



Addressing the needs of rural and remote people in a national dementia strategy for Canada

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Abstract

A number of organizations such as the Canadian Academy of Health Sciences have identified the growing need for a National Dementia Strategy in Canada to improve the quality of life for people with dementia. This commentary highlights the necessity of addressing stigma, social inclusion, and supports for people affected by dementia, specifically those living in rural and remote communities. Drawing on Saskatchewan-based examples, we discuss the importance of recognizing the unique needs of rural and remote communities in developing a National Dementia Strategy for Canada. We believe that a national strategy needs to be built from the ground up and not imposed from the top down. Only through the development of evidence-informed research and collaborative partnerships can we ensure that there is equitable access to services and supports for people with dementia in rural and remote communities.

Résumé

Des organismes comme l'Académie canadienne des sciences de la santé ont défini le besoin croissant d'une stratégie nationale sur la démence au Canada pour améliorer la qualité de vie des personnes qui en sont atteintes. Dans ce commentaire, nous soulignons la nécessité d'aborder la stigmatisation, l'inclusion sociale et les mesures de soutien aux personnes touchées par la démence, surtout en milieu rural et éloigné. En citant des exemples de la Saskatchewan, nous expliquons l'importance de reconnaître les besoins particuliers des milieux ruraux et éloignés dans l'élaboration d'une stratégie nationale sur la démence

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pour le Canada. Nous considérons qu'une stratégie nationale doit se construire à partir de la base et non du sommet. Ce n'est qu'en menant des études éclairées par les données probantes et en formant des partenariats de collaboration que nous garantirons un accès équitable aux services et aux mesures de soutien pour les personnes atteintes de démence en milieu rural et éloigné.

Keywords Dementia · Rural · Remote · Older adults

Mots-clés Démence · Milieu rural · Milieu éloigné · Personne âgée

Introduction

Across Canada, there is a growing call for a National Dementia Strategy to improve public awareness, reduce stigma, and effectively support people living with dementia and their families. Recently, the Canadian Academy of Health Sciences (CAHS 2019) released a report emphasizing the need to overcome stigma and improve quality of life for people affected by dementia. Despite this growing call, there is a paucity of evidence-based research to reduce stigma and support people with dementia living outside of large urban centres. More research is needed to better understand the unique needs of rural and remote people affected by dementia. In developing a National Dementia Strategy, it is essential to recognize that Canadians live in diverse communities. We believe that a national strategy needs to be built from the ground up and not imposed from the top down. Only through the development of evidence-informed research and collaborative partnerships, can we ensure that the needs of all people affected by dementia are addressed.

The case of Saskatchewan: where rural and remote still matter

In Saskatchewan, over 19,000 individuals live with dementia, and an estimated 60% of those individuals reside in their own homes (Kosteniuk et al. 2015). Rural communities are disproportionately affected by dementia as older adults in the province tend to reside in rural communities (Morgan et al. 2009). Outmigration of youth along with increasing life expectancy have contributed to Saskatchewan's aging rural population. For example, older adults comprise 22.4% of the population of towns and 21.7% of villages, compared with 14.7% of cities (Morgan et al. 2009). By 2038, dementia is expected to cost over \$35.9B in health and caregiver costs in Saskatchewan, and it is projected that community care will become the dominant mode of dementia care by 2028 (Smetanin and Kobak 2009). Addressing dementia supports is essential for improving health outcomes, quality of life, and savings for the health system.

In rural and remote communities in Saskatchewan, people with dementia and their caregivers who are currently accessing limited available resources are doing so at the point of crisis (Morgan et al. 2009). These seniors face unique barriers to accessing dementia care that are compounded by

limited finances, information, and transportation, as well as issues related to geographic distance (Forbes and Hawranik 2012). While only 18.9% of the Canadian population live in rural areas, this number rises to 33% in Saskatchewan (Statistics Canada 2011). This is complicated by the fact that the province has a low population density and covers a large geographic area. As the bulk of dementia supports and services exist in urban settings, this means rural and remote residents must either travel to access services or forego them. With the recent elimination of the Saskatchewan Transportation Company (a publicly owned intercity bus service), and the end of Greyhound Inc.'s western bus service, Saskatchewan no longer has any widely available road transportation service between communities. This makes access to dementia care for people in rural and remote communities even more difficult. Subsequently, the restricted availability of dementia care resources is expected to continue and may decrease social inclusion and impact the well-being of seniors with dementia and that of their care partners. For this population, the already challenging navigation required to access these supports will only increase.

