



Canadian Geriatrics Society

SHORT END OF THE STICK? HEALTH CARE INEQUITY IN A VULNERABLE POPULATION OF INDIVIDUALS WITH DEMENTIA

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Introduction

The first of the largest recent Canadian birth cohort—the baby boomers—turned 65 in 2011, and by 2015 Canada will have more individuals aged 65 years and over than it will under age 15¹ Dementia is one of the most significant causes of disability among Canadians 65 and over. People with dementia describe a loss of control and self-identify, as well as a range of emotions including anger, fear, shame, frustration, and stigmatization.² An early, accurate diagnosis of dementia and appropriate long-term management helps older adults and their caregivers to access health care and social resources that ensure an understanding of what to expect and the ability to create care plans that honour individual preferences expressed prior to significant declines in cognition.

Résumé

Au Canada, les premiers baby-boomers – la plus importante cohorte de naissances de l'histoire récente du pays – ont eu 65 ans en 2011; d'ici 2015, les Canadiens de 65 ans ou plus seront plus nombreux que les moins de 15 ans¹. La démence est l'une des premières causes d'invalidité chez les Canadiens de 65 ans et plus. En plus d'éprouver une perte de contrôle et d'identité, les personnes atteintes vivent toute une gamme d'émotions – colère, peur, honte, frustration – en plus de devoir affronter les préjugés². Un diagnostic précoce et précis de démence, suivi d'une prise en charge adéquate à long terme, aide les personnes âgées et ceux qui les soignent à avoir accès aux soins de santé et aux ressources sociales qui leur permettent de savoir à quoi s'attendre et d'établir des plans de soins en fonction des préférences personnelles exprimées avant un déclin important des fonctions cognitives.

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The Primary Care Physician and Dementia Care Guidelines

In Canada, primary care physicians are key contacts in establishing a diagnosis, managing the clinical aspects of dementia, and, ideally, connecting patients with community resources. Most primary care physicians do not have specialized geriatrics training and are unlikely to see more than a handful of incident cases of dementia in any given year. Given this, best practice dementia care guidelines can play an essential role in helping primary care physicians diagnose the condition and then make decisions around managing the care of their patients.

Over the past thirty years, several position papers and guidelines published in the US and Canada articulate steps involved in evaluating people suspected of having dementia and providing subsequent dementia care. Canada first produced national guidelines in 1989 through a national consensus conference of experts in geriatrics.³ The 2006 consensus conference resulted in a series of six papers detailing⁹ [risk factors](#), [diagnosing](#) and [managing mild cognitive impairment, mild to severe dementia](#), and the use of [pharmacological and non-pharmacological therapies](#).⁴⁻⁹

Despite a high degree of diagnostic accuracy when guidelines are applied, and despite evidence that adherence to guidelines can improve quality and outcomes for patients, reports of poor detection and inadequate management persist.^{10,11} Dementia is often underdiagnosed in primary care, with some estimating that as many as two-thirds of patients with dementia are not being identified.¹²⁻¹⁴ Busy primary care physicians have expressed concern regarding the lack of resources, expertise, and time to provide the level of dementia care required.¹⁰ In part this is due to the complexity faced through behavioural symptoms that accompany dementia, which tend to be outside the clinical expertise of physicians.¹⁵ Other [barriers](#) include physician gaps in knowledge, skills, and attitudes, as well as broader structural barriers.¹⁶ Given the challenges that physicians report facing, it became clear that a comprehensive portrait of how community-based primary care physicians practice dementia care, vis-a-vis published guidelines, was missing.

Wide Variations in Dementia Care—Lesson Learned

Our objective in a recently published systematic review¹⁷ was to understand the existing research literature on physician practice patterns associated with the care of people with dementia and to what extent it is consistent with published guidelines. We defined dementia care processes based on available national Canadian, American, and European dementia care guidelines. The types of processes were comprehensive, ranging from diagnostic services (i.e., conducting a formal cognitive status test, imaging, and blood work to exclude other causes of cognitive impairment), management

(i.e., implementing pharmacological and non-pharmacological interventions and counselling the patient and caregiver), and referrals (i.e., to community services and specialists), all of which are highly recommended for receiving good dementia care.

