Title

Home care service utilisation by people with dementia – a retrospective cohort study of community nursing data in Australia

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Abstract

Progressive aged care reforms are shifting dementia care into the community. These efforts have been shown to prevent transition to residential aged care facilities and hospitals. There is a paucity of studies examining the utilisation of home care services for people living with dementia. This study aims to address the current knowledge gap by providing a comprehensive summary of older adults receiving home care and comparing service use for people with and without dementia. A retrospective secondary data analysis was conducted using routine data prospectively collected from a cohort (n= 2,703 with dementia matched to 9,224 without dementia; total 11,927) using a community home nursing service in metropolitan Melbourne, Australia in 2014. Descriptive statistics compared individuals with and without dementia on client-level demographics and their episode of home care service use. A comparative analysis on select variables was also performed using a conditional Poisson regression to estimate risk ratios (RR). Compared to older adults without dementia, people with dementia were more likely to be born overseas (RR 1.10, 95% CI [1.03-1.19]), require an interpreter (RR 1.41, 95% CI [1.26-1.59]) and live with family (RR 1.09 [1.01-1.16]). When examining an individual's episode of care, people with dementia were more likely to require acute care (RR 1.07, 95% CI [1.01-1.14]) and be discharged from home care with personal care services (RR 1.46, 95% CI [1.24-1.72]). People with dementia were less likely to be referred from a hospital (RR 0.73, 95% CI [0.69-0.77]), achieve their home care goals (RR 0.91, 95% CI [0.87-0.94]), or die whilst in receipt of home care services (RR 0.82, 95% CI [0.72-0.94]). Our findings suggest that people with dementia have different socio-demographic characteristics and interactions with home care services compared to people without dementia.

Keywords

Dementia; Alzheimer disease; home care; community services; health service use

What is already known about this topic

- There has been a recent shift away from an institutionalised-style of dementia care
- Home care services have been shown to support informal carers, maintain an individual's independence, reduce social isolation and prevent care transitions
- There is a paucity of studies examining the utilisation of home care services for people with dementia

What this paper adds

- An example of the value of using routinely collected administrative data to better understand a population of home care clients
- A comprehensive summary of client demographics and home care service utilisation for a large population of older adults with and without dementia in Australia
- The comparative analysis highlights the impact of dementia on the utilisation of home care services

Introduction

In 2016, it was estimated that 47 million people lived with dementia worldwide (Prince, Comas-Herrera, Knapp, Guerchet, & Karagiannidou, 2016). This number is expected to double every 20 years, increasing the worldwide population of people with dementia to 131 million by 2050 (Prince et al., 2015). This growth is mirrored in Australia, where it is estimated that 6.4 million people will be diagnosed with dementia in the next 40 years. Nationally, the cost of dementia was \$14.25 billion in 2016, equating to an average cost of \$35,550 per person with dementia (Brown, Hansnata, & La, 2017). The provision of care and support for people living with dementia is one of Australia's largest healthcare challenges (Alzheimer's Australia, 2016).

The Australian Government has responded to this challenge by recognising dementia as a National Health Priority Area. The National Framework for Action on Dementia 2015-2019, endorsed by the Australian Health Ministers Advisory Council (AHMAC) in 2012, outlines comprehensive key action areas to improve treatment and care options for people with dementia (Australian Health Ministers Advisory Council, 2015). In addition to this framework, aged care reforms are being progressively implemented to offer sustainable,

consumer-directed care options to enable people with dementia to remain at home for longer and prevent unnecessary transition to hospitals and residential aged care facilities (Bartfay, Bartfay, & Gorey, 2016; Commonwealth of Australia, 2017b). The Commonwealth Home Support Programme (CHSP) is one such reform that provides home care packages funded by the Australian Government. The CHSP provides a large number of older people with a range of home and support services, including support for community and domestic tasks, personal care, nursing, case management, allied health and other clinical services through approved home care providers (Commonwealth of Australia, 2017a). These services are provided to the community by local councils, hospitals, community health services and various other government and non-government organisations (Department of Health, 2013). The Aged Care Assessment Service (ACAS) consists of a dedicated multi-disciplinary team who determine program eligibility. The ACAS undertake comprehensive functional assessments to gain a broad understanding of the older person and their carer. The ACAS is then able to provide detailed information about the available service options available to the individual (Department of Health, 2011). To plan appropriate care, home care providers need to better understand the way that people with dementia utilise their services.

