

Insights on the Healthcare Trajectories of People Living With Dementia

Raquel Souza Dias Betini, Masud Hussain, Rachel Latus, Allie Chen, Liudmila Husak, Catherine Pelletier and Larry Shaver

Abstract

People living with dementia follow different healthcare trajectories based on the individual healthcare needs and external supports available to them. We explored healthcare trajectories involving home care and long-term care settings, associated factors and hospitalizations prior to transitioning to these settings. This study was part of a collaborative project between the Canadian Institute for Health Information and the Public Health Agency of Canada that supported the implementation of the national dementia strategy (PHAC 2019) through the Enhanced Dementia Surveillance Initiative (Government of Canada 2023). This initiative aimed to inform public health actions with new findings from surveillance and data.

Introduction

Nearly 6.3% of Canadians over the age of 65 years were living with dementia in 2021–2022, and as the incidence of dementia increases with age (Government of Canada 2024; PHAC 2019),¹ the number of Canadians diagnosed with the condition is expected to increase with an aging population. Dementia is an umbrella term that describes a set of symptoms affecting brain function that tends to increase in severity over time, resulting in cognitive and functional decline. As the condition progresses, people living with dementia (PLWD) often need more specialized care provided by different healthcare professionals working in homecare and long-term care (LTC) sectors. In addition, the healthcare trajectories tend to be influenced by socio-demographic and caregiver factors, along with the clinical characteristics of the PLWD. Understanding these factors can help policy and decision makers to identify and address gaps in the healthcare system and inform service provision to better support PLWD and their caregivers.

Approach

We followed a cohort of close to 60,000 PLWD from across four provinces (Alberta, British Columbia, Ontario and Newfoundland and Labrador) over a five-year period (2017–2022). We identified the initial record of dementia in 2017 using information from physician billing claims, hospital records and prescription drug claims found in the Canadian Institute for Health Information (CIHI) data holdings, using a validated case definition (Jaakkimainen et al. 2016).² We also leveraged data holdings from hospital, LTC and homecare settings to identify healthcare trajectories of PLWD and examine associated caregiver, clinical, equity and socio-demographic factors.

Key Findings

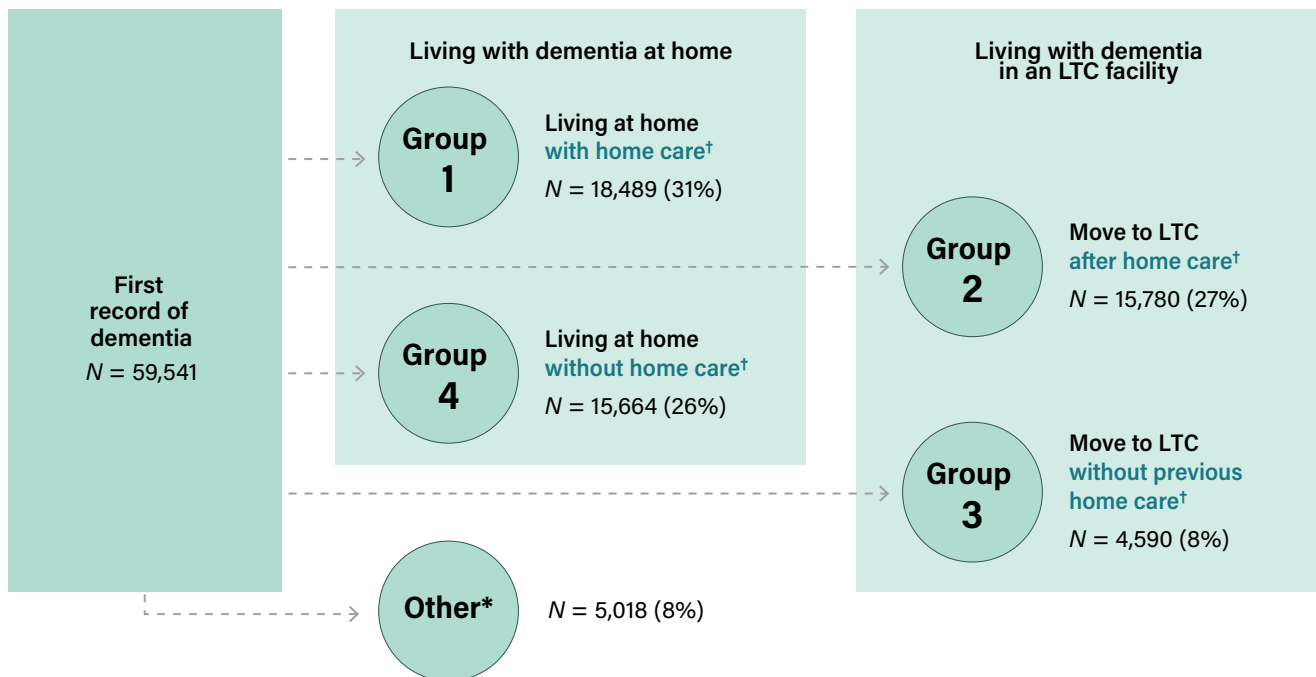
This paper highlights four key findings presented in more detail in the study report titled *Understanding Health Care Trajectories of People Living With Dementia* (CIHI 2024).