Age is the greatest risk factor for developing dementia, and the number of Saskatchewan residents aged 65+ is rising. Currently, 15.5% of the rural population in Saskatchewan is comprised of older adults aged 65+ (Moazzami 2015). Population aging statistics show that older adults (65+ years old) now outnumber children (0–14 years old), and older adults are projected to increase to almost 25% by 2031 (Statistics Canada 2017). While rare, an estimated 2–8% of all dementia cases in Canada are young-onset dementia that occurs before the age of 65 (Alzheimer Society of Saskatchewan 2019). By 2038, an estimated 25,800 Saskatchewan residents will have dementia (Smetanin and Kobak 2009).

A recent study found that dementia and cognitive impairment are more prevalent among rural seniors than urban older adults (Weden et al. 2018). In Saskatchewan, seniors are more likely than younger persons to live in rural areas (Morgan et al. 2009). However, access to dementia services in rural and remote communities remains a substantial challenge (Standing Senate Committee on Social Affairs, Science and Technology 2016).

The unmet community needs of rural and remote people with dementia have severe consequences, including depression, shame, spousal hiding, social isolation, and suicide

(Alzheimer Disease International (ADI) 2016). Recently, a Leger survey for the Alzheimer Society of Canada found that almost 50% of Canadians would not want others to know they had dementia (Alzheimer Society of Canada 2017). Currently, a lack of dementia knowledge perpetuates stigma of dementia, especially outside of large urban centres (Forbes and Hawranik 2012). However, if these needs continue to go unmet, there are substantial implications that impact early dementia diagnosis, health service utilization, interactions with health providers, and caregiver burden.

There are significant consequences and an urgent need to reduce stigma and improve supports for people with dementia and their families. Some examples of consequences related to unmet needs of people affected by dementia include adverse health outcomes, social isolation, and care partner burnout (Alzheimer Disease International (ADI) 2016). However, with proper supports, people with dementia are able to remain within their own homes longer, and as many as 90% stay within their communities (Standing Senate Committee on Social Affairs, Science and Technology 2016).

Evidence-informed research and collaborative partnerships: a way forward

Supporting rural and remote people with dementia requires local input and innovation, and the development of evidence-informed research to address not only the biomedical determinants but also the social determinants of health such as education and culture. In particular, research is needed to examine the complex interactions between the different determinants of health to better address issues of social inclusion and stigma for rural and remote people living with dementia. Further research is also required to identify and assess the effectiveness of interventions for reducing dementia-related stigma.

The vast majority of services and programming for people living with dementia and their care partners will be financed by provincial governments and delivered by agencies of, or working on behalf of, those governments. What services get delivered where and how will depend on the specific configurations of need within and across each province. Any national strategy must take into account that these configurations of need will differ significantly across the country and be adaptable to those different circumstances.

Rural and remote people face unique barriers to accessing dementia care and supports, ranging from limited finances to inadequate public transportation. Despite these challenges, recent literature suggests that local knowledge and ingenuity within rural communities has led to creative solutions (Bacsu et al. 2017). Subsequently, collaboration with older adults affected by dementia can help to facilitate awareness, lived-experiences, and local insight to improve the quality of life for people with dementia and their families. Furthermore, partnerships with organizations such as the Alzheimer Society

of Saskatchewan (ASOS) and the Rural Dementia Action Research (RaDAR) Team provide education, information, networking, knowledge-exchange opportunities, and interventions to support people with dementia across the province. Some examples of ASOS interventions include a Dementia Friendly Communities initiative, a Warning Signs campaign, a Dementia Friends program, and a Dementia Helpline. The RaDAR Team provides a telehealth-assisted interdisciplinary Rural and Remote Memory Clinic to support people affected by dementia. In developing effective strategies to support rural and remote people affected by dementia, it is essential to engage in partnerships and collaboration. In moving forward, research is needed to examine ways of effectively engaging people with dementia in collaborative research, especially in rural and remote communities.

Conclusion

In Saskatchewan and most provinces across Canada, urgent action is required to support people affected by dementia, especially in rural and remote communities. While our discussion draws on Saskatchewan as a case study, other jurisdictions face similar situations across Canada. Addressing dementia-related stigma and improving supports for people with dementia is necessary to optimize cognitive health promotion, facilitate preventive interventions, and support early dementia diagnosis in rural and remote communities (World Health Organization 2012).

The CAHS (2019, p. 2) report provides compelling evidence highlighting the need for a national strategy to provide a “central vision” and direct resources to meet the needs of people with dementia and their caregivers. However in developing a National Dementia Strategy for Canada, addressing the unique needs of rural and remote people affected by dementia must be identified as a key priority. It is critical that this strategy is collaborative and built from the ground up. Moreover, it must reflect the realities of rural and remote people affected by dementia in a wide variety of community contexts. As such, further research is needed to build an evidence-informed knowledge base to address issues of dementia-related stigma and better understand the unique needs of rural and remote people affected by dementia. Only through the development of collaborative partnerships and evidence-informed research can we ensure that the needs of rural and remote people affected by dementia are addressed.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

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