Home care is considered the single most important service for supporting people with dementia in their own homes (Department of Health Working Group, 2009). High quality and flexible home care services have been shown to maintain an individual's independence, support informal caregivers, reduce social isolation and prevent admission to residential aged care facilities and hospitals (Commission of Social Care Inspection, 2006). Although informal carers play a pivotal role for people with dementia, funded caregiving is available to either substitute or supplement the assistance provided by the family (Australian Institute of Health and Welfare, 2012; Prince, Prina, & Guerchet, 2013). This type of formal care can help families balance caregiving with other life demands, whilst also having distinct economic savings for governments (Brodaty & Donkin, 2009; Schwarzkopf, Menn, Leidl, Graessel, & Holle, 2013). A study of home care clients by Vu and colleagues (Vu et al., 2014) concluded that a significant proportion of home care clients may be at a critical point in terms of their continued ability to remain in their own home. A comprehensive system of community dementia care services should form part of a seamless continuum of service provision for people with dementia (Prince et al., 2013).

Numerous studies have examined the relationship between dementia and nursing home use, however, there is no clear understanding of the common pathways through community aged

care services for people with dementia (Runge, Gilham, & Peut, 2009). Currently, the majority of available research has been conducted in Canada using the Home Care Reporting System (HCRS) (Bansal, Hirdes, Maxwell, Papaioannou, & Giangregorio, 2016; Bartfay et al., 2016; Maxwell et al., 2013; Vu et al., 2014). The HCRS has captured assessment data from publicly funded home care services in Ontario since 2006 (Canadian Institute for Health Information, 2017). The HCRS provides a comprehensive cross-sectional assessment of sociodemographic characteristics, physical and cognitive status and health conditions diagnosed by a medical professional (Vu et al., 2014). Due to the cross-sectional nature of these studies, there is a distinct lack of information pertaining to service use over time. In Australia, there have been several population studies examining data from the Home and Community Care (HACC) and Aged Care Assessment Program (ACAP) Minimum Data Sets (MDS) (Karmel, Gibson, Anderson, Wells, & Duckett, 2012; Vecchio, Fitzgerald, Radford, & Fisher, 2016; You, Dunt, White, Vander Hoorn, & Doyle, 2014). The HACC and ACAP MDS does not include formal diagnostic information and instead report 'memory problems' as a surrogate measure of dementia (Vecchio et al., 2016). People with dementia in the community are more likely to possess early to mid-stage dementia and therefore under-diagnosis may limit the statistical differences within these studies (Prince et al., 2016; Vu et al., 2014). A systematic review by Low and colleagues found that although Canada and Australia offer similar models of healthcare, the heterogeneous nature of home care studies makes comparison difficult (Low, Yap, & Brodaty, 2011). Previous research has recommended system level research to support health system adaptation for the specific needs of our ageing population (Allen, Hutchinson, Brown, & Livingston, 2014; Centre of Excellence in Population Ageing Research, 2014; Vecchio, 2013). This, and the absence of data on service use in Australian studies, prompts the need for further studies examining home care for people with diagnosed dementia in Australia.

To address the current knowledge gap for people with dementia in Australia, our objectives were to:

1. Describe the socio-demographics and service utilisation of a large retrospective cohort of home care clients;
2. Explore the variations in the above characteristics for older adults with dementia compared to a matched group of home care clients without dementia.

Methods

This study is reported in accordance with the Reporting of studies Conducted using Observational Routinely-collected health Data (RECORD) Statement (Benchimol et al., 2015).

