. *Frameworks of Integrated Care for the Elderly: A Systematic Review*. Canadian Policy Research Networks. Retrieved March 29, 2019. <<http://www.integrationresources.ca/resources/frameworks-of-integrated-care-for-the-elderly-a-systematic-review/>>.
- McAiney, C.A., L.M. Hillier, P. Stolee, D. Harvey and J. Michael. 2012. "Throwing a Life-Line: The Role of First Link™ in Enhancing Supports for Persons with Dementia and their Care Partners." *Neurodegenerative Disease Management* 2(6): 623–38.
- McLeod, L., G. Buckley and A. Sweetman. 2016. "Ontario Primary Care Models: A Descriptive Study." *Canadian Medical Association Journal Open* 4(4): E679–88. doi:10.9778/cmajo.20160069.
- Mitchell, G.K., L. Burridge, J. Zhang, M. Donald, I.A. Scott, J. Dart et al. 2015. "Systematic Review of Integrated Models of Health Care Delivered at the Primary-Secondary Interface: How Effective Is It and What Determines Effectiveness?" *Australian Journal of Primary Health* 21(4): 391–408. doi:10.1071/PY14172.
- Mitchell, S.M. and S.M. Shortell. 2000. "The Governance and Management of Effective Community Health Partnerships: A Typology for Research, Policy and Practice." *Milbank Quarterly* 78(2): 241–89. doi:10.1111/1468-0009.00170.
- Nicholson, C., C. Jackson and J. Marley. 2013. "A Governance Model for Integrated Primary/Secondary Care for the Health-Reforming First World – Results of a Systematic Review." *BMC Health Services Research* 13: 528. doi:10.1186/1472-6963-13-528.
- Ontario Government. 2017. *Population Projections for Each Local Health Integration Network*. Retrieved April 6, 2018. <<https://www.ontario.ca/data/population-projections>>.
- Patterson, C., S. Gauthier, H. Bergman, C. Cohen, J.W. Feightner, H. Feldman et al. 2001. "The Recognition, Assessment and Management of Dementing Disorders: Conclusions from the Canadian Consensus Conference on Dementia." *Canadian Journal of Neurological Sciences* 28(1 Suppl.): S3–S16.
- Pimlott, N.J., M. Persaud, N. Drummond, C.A. Cohen, J.L. Silvius, K. Seigel et al. 2009. "Family Physicians and Dementia in Canada. Part 2. Understanding the Challenges of Dementia Care." *Canadian Family Physician* 55(5): 508–09.
- Pimlott, N.J.G., K. Siegel, M. Persaud, S. Slaughter, C. Cohen, G. Hollingworth et al. 2006. "Management of Dementia by Family Physicians in Academic Settings." *Canadian Family Physician* 52(9): 1108–09.

- Ranmuthugala, G., J.J. Plumb, F.C. Cunningham, A. Georgiou, I. Westbrook and J. Braithwaite. 2011. "How and Why are Communities of Practice Established in the Healthcare Sector? A Systematic Review of the Literature." *BMC Health Services Research* 11: 273. doi:10.1186/1472-6963-11-273.
- Resnick, B., C. Quinn and S. Baxter. 2004. "Testing the Feasibility of Implementation of Clinical Practice Guidelines in Long-Term Care Facilities." *Journal of the American Medical Directors Association* 5(1): 1–8. doi:10.1016/S1525-8610(04)70037-7.
- Samsi, K. and J. Manthorpe. 2014. "Care Pathways for Dementia: Current Perspectives." *Clinical Interventions in Aging* 9: 2055–2063. doi:10.2147/CIA.S70628.
- San Martin-Rodriguez, L., M.D. Beaulieu, D. D'Amour and M. Ferrada-Videla. 2005. "The Determinants of Successful Collaboration: A Review of Theoretical and Empirical studies." *Journal of Interprofessional Care* 19(Suppl. 1): 132–47. doi:10.1080/13561820500082677.
- Scott, I. 2008. "Chronic Disease Management: A Primer for Physicians." *Internal Medicine Journal* 38(6): 427–37. doi:10.1111/j.1445-5994.2007.01524.x.
- Scott, T., R. Mannion, H.T. Davies and M.N. Marshall. 2003. "Implementing Culture Change in Health Care: Theory and Practice." *International Journal for Quality in Health Care* 15(2): 111–18.
- Seniors Care Network. 2014. *Gerontological Training Needs Assessment Final Report*. Retrieved April 6, 2018. <<http://seniorscarenetwork.ca/wp-content/uploads/2015/03/3.1.4Seniors-Care-Network-Training-Needs-Assessment-Report-FINAL-2014.pdf>>.
- Seniors Care Network. 2015. *Geriatric Assessment and Intervention Network (GAIN)*. Retrieved April 16, 2018. <<http://seniorscarenetwork.ca/programs-initiatives/programs/geriatric-assessment-and-intervention-network/>>.
- Statistics Canada. 2013a. *Central East (Health Region), Ontario and Ontario (table). Health Profile. 2011 Census. Statistics Canada Catalogue No.82-228-XWE*. Ottawa, ON, Statistics Canada. Retrieved April 6, 2018. <<http://www12.statcan.gc.ca/health-sante/82-228/details/page.cfm?Lang=E&Tab=1&Geo1=HR&Code1=3509&Geo2=PR&Code2=35&Data=Rate&SearchText=Central%20East&SearchType=Contains&SearchPR=01&B1=All&Custom=&B2=All&B3=All>>.
- Statistics Canada. 2013b. *Champlain (Health Region), Ontario and Ontario (table). Health Profile. 2011 Census. Statistics Canada Catalogue No. 82-228-XWE*. Ottawa, ON.
- Statistics Canada, 2016 Census Profile, Northumberland County. Retrieved April 30, 2019. <<https://www12.statcan.gc.ca/census-recensement/2016/dp-pd/prof/details/page.cfm?Lang=E&Geo1=CD&Code1=3514&Geo2=PR&Code2=35&SearchText=Northumberland&SearchType=Begins&SearchPR=01&B1=All&GeoLevel=PR&GeoCode=3514&TABID=1&type=0>>.
- Stolee P., J. Elliott, H. McNeil, V. Boscart, G.A. Heckman, R. Hutchinson et al. 2015. "Choosing Healthcare Options by Involving Canada's Elderly: A Protocol for the CHOICE Realist Synthesis Project on Engaging Older Persons in Healthcare Decision-Making." *BMJ Open* 5:e008190. doi: 10.1136/bmjopen-2015-008190.
- Stolee, P., J. Esbaugh, S. Aylward, T. Cathers, D.P. Harvey, L.M. Hillier et al. 2005. "Factors Associated with the Effectiveness of Continuing Education in Long-Term Care." *The Gerontologist* 45(3): 399–26. doi:10.1093/geront/45.3.399.
- Tan, Z.S., L. Jennings and D. Reuben. 2014. "Coordinated Care Management for Dementia in a Large Academic Health System." *Health Affairs* 33(4): 619–25. doi:10.1377/hlthaff.2013.1294.
- Wenger, E., R.A. McDermott and W.M. Synder. 2002. *Cultivating Communities of Practice: A Guide to Managing Knowledge*. Boston, MA: Harvard Business School Press.
- Wandersman, A., J. Duffy, P. Flaspohler, R. Noonan, K. Lubell, L. Stillman et al. 2008. "Bridging the Gap between Prevention Research and Practice: The Interactive Systems Framework for Dissemination and Implementation." *American Journal of Community Psychology* 41(3-4): 171–81. doi:10.1007/s10464-008-9174-z.



