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## Original Research

# Dementia care in Ontario, Canada: evidence of more timely diagnosis among persons with dementia receiving care at home compared with residential facilities

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## ABSTRACT

**Objective:** Home care (HC) has been promoted as an efficient alternative to residential care (RC). However, little is known about the individuals who receive HC. This study compared the cognitive and functional statuses of persons with dementia receiving HC or RC at the time of diagnosis with dementia. It was hypothesized that persons with dementia receiving RC would have declined further, both cognitively and functionally.

**Study design:** Population-based secondary data analysis.

**Methods:** Data from the Canadian Institute for Health Information's Continuing Care Reporting System and the Home Care Reporting System, 2009–2011, were used. Respective populations of 39,604 and 21,153 persons with dementia who received either RC or HC were included. Cognitive and functional statuses were measured using a cognitive performance scale (CPS) and an activities of daily living (ADL) scale, respectively.

**Results:** The mean CPS score was higher for the RC group (3.2 vs 2.5). The proportion of individuals diagnosed when impairment was moderate to very severe (CPS  $\geq 4$ ) was higher in the RC group (32.0% vs 13.3%). The mean ADL score was also higher for the RC group (3.5 vs 1.6). The proportion of individuals diagnosed when they required extensive assistance or were totally dependent (ADL  $\geq 3$ ) was markedly higher in the RC group (72.3% vs 27.3%). All findings were statistically significant ( $P < 0.0001$ ). Multivariable analysis suggested that RC clients were nearly four times more likely than HC clients to be diagnosed at a later stage (odds ratio = 3.74, 95% confidence interval 3.54–3.95).

**Conclusions:** Persons with dementia in RC facilities in Ontario are diagnosed when their cognitive and functional statuses have declined more than those of their HC counterparts.

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## Introduction

Globally, timely diagnosis is now recognized as a major challenge in dementia care.<sup>1</sup> Evidence suggests that the situation is as pressing in high-income countries as in low- and middle-income countries. The UK Government, for example, reported that more than half of its citizens living with dementia did not receive proper diagnoses.<sup>2</sup> In low- and middle-income countries, the rate of undetected cases has been estimated to be 77% in Brazil<sup>3</sup> and as high as 90% in India.<sup>4</sup>

Canada is no exception to this predicament.<sup>1,5</sup> In 2010, the Canadian Institute for Health Information (CIHI) released a report stating that approximately 40% of residents of residential care (RC) facilities did not have a diagnosis of dementia.<sup>6</sup> As age is one of the most significant risk factors for developing dementia,<sup>7</sup> some ‘dementia-free-at-admission’ individuals are likely to develop the condition during their stay at a facility. When the condition develops after they become a resident at a RC facility, evidence suggests that it may not always be recognized.<sup>1,8</sup>

### Residential care

Many older individuals prefer to stay at home for as long as they can. Nonetheless, when the level of care requires extended hours and extensive care attendants, admission to a residential care (RC) facility may be necessary. It is widely acknowledged that the prevalence of dementia is higher at the institutional level than at the community level.<sup>5</sup> However, as day-to-day cognitive demands are usually fewer at RC facilities, cognitive deficits are easily overlooked. Two recent Canadian studies raised concerns of missed and delayed diagnoses of dementia among individuals who resided at RC facilities. Bartfay et al.<sup>1,5</sup> reported that as many as 12% of residents may have experienced missed diagnoses. The authors further found that, among all RC facility clients, a diagnosis of dementia after admission to an institution was more likely to be made at a worse stage of cognitive decline than a diagnosis made before admission.

### Home care

Individuals aged  $\geq 65$  years represent the fastest growing segment in the world. It is not surprising that we are experiencing a major shift in healthcare restructuring in order to accommodate the growing needs of older individuals. Home care (HC) has been promoted as an efficient alternative to traditional institutional-style care since the 1990s.<sup>9</sup> Benefits such as fostering independent living, postponing institutionalization and reducing unplanned hospitalization have been heavily publicized to endorse the practice.<sup>10</sup>

In Ontario, Canada, the transition from hospital care to community care and HC began in the 1990s. Patients were discharged from hospitals a lot sooner than ever before, and their care was managed by community care access centres (CCACs). Today, Ontario's HC services are maintained by 14 geographically distinct local health integration networks, which directly oversee the 14 CCACs within its geographic boundaries.<sup>11</sup> The use of HC, and its associated cost, have

increased steadily over the past several decades, reaching \$3.4 billion in 2003–2004.<sup>12</sup>

Many countries now have programmes that deliver community- and home-based services, all with the goal of providing and improving functional, emotional and social support to clients and their informal caregivers.<sup>13,14</sup> In Australia, for example, the ‘community-aged care package’ was introduced to administer services that promote independent living at home.<sup>14</sup> Similarly, several European countries have prioritized HC services, and jointly conducted the Aged in Home Care study.<sup>15</sup>

### Home care use among persons with dementia

The need for HC will certainly grow in the years to come.<sup>15,16</sup> Having a good understanding of the end-users can be tremendously beneficial to both the providers and the recipients. To date, only a handful of studies have examined the characteristics of HC users in Canada. Many focused on the differences between urban and rural residents,<sup>17–19</sup> and others assessed the unfulfilled needs of users.<sup>20–22</sup>

A recent report by CIHI<sup>6</sup> provided a glimpse of the characteristics of HC and RC facility users with dementia. In the report, CIHI noted that one in five HC recipients had been diagnosed with dementia. Their focus, however, was on the reasons for admission to RC facilities. While usage and demand grow steadily, research on HC continues to be lacking.<sup>15</sup>

### Study aim and hypothesis

The primary aim of this study was to compare the stages of decline in cognitive and functional statuses (CS and FS, respectively) of persons with dementia receiving either HC or RC at the time of diagnosis with dementia. These two groups of individuals were chosen for the study because they represented two distinct groups of healthcare consumers, where timely diagnosis is equally central in their care trajectories. The former group of individuals will be referred to as ‘HC clients’, and the latter group of individuals will be referred to as ‘RC clients’. It was hypothesized that, at the time of diagnosis with dementia, RC clients would have declined further, both cognitively and functionally, than their HC counterparts.

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## Methods

This study employed a population-based secondary data analysis approach. Two groups of individuals were included: (1) all residents of any Ontario RC facilities (RC clients), and (2) all recipients of the publicly funded HC programmes in the province of Ontario (HC clients), between the years of 2009 and 2011. RC clients were residents of either hospital-based facilities or residential continuing care facilities that provided 24-h nursing care. HC clients were recipients of publicly funded HC programmes while living at home. HC clients were aged  $\geq 65$  years and were expected to receive HC services for at least 60 days.

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