Study design, setting and sample frame

A retrospective cohort design was employed with analysis of routinely collected prospective data by a non-government organisation (NGO) that delivers community home nursing and healthcare services in Victoria, Australia. The NGO is a major health service provider and the largest home-nursing provider in Victoria. It delivers best practice general nursing, personal care, allied health services and specialist nursing care to individuals in their place of residence, which may be a private residence or retirement village. These services are accessed privately or through either the CHSP or an approved Home Care Package (Commonwealth of Australia, 2017a).

At the time of this study, the NGO predominantly delivered care to people residing in Melbourne, Australia's second-largest city. In 2016, the median age of people living in Greater Melbourne was 36 years, with 14% of the population aged over 65 years (Australian Bureau of Statistics, 2017). Melbourne is known for being a multicultural city, with 34% of the population born overseas and 32% speaking a language other than English at home (Australian Bureau of Statistics, 2017).

The cohorts were identified from a data set containing all clients with an active episode of care between 1st January 2014 and 31st December 2014. The sample frame was refined to include 34,741 community-dwelling home care clients aged 65 years or older.

Population selection and matching strategy

The International Classification of Diseases (ICD) versions 9 and 10 classified the diagnostic codes for each client (World Health Organization, 2016). These conditions were extracted from the client's medical record and were diagnosed by medical professionals. All clients with an ICD 10 (F00 – F04, G30 – G31) and ICD 9 (290, 331) code for dementia were included. Diagnostic codes related to mild cognitive impairment, substance-induced cognitive impairment and delirium were excluded. There were 2,308 care recipients with an included diagnostic code for dementia. These clients were matched by random selection with replacement for age group and gender (male/female) with data drawn from the entire dataset of clients without a diagnostic code for dementia. One client with dementia had gender listed

as ‘undefined’ and was excluded from the matching process. The matching strategy identified four comparators from the identified sample frame for each person with dementia, creating 2,307 matched sets; 2,307 with dementia and 9,224 without dementia. We applied this matching strategy using the known confounders of age and gender because this was an exploratory study and we wanted to better understand the differences between the two groups in this large sample of service users. We matched on age and gender only, therefore allowing an exploratory analysis into the descriptive statistics of other variables. We limited the matching factors as it can reduce the efficiency and diminish the statistical power even when it produces no sample-size reduction and if the matching variable is a confounder (Faresjö & Faresjö, 2010; Greenland & Morgenstern, 1990). Multiple normative comparators for each client are beneficial in increasing study precision; however, previously, more than four comparators have not been shown to increase the precision of results (Breslow, Day, Davis, & International Agency for Research on Cancer, 1980; Rigby & Robinson, 2000).

Data variables

The de-identified community nursing service data was collected by nursing staff working in the community. We examined the following areas: clients’ socio-demographic characteristics (age, sex, country of birth, interpreter requirements and socioeconomic status); clients’ home environment (living situation and accommodation type); service utilisation (referral source, nursing interventions, care outcomes, discharge status, discharge reason, discharge location and services on discharge). The client’s Local Government Area (LGA) was matched to Australian Bureau of Statistics 2011 Socioeconomic Indexes for Areas (SEIFA) scores to provide an estimate of socioeconomic status. SEIFA scores are a comprehensive measure of relative socioeconomic advantage and disadvantage of people living in LGAs, and include information on income, education, unemployment, house expenditure and assets (Australian Bureau of Statistics, 2016). The SEIFA scores were converted into deciles, where one represented the most disadvantaged clients and 10 the least. To simplify the results, infrequently used data codes were included in a category titled ‘other’. Missing data was omitted from the analysis using listwise deletion. The large sample size and positive assumption that data was missing completely at random means that listwise deletion produces unbiased estimates and conservative results (Kang, 2013).