Innovative Model of Interprofessional Geriatric Consultation: Specialized Seniors Clinics



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Abstract

As the Canadian population ages, healthcare systems have become increasingly interested in exploring new ways to deliver services to frail older adults, and in particular older adults with dementia. The Specialized Seniors Clinics (SSCs) are an innovative integrated network of six outpatient clinics in BC's Fraser Health Authority that utilize interprofessional teams to provide comprehensive geriatric assessments and care planning for frail older adults. The SSCs provided approximately 19,000 appointments in the past fiscal year, and clients and primary care physicians are highly satisfied with the model. This article describes the SSC model and provides reflection on the model development, implementation and standardization processes.

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Introduction

As the Canadian population ages, the health of older adults is becoming an increasingly important focus for healthcare systems. Frailty is generally used to describe vulnerable older adults who have limited health reserves and are at increased risk for adverse health outcomes (Hamerman 1999). Dementia shares a complex relationship with frailty and they are often found together as comorbid conditions (Sampson 2012). Dementia is currently a major concern for healthcare systems, and by 2038, it has been estimated that more than 1 million Canadians will have some form of dementia (Smetanin et al. 2009). For dementia, early diagnosis, treatment and follow-up are key to providing effective care (Leifer 2003); however, challenges in managing and diagnosing dementia may be encountered such as needing appointments of longer duration and difficulty accessing specialists (Hinton et al. 2007).

Fraser Health Authority has developed a Specialized Seniors Clinic (SSC) model, which is a secondary outpatient healthcare delivery model. The SSC model has been developed to support primary care and meet the needs of frail older adults who have dementia or multiple/complex healthcare needs. There are three key components to the SSC model: integrated care, interprofessional teams and comprehensive geriatric assessment and care planning. The development of the SSC model was unique in that it involved taking six already existing clinics providing similar services and standardizing them into an integrated network. Important enabling factors for this process included having strong leadership, capitalizing on windows of opportunity for change and the use of information technology. Challenges that were encountered included resistance to change and differing care philosophies, competition for resources and the equity of resources among clinics (e.g., differences in

staffing). The purpose of this article is to share the SSC model and provide reflection on the development of the model.

Setting and Policy Context

Fraser Health Authority is responsible for providing healthcare services to more than 1.6 million people living in the province of British Columbia (BC), of which approximately 16.1% (249,250) are aged 65 and over (Health & Business Analytics, Fraser Health Authority 2012). The age-specific prevalence rate for dementia in Fraser Health in 2008/2009 was estimated at 6.1%, amounting to approximately 17,000 people (Decision Support Services 2010).

For 2014-2017 Fraser Health has identified ten priority actions to guide organizational improvements, including capacity and patient centeredness (Fraser Health 2014). The SSCs are one way that Fraser Health is working towards meeting these strategic priorities, and these goals fit within the wider provincial objective of the BC Ministry of Health for dementia care and increased integration of primary and community care.

Conceptual Background

Increasingly, in recent years, healthcare systems have been turning to the concept of integrated care to improve their delivery of services through strategies aimed at increasing the continuity and collaboration between services/care providers. For older adults with dementia, Callahan et al. (2009) have recommended the use of integrated care for a number of reasons including existence of comorbid conditions and requirement of large amounts of healthcare resources. The SSC model combines a number of the strategies of integrated care, most notably of which are the use of interprofessional teams and comprehensive geriatric assessments.

Interprofessional collaboration “involves the continuous interaction of two or more

professionals or disciplines, organized into a common effort to solve or explore common issues, with the best possible participation of the patient” (Barrett et al. 2007: 1). The American Geriatrics Society has recommended the use of interdisciplinary care for older adults with complex needs (Geriatrics Interdisciplinary Advisory Group 2006).

Comprehensive geriatric assessments are useful for older adults because they often have complex, multi-system conditions that require a range of biopsychosocial interventions (Stuck and Iliffe 2011). Comprehensive geriatric assessments have been found to produce a number of benefits for older adults, including increased likelihood of remaining in the home, decreased functional decline and improved cognition (Ellis et al. 2011).

SSC Model

The SSCs are secondary outpatient services that provide interprofessional consultation services for frail older adults. The focus of SSC services includes early diagnosis of dementia, assessment of complex medical and comorbidities, and development of an interprofessional Health Improvement Plan (HIP). Currently there are six SSCs operated by Fraser Health (Abbotsford, Delta, Mission, New Westminster, Surrey and White Rock). All of the SSCs are co-located with, or have a close working relationship with, a nearby acute care hospital. The Older Adult Program within Fraser Health is responsible for overseeing the management and operation of the SSCs, and four SSC managers are responsible for the clinics. The clinics vary in size, resources and the composition of their interprofessional teams, but they all share the same principles and goals, and operate under the same service delivery model. The SSC model is based on four principles of care: (1) client-centred care, (2) evidence-based clinical practice, (3) integrated care and (4) elder-friendly environment.