Finding #1: PLWD may follow different healthcare trajectories

In this study, 92% of PLWD followed four healthcare trajectories (groups 1–4) (Figure 1), and 72% of them had interactions with home care and/or LTC sectors at some point within the five years of the study. The remaining 28% (group 4) of PLWD did not receive publicly funded long-stay home care or publicly funded LTC and were more likely to be younger (less than 65 years) than PLWD in the other groups (15% vs. 4%). Other than that, there were no other substantial differences between the age groups in each trajectory.

It is important to note that PLWD in group 4 could have been receiving short-stay homecare or community support services or living in one of the regions that do not submit homecare data to CIHI.

FIGURE 1. Trajectories in the healthcare system after first record of dementia: NL, ON, AB and BC



*Other includes people living with dementia (PLWD) who had a first record of dementia while living in LTC (N = 3,180, or 5%) and PLWD who moved to LTC and had publicly funded home care prior to a first record of dementia (N = 1,838, or 3%). These groups were not described in the original report.

† Publicly funded home care.

AB = Alberta; BC = British Columbia; LTC = long-term care; NL = Newfoundland and Labrador; ON = Ontario.

Sources: Home Care Reporting System, Continuing Care Reporting System, Integrated interRAI Reporting System, Patient-Level Physician Billing Repository, Discharge Abstract Database, Ontario Mental Health Reporting System, National Ambulatory Care Reporting System and National Prescription Drug Utilization Information System, 2017–2018 to 2022–2023, the Canadian Institute for Health Information.

Finding #2: More than half of PLWD (58%) received publicly funded home care as part of their trajectory (groups 1 and 2)

Almost half of this group subsequently moved to an LTC facility (group 2) within the five years of the study period. The 10 most important factors associated with higher odds of moving to LTC were the following:

- *Clinical factors* include moderate to severe cognitive impairment (75% greater odds); having a hospitalization within the first year of receiving home care (46% greater odds); frequent wanderings (44% greater odds); and severe hearing impairment (36% greater odds).
- *Caregiver experiences* include feeling distress (42% greater odds) and not living together with the PLWD (40% greater odds).
- *Equity and sociodemographic factors* include the PLWD located in a remote area (50% greater odds); speaking English as a primary language (47% greater odds); being 85 or older (45% greater odds); and being a widow before LTC admission (26% greater odds).

These results reflect the complexity of factors related to transitions from home care to LTC and are also in alignment with findings from our previous report, *Dementia in Canada* (CIHI 2018).