Statistical analysis

Data were entered into the Statistical Package for Social Sciences (SPSS) version 24 (IBM, Armonk, NY, USA) for descriptive analysis. Categorical variables were presented as

proportions with 95% confidence intervals, and continuous variables were presented as mean and standard deviation (SD) for non-skewed data. Values outside of the 95% confidence intervals were considered significant. In a matched study design, unlike in case-control studies, there is no need to account for the matching in the analysis and, therefore, the descriptive statistics for the two broad groups were displayed.

Conditional Poisson regressions were used to examine any differences in the characteristics of service users using a dichotomous outcome (1/0) representing a diagnosis of dementia or not. Multiple conditional Poisson regressions were done with the dependant variable of dementia (1/0) and four independent variables of age, gender, matched set and another characteristic of interest. The independent variables of interest were the other variables available in the electronic client record. The relative risks were calculated from these Poisson regressions. We included a variable that accounted for the matched sets when estimating the relative risks, as this has been shown to increase the precisions of the results (Cummings & McKnight, 2004; Cummings, McKnight, & Greenland, 2003). For these analyses, an alpha level of 0.05 was applied. Therefore, if a statistically significant relative risk was produced using conditional Poisson regression, there was less than a 5% probability of a type 1 error. Conditional Poisson regression was chosen as it has been shown to produce the same results as conditional logistic regressions but has less computational limitations and can be readily done using large datasets such as ours (Armstrong, Gasparrini, & Tobias, 2014)

Ethics approval

Human Research Ethics approval for all aspects of this study was gained from the Health Services Ethics Committee (Project Number: 168) prior to project commencement.

Results

Socio-demographics

The socio-demographic characteristics of the included home care clients are outlined in Table 1. The mean age was 84 years and 63% were female. The distribution of SEIFA deciles did not differ significantly between groups. People with dementia were more likely to be born outside of Australia, require an interpreter and live with others.

(Insert Table 1 about here)

Service utilisation

Home care service use for people with and without dementia is outlined in Table 2. People with dementia were more likely to be referred for home care services from the community (Aged Care Assessment Service (ACAS), community health services or a family member, friend or neighbour). In terms of service provision, there was a trend towards increased monitoring and surveillance, assessment and although not statistically significant, support for informal carers for people with dementia. People with dementia were more likely to deteriorate and have a subsequent unplanned discharge from home care services. An increased proportion of this population was discharged to acute, permanent, respite and informal care services.

(Insert Table 2 about here)

Relative risks

The relative risks (RR) for select variables are presented in Figure 1. Compared to those without dementia, people with dementia were more likely to be born overseas (RR 1.10, 95% CI [1.03-1.19]), require an interpreter (RR 1.41, 95% CI [1.26-1.59]), and live with family (RR 1.09 [1.01-1.16]). When examining an individual's pathway through home care, people with dementia were more likely to require acute care (RR 1.07, 95% CI [1.01-1.14]) and be discharged from home care with personal care services (RR 1.46, 95% CI [1.24-1.72]).

People with dementia were less likely to be referred from a hospital (RR 0.73, 95% CI [0.69-0.77]), achieve their home care goals (RR 0.91, 95% CI [0.87-0.94]) and die whilst in receipt of home care services (RR 0.82, 95% CI [0.72-0.94]).

(Insert Figure 1 about here)

Discussion

In this study, people with dementia had different socio-demographic characteristics and home care service utilisation compared to those without dementia. Poisson regression determined that these differences could not be due to a person's age or gender. Our work expands on previous studies by providing a comprehensive examination of a large population of home care clients with a diagnosis of dementia. To our knowledge, this is the first study examining features of home care service admission, service utilisation and discharge. Overall, our age and gender findings are validated by previous retrospective cohort studies examining home care clients with dementia (Bartfay et al., 2016; Karmel et al., 2012; Lee, Yim, Cho, & Chung, 2014; Tranmer, Croxford, & Coyte, 2003; Vecchio et al., 2016; Vu et al., 2014). The majority of clients in other studies were female (62-73%) with a mean age between 79 and 83

years. The clients in this study were marginally older with a mean age of 84 years. The similarity between cohorts of home care clients improves the generalisability of these results.