Target Population

The target population for SSC services are frail older adults with undiagnosed cognitive impairments or other complex medical conditions. The majority of referrals to SSCs come from primary care physicians (PCPs) who require specialized geriatric expertise for their clients. The primary reason for client referral to the SSCs is memory/cognitive changes, accounting for more than 60% of referrals.

Interprofessional Teams

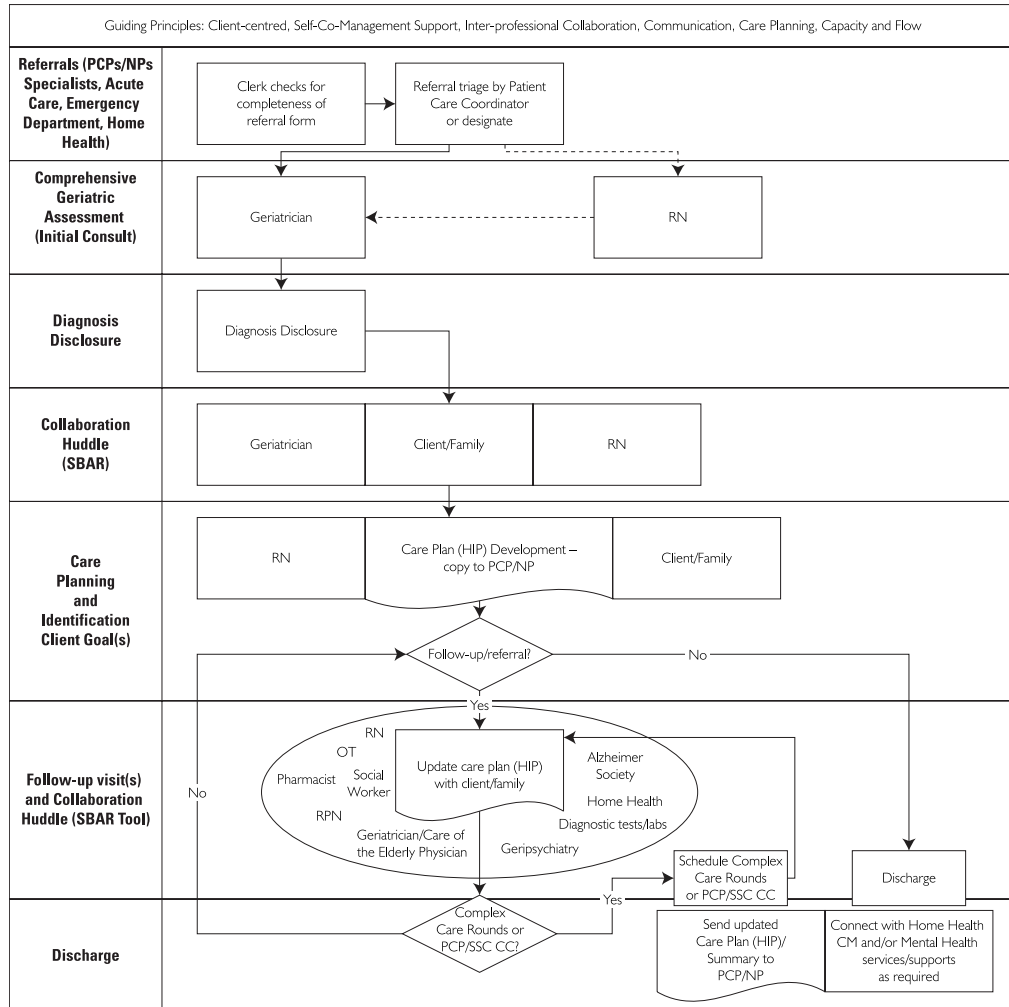
The core members of the teams are a geriatrician/care of the elderly physician, patient care coordinator, registered nurse and clerk. Composition of the SSC interprofessional teams varies by location, and additional team members may include geriatric psychiatrist, occupational therapist, physiotherapist, social worker, pharmacist and dietician. The patient care coordinator is responsible for organizing the interprofessional team and managing day-to-day operations of the SSC. The patient care coordinator is also responsible for screening and triaging the clients who are referred to the clinic. New clients undergo a comprehensive geriatric assessment and a HIP is then developed. Follow-up visits will be provided if required; however, during the period that the older adult is an SSC client regular, primary care is still delivered by their PCP. Figure 1 provides an overview of the SSC service delivery model.

Special Features of SSC Model

Capacity to Serve a Large Volume of Clients

The larger SSCs are open Monday through Friday, from 8:30 am to 4:30 pm (excluding statutory holidays). The smaller satellite clinics are open one to two days a week. For the fiscal year 2012–2013, the total number of attended appointments was approximately 19,000.

Figure 1. Care delivery model – Specialized Seniors Clinics



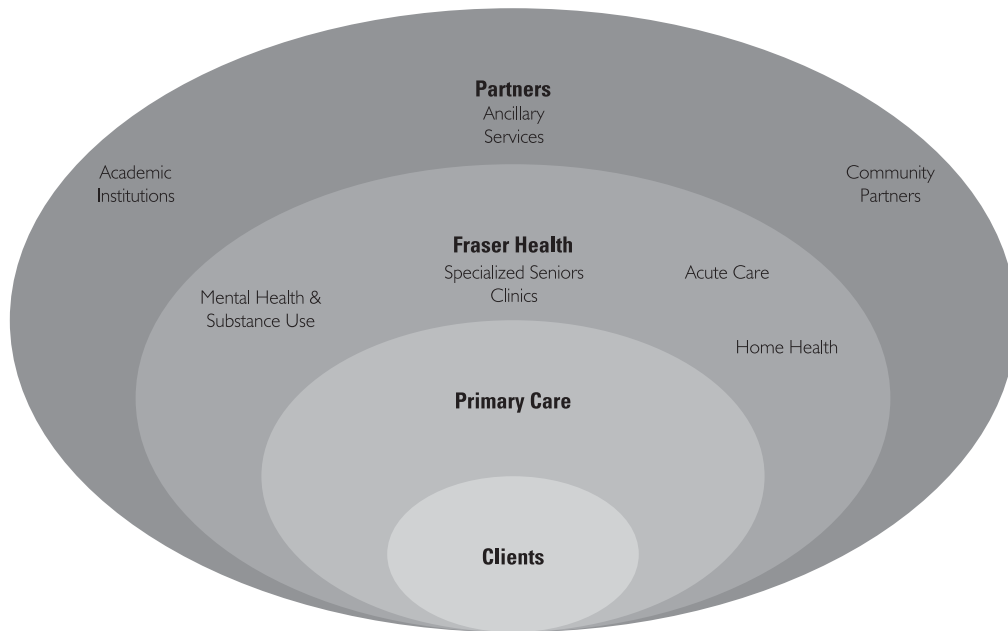
October 2014
 Abbreviations: RN (Registered Nurse), SBAR (Situation, Background, Assessment, Recommendation), HIP (Health Improvement Plan), OT (Occupational Therapist), RPN (Registered Psychiatric Nurse), CM (Case Manager), PCP (Primary Care Physician/NP), CC (Case Conferencing), NP (Nurse Practitioner)