Our [results](#) demonstrate widespread variation in the proportion of physicians who report providing guideline-consistent dementia care. We saw a 24-fold difference (4–96%) in the percentage of physicians who report providing a formal memory test, required by guidelines for an accurate diagnosis of dementia. Given this is the most mature of all the dementia care processes, with a large number of formally validated tools, it was surprising that these values were not higher. Similar variations were seen in physicians who report using therapeutics (33–91%), making referrals to specialists (12–81%), and making referrals to community services (26–83%)—the former two being better able to assist in managing the more difficult symptoms of dementia. There was less variation in other services accessed and, encouragingly, exclusionary blood work and provision of counselling had reports of consistently high proportions of use.

The large variations in dementia care processes are eye-opening, because they indicate that patients are not receiving equitable or, in some cases, adequate care. This, in turn, can have significant consequences for the accuracy of their diagnosis, access to resources, management, and future outcomes of care. Indeed, recent data indicate that patients with a diagnosis of dementia account for the highest number of alternate level of care hospitalizations and length of stay.^{18,19} Early diagnosis and management of dementia, as well as crisis prevention, would therefore not only ensure better outcomes for patients but could also contribute to health care resource cost savings.

There are, however, some reasons to be cautious in interpreting these findings. There are several factors unrelated to physician practice that could contribute to the variation we noted, including geography, patient demographic characteristics, and changes in recommendations over time. The heterogeneity of study populations and settings made it impossible to assess these factors in the review. Perhaps more importantly, the guidelines do not recommend that all patients newly diagnosed with dementia receive the services outlined. For example, referrals to specialists are recommended only in cases where behavioural issues are not manageable or diagnosis is unclear or complex.²⁰ As well, all the studies were self-reported cross-sectional surveys with associated biases and had varying sampling strategies and sample sizes.

As a counter to some of these limitations, we conducted an analysis of the provision of dementia care using population-based health care services use data in British Columbia.²¹ Using these comprehensive data allowed us to assess the dementia care processes in more depth

while also being able to adjust for patient demographic factors that may contribute to any observed variation. This is, we believe, the first study to look at primary care practice patterns using administrative, rather than survey, data. Similar work is ongoing with electronic medical records, which will help corroborate results.

Persisting Patterns of Inequality

Our population-based study of community-dwelling seniors demonstrates that a high percentage of patients receive guideline-consistent laboratory tests and imaging, part of the diagnostic criteria for dementia, and part of the set of care processes expected to be more universally applied. In contrast, use of pharmacological interventions differ. Given the variable efficacy and sometimes serious side effects of the currently available treatments for dementia, it is not surprising that there is a general low use of cholinesterase inhibitors (donepezil, rivastigmine, and galantamine) and N-Methyl-D-aspartate (NMDA) inhibitor (memantine). However, over one-quarter of patients receive an antipsychotic (typical or atypical) and, despite cautions, a quarter received benzodiazepines.

These results are particularly compelling because they are limited to community-dwelling seniors. Physician practice patterns are different in long-term care settings, and rates of pharmacological interventions tend to be higher in this population because many have complex neuropsychiatric symptoms that prevent them from living in the community safely.²² Therefore, these results were not anticipated for community-dwelling seniors.

Literature around the off-label use of antipsychotics and benzodiazepines in seniors with dementia shows modest efficacy at best and, in the case of antipsychotics, an association with falls, increased risk of cerebrovascular adverse events, and increased risk of mortality.^{23–25} Measurements of the use of these drugs were during the initial diagnosis of dementia, at a time when it is not expected that neuropsychiatric symptoms would be fully manifest to justify the use of these therapeutics. [Alternative options](#) to control these behavioural symptoms include environmental interventions, such as verbal redirection, reassurance, reduced stimulus, and determining triggers and eliminating them, which require more frequent monitoring for effectiveness and adaption with the aid of specialists or community services.^{23,26,27} Indeed, our data reveal that people with lower income or those living in health regions with smaller urban centres, and potentially less access to specialists or specialized community services, are more likely to receive antipsychotics or benzodiazepines, pointing to a need to re-evaluate current prescription practices, education, and support for primary care physicians in these areas. One such resource can be found in an [earlier edition](#) of this journal.