There was significant cultural diversity in this home care population with almost half of those diagnosed with dementia being born outside of Australia. This finding reflects the Australian Bureau of Statistics Survey of Disability, Ageing and Carers (SDAC) 2009 where 53% of community-dwelling older people with dementia were born overseas. This compares with only 31% of people in residential aged care facilities (Australian Institute of Health and Welfare, 2012). A Danish study by Stevnsborg and colleagues (Stevnsborg, Jensen-Dahm, Nielsen, & Gasse, 2016) proposed that cultural and socio-economic barriers could account for non-Western immigrants being 50% less likely to live in residential aged care. Alongside these findings, this study showed interpreter services to be utilised by over 15% of home care clients with dementia. It is encouraging that home care staff are utilising professional interpreter services for their consultations as language has been shown to impact service use for ethnic minorities (Mukadam, Cooper, & Livingston, 2011). Home care staff should continue adhering to the clinical practice guidelines that recommend information be provided in a client's preferred language, bilingual care staff are employed and where appropriate, engage professional interpreters (Guidelines Adaptation Committee, 2016). Further research is required to better understand the culturally diverse home care population in terms of their service utilisation and care needs.

Although home care clients with dementia were more likely to live with family, this study found that almost 40% live alone. This was in contrast to SDAC data which showed that 88% of community-dwelling older people with dementia live in private dwellings with others, whilst only 12% live alone (Australian Institute of Health and Welfare, 2012). This difference may be distorted by factors not examined in this study, for example, a high proportion of clients living in urban areas with other sources of support in close proximity. Although we were unable to compare socioeconomic data with the SDAC findings, a relatively high SEIFA score in the study sample may influence living arrangement by increasing access to other private care services. This discrepancy may also suggest that home care services in the region studied are allowing people with dementia to remain at home alone for longer periods of time. A study by Eichler and colleagues (Eichler et al., 2016) found that although people with dementia who live alone were older, female and more likely to be widowed, they had no cognitive or functional differences compared to people living with others. They did, however, find that people with dementia who lived alone utilised

significantly more home help, assistance with medications, home-delivered meals and housekeeping assistance. Given the economic benefit, governments and health system planners should direct resources and funding to home care services to enable older people with dementia to remain at home for longer.

Our findings show that people with dementia follow unique referral pathways into home care services. In particular, people with dementia accessing home care services had twice the proportion of ACAS referrals compared to people without dementia. This adds to previous research that found that home care services were the first step in aged care service provision following ACAS assessment. This was utilised by 28% of people without previous service use (Australian Institute of Health and Welfare, 2011). This may be due to the assessment team's ability to educate about the aged care system and eligibility for certain services (Karmel et al., 2012). Furthermore, people with dementia received more than double the number of referrals into home care from family, friends and neighbours compared to people without dementia. We propose that this finding reflects the high levels of assistance required by people with dementia and that carers are referring this population to formalised care services to assist with their own informal care (Maxwell et al., 2013; Vu et al., 2014). Alternatively, there was no difference in the number of referrals received from general practitioners between groups. General practitioners have identified the coordination of support services as an area of difficulty when managing people with dementia (Turner et al., 2004). General practitioners are well placed to facilitate early requests for formal support from home care services (Iliffe et al., 2009). Improved visibility of the services available and pathways of entry to home care should be a priority for providers. These findings exemplify the need for home care providers to have established relationships with aged care assessment teams and other community health agencies to expand the provision of their services to people with dementia.

Despite the provision of home care services, people with dementia were more likely to deteriorate and require admission to hospital or permanent care. This is compared to those without dementia who were more likely to be referred to home care for nursing procedures and, therefore, receive more acute, short-term care where they would achieve their care goals and be subsequently discharged from the service. A study of community-dwelling older adults with dementia found that a previous hospital admission or previously worse cognition increased the risk of hospital admission or death. Use of community services was considered a short-term protective factor (You et al., 2014). The progressive nature of dementia and the

long duration of dependency may limit the possibility of remaining at home until the end of life. Further studies are needed to help guide people with dementia, their families and healthcare providers through challenging events (Badrakalimuthu & Barclay, 2014).