Integrated Network of Services

The six SSCs currently operate together as part of an integrated network of services designed to support primary care. Extensive work has been undertaken to standardize operations within the clinics so they all currently operate under the same service delivery model. This has enabled the SSCs to maximize efficiencies by allowing staff to be floated between sites and also the co-location of positions. All of the clinics share the same electronic medical record system (Meditech), and clients can potentially

receive services at any clinic. The integrated network also allows the different SSC locations to collaborate with each other, and members of the different professions meet one or two times a month to discuss topics related to their practice.

The SSCs are also integrated within the wider healthcare system in Fraser Health. The SSC network has formed relationships with acute care, other Fraser Health programs, primary care and Divisions of Family Practice, external partners (e.g., community organizations, academic

Figure 2. SSC model

institutions, etc.) and ancillary services (e.g., laboratories, medical imaging, etc.; Figure 2). For example, a partnership is currently being developed between the SSCs and the Mental Health and Substance Use Program community geriatric mental health services at some locations to enable enhanced integration and communication on shared clients.

Client-Centred Care

The SSCs are committed to providing client-centred services by focusing on the needs of both clients and their families. Clients and their families play an important role in the development of the HIPs at the SSCs. In addition, the SSCs have recently introduced a client-focused screening questionnaire, and work is being done to develop chronic disease self/co-management programs to increase the involvement of clients in their care.

Educational Opportunities

The SSCs provide educational opportunities for their interprofessional team members

and other health professionals. For the SSC teams, a regional clinical nurse educator provides educational training, orientations and information on clinical decision support tools and organizes workshops.

Interprofessional team members also have opportunities to collaborate with and learn from each other, for example, through participation in complex care rounds. The SSCs serve as educational sites for the University of British Columbia Faculty of Medicine. Lectures, rotations for residents and fellows and clinical placements for other health professionals are offered at some SSC sites.

Model Development, Implementation and Standardization

Model Development

The catalyst for the development of the SSC model was the introduction of Program Management to Fraser Health, which occurred over the fall 2009/winter 2010 period. This led the six clinics, which had previously been separately managed and

unlinked, to fall under the management of the Older Adult Program. The decision was made to standardize the clinic models and give them the name Specialized Seniors Clinics, with the vision of creating an integrated network of services. The SSC model was grounded in evidence, and was based on resources such as the BC Expanded Chronic Care Model (Ministry of Health 2013) and consultations with the SSC teams. The SSC model cemented the SSCs as specialized secondary care providers, and strengthened the care planning and evaluative components of the service.

Model Implementation

Within the Older Adult Program, there was support from the Program Executive Director, Program Directors and Medical Director from the beginning, and leadership teams were established at various levels within the Older Adult Program to assist with the visioning and implementation process. It was also necessary to ensure that the physicians and interprofessional teams already working within the clinics supported the vision and had input in the planning. The Program Medical Director engaged with the physicians to ensure they were aware of the developments and provided feedback on the model development (later on a Regional SSC Physician and Clinical Leadership Committee was established). In the clinics, the interprofessional teams were consulted, and during the implementation phase, a clinical nurse specialist and clinical nurse educator spent a large amount of time working in the clinics to provide mentoring and ensure that the processes were working. Instituting change can be a difficult process, and while there was some resistance to change at first, this was overcome primarily through explanation and demonstration of the proposed changes. In addition, there was also a need to be flexible and allow for minor variations in the model, as the clinics had different resources in terms of space, staffing and technology.

Model Standardization

Standardization of the clinics was a key step for implementing the SSC model. A Frontline Leaders Group (consisting of the SSC managers, the clinical nurse specialist, the clinical nurse educator and the patient care coordinators) played a key role in this process. The first step for the clinics was to standardize their communication and referral processes. The movement of the Surrey SSC to the Jim Pattison Outpatient Care and Surgery Centre (JPOCSC) in the summer of 2011 was an important enabler for the standardization and introduction of new information technology to the SSCs. Resources were available in Fraser Health at this time to facilitate the opening of the new centre. At JPOCSC there were plans to introduce information technology such as community-wide scheduling and Meditech charting, which made it possible to introduce these at all the SSCs. When standardizing forms and information technology systems, it was necessary to at the same time be planning ahead for future data collection and evaluation needs, and forms had to be customized to collect specific evaluation data. From the summer of 2011 to the end of 2012, the staggered implementation of the SSC service delivery model took place. The SSC model has now been successfully implemented in all six of the SSCs, though there still remains some minor standardization work to be done.

Ongoing Operational Evaluations

Ongoing operational evaluations are currently being conducted at the SSCs. For example, continuous monitoring of the number of client appointments is occurring and targets are being set for yearly increases. In addition, the Plan-Do-Study-Act cycle is being used to guide the development of quality improvement initiatives. Implementation of the SSC model and standardization of the clinics was only completed recently, so system-level utilization impacts are not yet being measured for

clients, but collection of these data will be the next priority for the clinics. Examples of system-level impacts that have been previously explored in the literature on dementia patients and may be used to evaluate the SSCs include physician and specialist visits, hospitalizations, emergency department visits and use of community services and supports (Weber et al. 2011).