Finally, the overall rates for dementia care management processes (specialist referrals, counselling, and in-office examination) were

also measured and found to be generally lower. More importantly, variation in these dementia care management processes were influenced by income and age. People in lower income categories were less likely to receive counselling or specialist referrals (compared to those in higher income categories), while those who were older were less likely to receive almost all the dementia care management processes. Given the multi-morbidity that occurs with advanced age, this variation was surprising, because in-office examinations, counselling, and referrals would allow physicians to better explore complex symptoms and alleviate potential pharmaceutical interactions while developing strategies to assist patients and their caregiver(s) in coping. It is possible that the severity of dementia at diagnosis, which we could not measure, plays a mediating role in the relation between age and these management care processes. As well, preference-sensitive decisions based on patient choice and relationships with physicians likely have a role. However, insofar as income and age are unrelated to patient need for service, these observations deserve further attention.

Conclusion

This systematic review demonstrates that self-reported dementia care practices by physicians have wide variability, particularly for the use of formal memory testing, therapeutics, and referrals to specialists or community services. This evidence was corroborated in our subsequent study using administrative data which show similar, varied use of pharmacological interventions and specialist referrals, along with in-office examinations and counselling. In particular, we observed patterns of antipsychotic and benzodiazepine prescription indicative of their use as substitutions for other types of social (non-pharmacological), rather than medical, care. Encouragingly, several other dementia care processes such as exclusionary blood work and imaging had relatively high proportions of use with less variation.

These results add to our understanding of physician dementia care practice patterns and highlight the gap between actual practice and guideline-recommended care. The lack of concordance despite evidence of better outcomes for patients continues to be a major issue. Several factors have been previously identified that include physicians' lack of awareness of guidelines, lengthy guidelines that are not user-friendly, perceived impracticality in some primary care settings, and potential lack of credibility due to the influence of the pharmaceutical industry.¹⁶ These results also have important implications, as they corroborate the qualitative literature around barriers to providing good dementia care. These barriers include inadequate time to fully explore issues during appointments, challenging behavioural symptoms, and problematic physician attitudes toward providing care to individuals with dementia, and they result in age discrimination, lack of interdisciplinary teams

to appropriately address the multifaceted psychosocial issues, and difficulty accessing community resources, which result in patterns of inequity.^{16,28,29}

If we are to see more physicians adopt guideline-consistent care for dementia patients, a reframing and refreshing of physician education may be necessary. Exposure needs to go beyond the pathophysiology and pharmacological treatment of dementia as a disease. Instead, education should emphasize dementia as a chronic, complex condition that can benefit from timely diagnosis, comprehensive biopsychosocial treatment, and management in the context of the patient's other conditions. Second, a shift in focus for guidelines needs to occur. Guidelines would be more effective if they provided more detail around long-term management. For example, physicians should be provided with evidence-based, relevant environmental interventions for behavioural symptoms, which are often the most difficult management aspect of dementia.^{26,30}

These results indicate a need to recognize that primary care physicians alone may not be able to provide adequate dementia care and that more resources are needed to support them. Patients living at home require a cooperative and coordinated response from physicians, home, community care, and social services.³¹ Fortunately, several promising models of care have been piloted and may provide a useful foundation. Case management programs that provide individualized, flexible responses to people's needs by integrating care across clinical and social services with high-intensity support have been shown to be particularly effective when appropriately implemented.³² These programs often include collaborative interdisciplinary teams, with the primary care physician at the core and other service providers, such as social workers, psychiatrists, and advanced practice nurses, helping to assess and monitor care. Collaborative interdisciplinary teams have been piloted in multiple clinical trials and have yielded better outcomes relating to incidence of adverse behavioural symptoms, quality of patient care, caregiver health scores, and adherence to guidelines.^{33,34,35} Another example is the increased role of skilled staff such as physician assistants, care coordinators, and nurse practitioners in situations of workforce or financial limitations, thought to be particularly effective in rural settings in the absence of access to specialists or community resources.^{36,37}

The gap between actual practice and guideline-recommended care and variations in the use of services across patient characteristics say more about equity in health care services use and that the current system of care for individuals with dementia is not adequately addressing their needs. This signals barriers to care that need to be examined in more detail to develop appropriate evidence-based approaches that provide target resources to physicians, patients, and their caregivers.

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