Home care clients with dementia were less likely to achieve the goals for the episode of care compared to those without dementia. The increase in monitoring and surveillance for individuals and support for informal carers is unlikely to reach a resolving endpoint for home care services. Instead, people with dementia were significantly more likely to have an unplanned discharge to acute care, permanent or respite care. There are a myriad of complexities surrounding the decision to transition from care at home to residential aged care. This often represents a 'forced choice' at a time of crisis due to escalating care requirements, for example, during an acute care admission (Alzheimer's Society, 2013). Decision aids have been shown to improve shared decision-making by informing health care choice for people with advanced dementia, however, further research is warranted into the effects of these tools in a community-dwelling cohort transitioning through home care services (Hanson et al., 2017).

In Australia, the policy environment is increasingly supporting the use of routinely collected data for research (Jorm, 2015). In 2009, the Council of Australian Governments released a National Government Information Sharing Strategy to facilitate a common and considered approach to sharing data (Australian Government Information Management Office, 2009). This offers a great potential for population health improvement because governments, healthcare providers and insurers are collecting large volumes of health-related data for operational purposes (Sinha, Peach, Poloniecki, Thompson, & Holt, 2013). Our study shows that using routinely collected data is cost effective and can improve population reach, enable long-term follow-up and avoid both attrition and reporting bias. Health services would benefit from developing their research workforce and investing in this research method to capitalise on this rich source of data (Jorm, 2015).

Limitations

Despite several strengths of the community nursing client data, including a comparatively large sample population, generalisability to the Australian population and detailed information pertaining to home care service use, some limitations must be noted. Firstly, the database captured routine data from a single community nursing provider, therefore, the demographics and characteristics of service use are only representative of the care provided

by this individual service. Due to the parsimonious nature of administrative datasets, the number of variables available for analysis were limited and measures of cognitive status, functional status and medical needs were not collected (dos Santos Silva, 1999; Jorm, 2015). Secondly, the dataset contained a small amount of missing data for a number of variables. Thirdly, there were no measures for the degree of cognitive impairment included in the database. The Mini Mental State Examination score is utilised in this population as part of the community nursing service assessment, however, this information was not recorded in the administrative database. Future studies would benefit from using a clinical cognitive assessment with an established reliability and validity to determine if the degree of cognitive impairment influences service use. Lastly, due to the diagnostic difficulties related to the insidious nature of dementia, diagnostic misclassification may have resulted. This may have reduced the ability to detect differences in the variables across some of our matched group. These diagnostic difficulties meant that dementia sub-types were unable to be differentiated. Future studies would benefit from listing the dementia sub-type, as this has been shown to be an important predictor of care needs (Karmel et al., 2012).

Conclusion

To our knowledge, this is one of the first studies examining the characteristics of home care admission, service provision and discharge for older people with dementia. This study demonstrates the value of using routinely collected administrative data to better understand a large home care population. The home care clients in the studied population were culturally and linguistically diverse with a large proportion living alone in their private residences. People with dementia accessed home care services through referral from individuals and organisations in the community. Once receiving the service, people with dementia were less likely to achieve care goals and have an unexpected deterioration requiring discharge to acute or permanent care. Further research on improving the provision of home care services is clearly warranted, particularly in relation to sub-populations of people living with dementia including the culturally and linguistically diverse and people who live alone.

References

- Allen, J., Hutchinson, A. M., Brown, R., & Livingston, P. M. (2014). Quality care outcomes following transitional care interventions for older people from hospital to home: A systematic review. *BMC Health Services Research*, 14(1), 346.
<https://doi.org/10.1186/1472-6963-14-346>

Alzheimer's Australia. (2016). *The Future of Australia's Aged Care Sector Workforce*. Melbourne.

Alzheimer's Society. (2013). *Low expectations: Attitudes on choice, care and community for people with dementia in care homes*. London.