However, as many SSC clients are in the early stages of dementia, having a diagnosis and the appropriate supports provided may be the main benefits of SSC services. For these clients, system-level impacts may not be measurable until later stages of the dementia disease trajectory. The other benefits that may be derived from early dementia diagnosis and care planning include earlier initiation of acetylcholinesterase inhibitors therapy, providing clients with the opportunity to participate in planning for their future care, referral to community support services and exercise programs, relieving feelings of anxiety and uncertainty, allowing for future safety risks to be anticipated and mitigated and educating and preparing caregivers for their role (Leifer 2003). An important priority for the SSCs is to provide positive client experiences and client-centred care, and ongoing work is being done to measure the impacts of the SSCs at the client level. Recently, both client and PCP surveys were conducted and showed high levels of satisfaction with the SSCs.

In February 2013, 234 client satisfaction surveys were distributed to clients/family over a 12-day period, and 215 were returned. More than 90% of the clients were mostly satisfied or very satisfied that their care team listened to and understood their needs, were skilled and knowledgeable and involved the client and their family in decisions about their care. Being provided with a diagnosis and the tools and resources needed to manage their condition made clients feel more confident about managing their health.

One client commented “My concerns and questions were answered. I left the appointment feeling positive, informed and knowing my next steps.” Currently a client-focused screening questionnaire is also being trialed in the SSCs with the purpose of better addressing clients’ health concerns, and these questionnaires will be linked with quality-of-life evaluations.

The PCP surveys were distributed to PCPs in Fraser Health through the SSCs. A total of 450 surveys were distributed and 172 were returned over the period of May 1 to July 10, 2013. In the surveys, 91% of PCPs who had used the SSCs were very satisfied or satisfied with the service, and generally, PCPs found the SSCs to be a valuable resource.

Conclusion

The SSC model is built upon three key components that are strongly supported in the literature as crucial components for healthcare services for frail older adults: integrated care, interprofessional teams and comprehensive geriatric assessment and care planning. Now that the SSC model has been fully implemented, focus for SSC model development has primarily moved past standardization and towards sustainability, evaluating the model and finding opportunities for quality improvement. Three new innovations that are currently being trialed in the SSCs are: a partnership with the Mental Health and Substance Use program, development of chronic disease self/co-management programs and a trial of the client-focused screening questionnaire. In addition, clinics are developing slots for urgent referrals which would reduce acute congestion by pulling clients from emergency and/or allowing early discharge. In the future with aging populations, healthcare systems will be looking for innovative ways to provide services to frail older adults with dementia or other complex conditions. The SSC model is an example of

a successful way to support primary care and provide positive client outcomes by providing interprofessional geriatric consultation for frail older adults.

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References

- Barrett, J., V. Curran, L. Glynn and M. Godwin. 2007. CHSRF Synthesis: Interprofessional Healthcare and Quality Primary Healthcare. Ottawa, ON: Canadian Health Services Research Foundation. Retrieved July 15, 2013. <http://www.cfhi/cass.ca/Migrated/PDF/SynthesisReport_E_rev4_FINAL.pdf>.
- Callahan, C.M., M. Boustani, G.A. Sachs and H.C. Hendrie. 2009. "Integrating Care for Older Adults with Cognitive Impairment." *Current Alzheimer Research* 6(4): 368–74. doi:10.2174/156720509788929228.
- Decision Support Services. 2010. Seniors Health Profile 2010. Surrey, BC: Fraser Health. Retrieved July 15, 2013. <http://www.fraserhealth.ca/media/Seniors_Health_Profile_2010.pdf>.
- Ellis, G., M.A. Whitehead, D. Robinson, D. O'Neill and P. Langhorne. 2011. "Comprehensive Geriatric Assessment for Older Adults Admitted to Hospital: Meta-Analysis of Randomised Controlled Trials." *British Medical Journal* 343(7832), 1–10.
- Fraser Health. (2014). Strategic and Operational Plan 2014/15 - 2016/17. Surrey, BC: Fraser Health. Retrieved September 29, 2014. <http://www.fraserhealth.ca/media/FraserHealthStrategicOperationalPlan_2014-2017.pdf>.
- Geriatrics Interdisciplinary Advisory Group. 2006. "Interdisciplinary Care for Older Adults with Complex Needs: American Geriatrics Society Position Statement." *Journal of the American Geriatrics Society* 54(5): 849–52.
- Hamerman, D. 1999. "Toward an Understanding of Frailty." *Annals of Internal Medicine* 130(11): 945.
- Health & Business Analytics, Fraser Health Authority. 2012. *Health Profile 2012: A Snapshot of the Health of Fraser Health Residents*. Surrey, BC: Fraser Health.
- Hinton, L., C. Franz, G. Reddy, Y. Flores, R. Kravitz and J. Barker. 2007. "Practice Constraints, Behavioral Problems, and Dementia Care: Primary Care Physicians' Perspectives." *Journal of General Internal Medicine* 22(11): 1487–92.
- Leifer, B. 2003. "Early Diagnosis of Alzheimer's Disease: Clinical and Economic Benefits." *Journal of the American Geriatrics Society* 51: 281–88.
- Ministry of Health. 2013. "Expanded Chronic Care Model." Retrieved August 26, 2013. <http://www.primaryhealthcarebc.ca/resource_eccm.html>.
- Sampson, E.L. 2012. "Frailty and Dementia: Common but Complex Comorbidities." *Aging and Mental Health* 16(3): 269–72. doi:10.1080/13607863.2012.657158.
- Smetanin, P., P. Kobak, C. Briante, D. Stiff, G. Sherman and S. Ahmad. 2009. *Rising Tide: The Impact of Dementia in Canada 2008 to 2038*. Toronto, ON: RiskAnalytica.
- Stuck, A.E. and S. Iliffe. 2011. "Comprehensive Geriatric Assessment for Older Adults: Should be Standard Practice, According to a Wealth of Evidence." *British Medical Journal* (Overseas & Retired Doctors Edition) 343(7832): 1029–30. doi:10.1136/bmj.d6799.
- Weber, S., P. Pirraglia and M. Kunik. 2011. "Use of Services by Community-Dwelling Patients With Dementia: A Systematic Review." *American Journal of Alzheimer's Disease and Other Dementias* 26(3): 195–204.