Finding #3: Sixty per cent of PLWD who moved to LTC were hospitalized in the three months before their move; only 12% were hospitalized in the three months after they moved

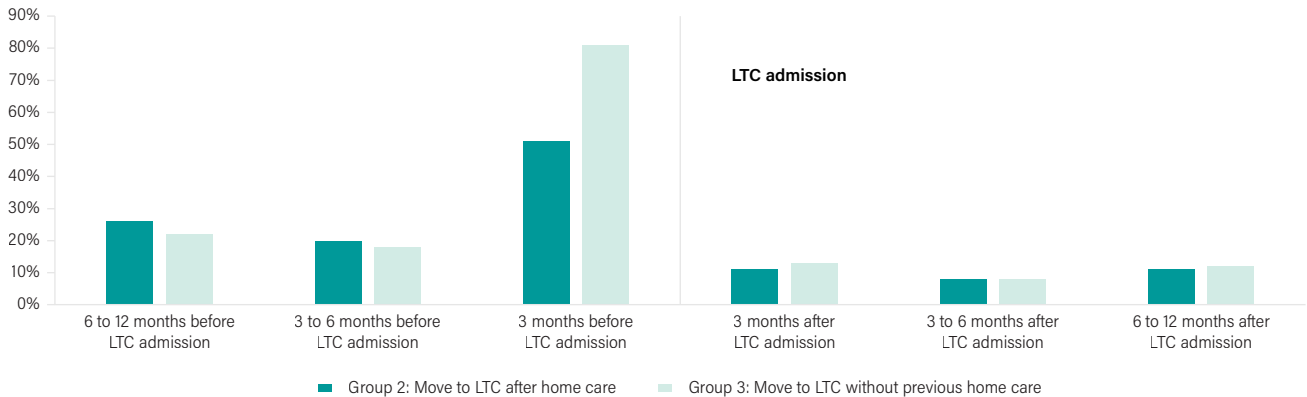
Our study also investigated hospitalizations that occur before and after transitions to LTC and how they differ by healthcare trajectory (Figure 2). We found that the group of PLWD moving to LTC without previous home care experienced a much higher rate of hospitalization before transitioning to LTC compared with the group that received home care before going to LTC (81% vs. 51%).

Finding #4: Overall, PLWD who have concurrent mental health and/or substance use disorders tend to face more challenges accessing homecare services and transitioning to an LTC facility

Our results show how this group was more likely to have alternative level of care (ALC) stays in the last hospitalization before home care (35% vs. 27%) and LTC admissions (81% vs.

FIGURE 2.

Percentage of PLWD who had at least one hospitalization before or after LTC admission, groups 2 and 3



LTC = long-term care; PLWD = people living with dementia.

Sources: Home Care Reporting System, Continuing Care Reporting System, Integrated interRAI Reporting System, Discharge Abstract Database, Ontario Mental Health Reporting System and National Ambulatory Care Reporting System, 2017–2018 to 2022–2023, the Canadian Institute for Health Information.

74%) compared with other PLWD without concurrent mental health and/or substance use disorder. They also had more ALC days (14 vs. 9 days for hospitalization before home care and 40 vs. 27 days for hospitalization before LTC), suggesting possible gaps in services or lack of appropriate support available for these patients with special needs.

Conclusion

Our study provides further insights into the influence of equity, socio-demographic and caregiver factors on the healthcare trajectories of PLWD, specifically with regard to the increased likelihood of transitioning from home care to LTC, highlighting the importance of policies that consider these factors (e.g., support to family caregivers). The results also show how hospitalizations often occur before transitioning to LTC, with extended ALC stays being more common for people with concurrent mental health or substance use disorders than among those without these concurrent conditions. Understanding the healthcare trajectories of PLWD and the specific components particularly impacted by socio-economic and equity factors can offer a helpful perspective to policy and decision makers aiming to ensure that PLWD receive the appropriate care to support their quality of life. **HQ**

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Notes

1. Many Canadian Chronic Disease Surveillance System (CCDSS) measures were influenced by the COVID-19 pandemic in 2021–2022 and should be interpreted with caution. Data from New Brunswick, the Northwest Territories and Saskatchewan were not available.
2. Dementia ascertainment followed the CCDSS (Government of Canada 2024) case definition, with the key difference that the date of the first of three billings was the record date, as opposed to the date of the last billing in the CCDSS. Furthermore, this study looked back three years to ensure that people in the cohort had no records of dementia prior to our defined first record of dementia in 2017–2018. This approach is different from the CCDSS approach that does not limit the previous records of dementia to three years only.

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