Mending the Cracks: A Case Study in Using Technology to Assist with Transitional Care for Persons with Dementia



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Abstract

Transitions between hospital and community are particularly challenging for vulnerable adults experiencing behavioural and psychological symptoms (BPSD) of dementia. Too often, miscommunication results in triggering a recurrence of disruptive behaviours leading to frustration of staff and families. As part of the implementation of Health Quality Ontario (HQP) Quality Standards, this project



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involved improving transitions using an electronic-based care plan on a 23-bed geriatric dementia unit in a mental health hospital. “My Dementia Careplan,” is an interprofessional care plan that was developed in the electronic medical record (EMR) to enhance communication of information between healthcare providers when patients are being discharged to the community. It is written from the patient’s perspective in collaboration with the family and interprofessional team. It describes strategies to manage behavioural challenges along with the standardized tools to objectively monitor progress. This care planning will help to support transition of knowledge between hospital and community.

Background

Improving transitional care in adults with dementia has been identified as a priority for improving health system outcomes (Chenoweth et al. 2015). Transitional care is defined as, “the actions involved in coordinating care for patients as they move through the health care system” (Epstein-Lubow et al. 2010). Research has found that care transitions in adults with dementia are associated with an increase in poor outcomes such as early readmission, mortality, change in behaviour or functional status and caregiver satisfaction (Tsilimingras et al. 2009). Despite the need to identify ways to improve transitional care for adults with dementia, there have been few transitional care practices developed for this population (Fortinsky and Downs 2014).

As dementia progresses, impaired cognition reduces an individual’s ability to communicate their needs or comprehend what is going on around them, making these patients very vulnerable during transitions (Kable et al. 2015). Risk increases when there are multiple transitions from hospital to community because of the need for symptom management for behavioural and psychological symptoms of dementia (BPSD) such as verbal agitation, intrusiveness, wandering, resisting care or physical aggression (Ray et al. 2015). For these reasons, it has been found that the complex nature of dementia requires transitional care with both higher levels of

coordination and improved communication during the discharge process to improve outcomes (Chenoweth et al. 2015; Epstein-Lubow et al. 2010).

Electronic medical records (EMR) have been found to enhance communication during transitions in care (Tsilimingras and Bates 2008). The use of an EMR-based interprofessional plan of care has been suggested as a tool that can improve communication during transitions (Dykes et al. 2014). Traditionally, the plan of care has been developed by a single discipline within a specific healthcare setting and as patients are transferred from one setting to another, a new plan of care is developed (Dykes et al. 2014). During these transitions, gaps in communication including incomplete, inaccurate or delayed information are associated with threats to patient safety (Dykes et al. 2014; Tsilimingras et al. 2009). The use of an EMR-based interprofessional plan of care has several advantages because it is developed by multiple disciplines and can pull together various elements that are relevant to the new care setting (Dykes et al. 2014). This provides information to the new setting that is accurate and readily available.

Health Quality Ontario (HQP) has developed Quality Standards for the Behavioural Symptoms of Dementia care for patients in hospitals and residents in long-term care homes (Health Quality Ontario 2016). This quality standard identifies 14 key

quality statements as having a significant potential for improvement in the quality of care for older adults living with dementia and experiencing symptoms of agitation or aggression. In 2016, Ontario Shores Centre for Mental Health Sciences committed a corporate goal to implement the HQO Quality Standards for the Behavioural Symptoms of Dementia Care. As part of this larger project, there was a focus on creating dementia-specific strategies to enhance seamless communication in an effort to improve transitional care of older adults with dementia as they are discharged back to the community. To achieve this goal, two HQO quality standards were used to provide the benchmark to improve transitional care; Individualized Care Plan and Transitions in Care. The objectives to meet these standards were to: (1) customize the EMR to create a dementiaspecific interprofessional care plan; and (2) use the EMR to facilitate an accurate and timely transition of information to community healthcare providers. This case study describes the development of these objectives in a specialized mental health hospital to meet the HQO Quality Standards and improve transitional care in adults with dementia experiencing BPSD. Key success factors and challenges to implementation will be presented.

Intervention

Ontario Shores Centre for Mental Health Sciences (Ontario Shores) is a public teaching hospital that specializes in a range of specialized assessment and treatment services to individuals experiencing complex mental illness. In 2009, Ontario Shores implemented an electronic medical record (EMR) and has since become the first Canadian hospital to achieve HIMSS (Healthcare Information and Management System Society) Stage 7 status. HIMSS developed an eightstage Electronic Medical Record Adoption Model (EMRAM) to reflect the EMR capabilities in hospitals

ranging from completely paper-based (score 0) to highly advanced digital patient record (score 7) (Van Poelgeest et al. 2015). The Geriatric Dementia Unit (GDU) at Ontario Shores is a 23-bed inpatient unit that specializes in the mental health needs of individuals living with dementia and experiencing challenging behaviours such as agitation and aggression. Ontario Shores is guided by the overarching philosophy of the Interprofessional Collaborative Recovery Model based on the principles of empowerment, hope, recovery, collaboration, identity, responsibility and meaning in life (Oades et al. 2009).

A documentation working group was established to focus on meeting the two HQO standards. It reported to an overall advisory group that was responsible for implementing all 14 of the HQO standards. The documentation working group comprised an interprofessional team of eight individuals, including: professional practice leaders (2), clinical nurse specialist in dementia (1), nursing (RN/RPN) (2), decision support (1), social work (1) and a clinical manager (1). The other working groups involved in the overall implementation of the HQO standards focused on: physician processes, education and training, outpatient and behavioural approach.

Objective 1: Dementia-specific interprofessional care plan

One of the key goals of the team was to design one dementia-specific care plan that could be documented against by the entire interprofessional team, including physicians, nurses (RN and RPN), occupational therapy and others. This was a change from the previous care plan functionality that because of the EMR design limited documentation accessibility to nursing and allied health professionals. The previous care plan also had multiple care plans for different types of medical and psychiatric goals. The aim of having an interprofessional care plan

was to promote effective communication among the team and enhance consistency in interventions. In addition, by integrating all medical and psychiatric care into one care plan, it would be simpler for staff to use and navigate.

To inform the content of a dementia-specific care plan, the working group reviewed and appraised the recommendations from The National Institute for Health and Care Excellence (NICE) guideline for, “Dementia ... supporting people with dementia and their carers in health and social care” (National Collaborating Centre for Mental Health [UK] 2007). Specific recommendations from this guideline were selected by the working group relevant to the needs of patients in a tertiary care specialized dementia unit (i.e., recommendations related to prevention or early identification were not reviewed). A gap analysis compared current care plan content and processes to the NICE guideline recommendations. Current care plan content and processes that were not aligned with the NICE recommendations were identified and a plan was developed to address these gaps and to implement them into the EMR.

A second area of focus was to integrate standardized clinical practice guideline (CPG) assessment tools into the care plan. Although the use of standardized assessment tools was well established on the unit, they were still stand-alone templates in the EMR or paper form. By customizing the EMR to integrate standardized assessment tools scores into the care plan, the results of the standardized assessment tools could directly inform the care plan. Based on the CPG assessment, standardized tools were identified, and permissions were obtained to reproduce them in the EMR. Requirements for the frequency of tool completion were built into the EMR based on the individual tool specifications and the working group consensus where appropriate (e.g., Cornell scale is assigned a frequency for completion

of every 7 days). This design provided a prompt whereby clinical staff would be notified when a standardized tool required completion.

A third focus of the care plan development was to develop a structured process to include family and Substitute Decision Makers (SDMs) in the phases of plan development, plan review and information to be transferred at discharge. Prior to this project, families and SDMs were key informants in the development of care plan goals; however, the working group determined that this process needed to be formalized with the use of the EMR to ensure consistency. As a result, an EMR template was developed to guide family meetings and to document their input and consent into the care plan.

Objective 2: Ensure the accurate and timely transition of knowledge to community healthcare providers

To provide the most accurate information, a new prompt needed to be added to the EMR to notify the interprofessional team to update the care plan just prior to discharge. Coordination of the discharge required a template to be built into the EMR with accountability for completion assigned to the social worker who was already the most involved in the discharge process. This template was designed primarily for documentation and communication of key care plan details regarding the transition between the team, community long-term care (LTC) and family/SDM in the form of an in-person or telephone conference. It also prompted the transfer of the care plan immediately upon discharge to enrolled community LTCs and the family/SDM through the Patient Portal.

Results

Objective 1: Dementia-specific interprofessional care plan

“My Care Plan: Dementia” was the name

Table 1. My care plan: dementia assessment and care planning domains

My behavioural needs
My physical health issues
My risk needs
My activities of daily living (ADL) needs
My quality of life/risk
My caregiver needs
My transition to the community status
Care plan reviewed
Care plan updated

Table 2. My care plan: dementia standardized assessment tools

Standardized assessment tools incorporated into my care plan: dementia	Description
Barthel Index	Activities of daily living
PAINAD	Pain
Choking	Choking risk
Falls	Falls risk
Braden scale	Predicting pressure ulcer risk
Holden	Communication scale
CAM	Delirium screening
Cornell	Depression in dementia
NPI-NH	Neuropsychiatric symptoms
Zarit	Caregiver burden

given to the new EMR interprofessional care plan that can be accessed and documented by the entire interprofessional team (nurses, allied health professionals and physicians). It is built as a single document that incorporates assessment and care planning within seven domains (Table 1). To align with the Interprofessional Recovery Model, the care plan was written in the first person to empower individuals with dementia to actively identify and participate into their care plan. The care plan is reviewed by nursing staff each shift and by the interprofessional team every 28 days during pre-scheduled patient conferences.

The gap analysis relative to the NICE guidelines, identified several areas that required action to be in aligned with same.

The additional items that were relevant to the development of the care plan included:

- expansion of admission documentation;
- creation of an incontinence template;
- addition of pain assessment;
- cognitive testing;
- build of interprofessional consult referral;
- carer assessment.

Several other items in the NICE guidelines such as capacity assessment, medical investigation and mental status exam had previously been integrated into the EMR and did not require any further action.

Standardized tools were reviewed and chosen by the working group based on evidence of reliability and validity, feasibility, ability to reproduce in the EMR and cost. After receiving permissions, several standardized tools were reproduced in the EMR and integrated into the assessment (Table 2).

A family meeting template was developed to capture relevant information from family meetings and to collaborate in the care plan and treatment goals. In addition, the family meeting template provides an area to document that the care plan has been reviewed with family/SDM. Family meetings are conducted within the first two weeks of admission, as needed for the duration of hospitalization and then again prior to discharge.

Objective 2: Ensure the accurate transition of information to community healthcare providers

A new pre-discharge order set was developed in the EMR that includes a repeated list of standardized assessment measurement to inform readiness for discharge. The scores from the repeated standardized assessment tools are automatically updated in *My Care Plan: Dementia* and sent to the LTC facility by printed form, by fax or by patient portal.

This process provides LTC providers with accurate and updated patient information. The transition process is initiated early in admission with a meeting (telephone or in-person) scheduled with the discharge facility to begin planning for discharge. Another meeting is arranged 1–2 weeks prior to discharge with the patient, family, LTC and community supports (Community Care Access Centre [CCAC], Ontario Shores Community Outreach Team, Psychogeriatric Resource Consultants). This final meeting provides an opportunity to transfer knowledge, progress, interventions and care strategies, and to identify proactive approaches to ensure a smooth transition.

To facilitate discharge, a new discharge checklist template was created. The discharge checklist is completed by the social worker with prompts to have a pre-discharge conference if required (including LTC and family/SDM) and to share information with family and the LTC providers. Completion of the checklist triggers the Health Information Management (HIM) department to send a current copy of *My Care Plan: Dementia* to the LTC facility and prompts the sending of physician discharge summaries.

Discussion

This case study describes the development of a dementia-specific care plan and transition process using the EMR to improve communication during transitions from hospital to community. Improving communication between healthcare facilities has been identified as an important mechanism to reduce gaps when transitioning individuals with dementia (Chenoweth et al. 2015). Although models of transitional care have been developed for other chronic health conditions, they rely on the patient to be an active participant in the process (Chenoweth et al. 2015; Farris et al. 2017). With the limited cognitive capacity of individuals with more severe dementia, this is not possible and often the responsibility to inform care transitions falls to the family (Chenoweth et al. 2015; Grealish et al. 2013). By customizing the EMR, the care plan and transition process can be adapted to enhance communication and better meet the specific needs and challenges of individuals with dementia.

There were several key factors that were important to successfully develop the dementia specific care plan and effectively inform the transition process. Other diagnosis specific care plans were subsequently developed within the organization using these principles. The key considerations for success in this work include:

1. Establishment of a governance structure: This project had senior leadership support as a corporate goal and the commitment of key resources within the organization. The governance structure with Advisory Group Leadership, inter-professional working groups and subgroups expedited decision-making and the clear division of responsibilities. The inclusion of both administrative and clinical staff in the working groups and subgroups created a better understanding of the impact of EMR changes on clinicians.
2. The development of an interprofessional care plan placing the patient at the centre with the entire team working together to achieve the patient's goals: Having one inter-professional care plan also consolidates care plan information providing greater consistency in approaches to care by team members.
3. The integration of assessments and interventions into one care plan: By using an EMR, standardized tools were integrated into the assessment process and informed the identification of interventions. Creating frequencies (qshift, qweek, q28 days etc.) provided a structured process for re-assessment, tracking progress and re-evaluation of interventions. Prior to discharge, all the standardized assessments are repeated to provide another measure of patient progress and benchmarks that help to identify any changes that occur during the transition process.
4. Strong communication between hospital and LTC facilities using both an EMR-based care plan and a transition process that includes conferences with patients, family/SDM and community providers, and

provides a comprehensive approach to the transfer of knowledge: In addition, transferring the inter-professional care plan alleviates the need to develop an entirely new care plan and promotes consistency in approach.

5. To align with Ontario Shores recovery philosophy, the care plan is written in the first person: By writing the care plan in the first person, people with dementia are given a voice in the identification of goals and interventions. It also allows staff to consider the daily care and management of BPSD from the patient's perspective. This reinforces the individualization of the care plan, an important part of the HQO Quality Standard.

There were some key challenges associated with the implementation of this project.

1. As with any new clinical process, change management is a vital component. Although staff was engaged early in the project and part of the change management process, competing projects often imposed increase work demands. In the case of this project, temporary increases in staffing levels were used to manage the change process.
2. Evaluating the effectiveness of transitional care is challenging because no objective measures are available (Coleman 2003). The team has now engaged our research department and will begin a study to measure the efficacy of incorporating video clips along with the care plan to support transitions in care.

Conclusion

This case study describes a mental health hospital's use of the EMR to develop a

dementia care plan and transition process. As the healthcare system continues to find new ways to meet the needs of a growing population of adults with dementia, using technology is an important means to facilitate and inform care.

References

- Chenoweth, L., A. Kable and D. Pond. 2015. "Research in Hospital Discharge Procedures Addresses Gaps in Care Continuity in the Community, but Leaves Gaping Holes for People with Dementia: A Review of the Literature." *Australasian Journal on Ageing* 34(1): 9–14. doi:10.1111/ajag.12205.
- 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): 549–55. doi:10.1046/j.1532-5415.2003.51185.x.
- Dykes, P.C., L. Samal, M. Donahue, J.O. Greenberg, A.C. Hurley, O. Hasan et al. 2014. "A Patientcentered Longitudinal Care Plan: Vision Versus Reality." *Journal of the American Medical Informatics Association* 21(6): 1082–90. doi:10.1136/amiajnl-2013-002454.
- Epstein-Lubow, G., A.T. Fulton, R. Gardner, S. Gravenstein and I.W. Miller. 2010. "Post-hospital Transitions: Special Considerations for Individuals with Dementia." *Medicine and Health, Rhode Island* 93(4): 125.
- Farris, G., M. Sircar, J. Bortinger, A. Moore, J.E. Krupp, J. Marshall et al. 2017. "Extension for Community Healthcare Outcomes—Care Transitions: Enhancing Geriatric Care Transitions Through a Multidisciplinary Videoconference." *Journal of the American Geriatrics Society* 65(3): 598–602. doi:10.1111/jgs.14690.
- Fortinsky, R.H. and M. Downs. 2014. "Optimizing Person-Centered Transitions in the Dementia Journey: A Comparison of National Dementia Strategies." *Health Affairs* 33(4): 566–73. doi:10.1377/hlthaff.2013.1304.
- Grealish, L., M. Jamieson, J. Brown, B. Draper, B. Moore, M. Proctor and D. Gibson. 2013. *The Interaction between Hospital and Community-based Services for People with Dementia and their Carers*. Sydney, AU: Alzheimer's Australia NSW.
- Health Quality Ontario (HQP). 2016. *Quality Standards Behavioural Symptoms of Dementia: Care for Patients in Hospitals and Residents in Long-Term Care Homes*. Toronto, ON: Author.
- Kable, A., L. Chenoweth, D. Pond and C. Hulleck. 2015. "Health Professional Perspectives on Systems Failures in Transitional Care for Patients With Dementia and their Carers: A Qualitative Descriptive Study." *BMC Health Services Research* 15: 567. doi:10.1186/s12913-015-1227-z.
- National Collaborating Centre for Mental Health (UK). 2007. *Dementia: a NICE-SCIE Guideline on Supporting People with Dementia and their Carers in Health and Social Care* (Vol. 42, No. 42.). Leicester; London, UK: British Psychological Society.
- Oades, L.G., T.P. Crowe and M. Nguyen. 2009. "Leadership Coaching Transforming Mental Health Systems from the Inside Out: The Collaborative Recovery Model as Person-Centred Strengths Based Coaching Psychology." *International Coaching Psychology Review* 4(1): 25–36.
- Ray, C.A., V. Ingram and J. Cohen-Mansfield. 2015. "Systematic Review of Planned Care Transitions for Persons with Dementia." *Neurodegenerative Disease Management* 5(4): 317–31. doi:10.2217/nmt.15.23.
- Tsilimingras, D. and D.W. Bates. 2008. "Addressing Postdischarge Adverse Events: A Neglected Area." *Joint Commission Journal on Quality and Patient Safety/Joint Commission Resources* 34(2): 85.
- Tsilimingras, D., B.-S. Kenneth and R. Brooks. 2009. "Postdischarge Adverse Events in the Elderly." *Journal of Patient Safety* 5(4): 199–242.
- Van Poelgeest, R., J.-P. Heida, L. Pettit, R.J. de Leeuw and G. Schrijvers. 2015. "The Association between eHealth Capabilities and the Quality and Safety of Health Care in the Netherlands: Comparison of HIMSS Analytics EMRAM data with Elsevier's 'The Best Hospitals' Data." *Journal of Medical Systems* 39(9): 90.

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