Armstrong, B. G., Gasparrini, A., & Tobias, A. (2014). Conditional Poisson models: a flexible alternative to conditional logistic case cross-over analysis. *BMC Medical Research Methodology*, 14(1). <https://doi.org/10.1186/1471-2288-14-122>

Australian Bureau of Statistics. (2016). SEIFA 2011 - Socioeconomic Indexes for Areas. Retrieved March 29, 2017, from <http://www.abs.gov.au/ausstats/abs@.nsf/mf/2033.0.55.001/>

Australian Bureau of Statistics. (2017). Regional Summary - Greater Melbourne (GCCSA) (2GMEL). Retrieved October 6, 2017, from http://stat.abs.gov.au/itt/r.jsp?RegionSummary®ion=2GMEL&dataset=ABS_REGIONAL_ASGS2016&geoconcept=ASGS_2016&measure=MEASURE&datasetASGS=ABS_REGIONAL_ASGS2016&datasetLGA=ABS_REGIONAL_LGA2016®ionLGA=LGA_2016®ionASGS=ASGS_2016

Australian Government Information Management Office. (2009). *National Government Information Sharing Strategy: Unlocking Government information assets to benefit the broader community*. Canberra. Retrieved from www.finance.gov.au/files/2012/04/ngiss.pdf

Australian Health Ministers Advisory Council. (2015). *National Framework for Action on Dementia 2015-2019*.

Australian Institute of Health and Welfare. (2011). *Pathways in Aged Care: Program Use After Assessment*. Canberra: AIHW.

Australian Institute of Health and Welfare. (2012). *Dementia in Australia*. Cat. no. AGE 70. Canberra.

Badrakalimuthu, V., & Barclay, S. (2014). Do people with dementia die at their preferred location of death? A systematic literature review and narrative synthesis. *Age and Ageing*, 43, 13–19. <https://doi.org/10.1093/ageing/aft151>

- Bansal, S., Hirdes, J. P., Maxwell, C. J., Papaioannou, A., & Giangregorio, L. M. (2016). Identifying Fallers among Home Care Clients with Dementia and Parkinson's Disease. *Canadian Journal on Aging*, 35(3), 319–331. <https://doi.org/S0714980816000325> [pii]
- Bartfay, E., Bartfay, W. J., & Gorey, K. M. (2016). Dementia care in Ontario, Canada: evidence of more timely diagnosis among persons with dementia receiving care at home compared with residential facilities. *Public Health*, 130, 6–12. <https://doi.org/10.1016/j.puhe.2015.10.002>
- Benchimol, E. I., Smeeth, L., Guttman, A., Harron, K., Moher, D., Peteresen, I., ... Langan, S. M. (2015). The REporting of studies Conducted using Observational Routinely-collected health Data (RECORD) Statement. *PLoS Medicine*, 12(10), 1–23. <https://doi.org/10.1371/journal.pmed.1001885>
- Breslow, N. E., Day, N. E., Davis, W., & International Agency for Research on Cancer. (1980). Volume 1 - The analysis of case-control studies. In *Statistical Methods in Cancer Research* (p. 346). Lyon.
- Brodaty, H., & Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience*, 11(2), 217–228. <https://doi.org/10.1002/gps>
- Brown, L., Hansnata, E., & La, H. A. (2017). *Economic Cost of Dementia in Australia 2016-2056*. Canberra.
- Canadian Institute for Health Information. (2017). Home Care Reporting System Metadata. Retrieved April 4, 2017, from <https://www.cihi.ca/en/home-care-reporting-system-metadata>
- Centre of Excellence in Population Ageing Research. (2014). *Aged care in Australia: Part I – Policy, demand and funding*. Sydney.
- Commission of Social Care Inspection. (2006). *Time to Care? An overview of home care services for older people in England, 2006*. London.
- Commonwealth of Australia. (2017a). About the Home Care Packages Programme. Retrieved April 5, 2017, from <https://agedcare.health.gov.au/programs/home-care/about-the-home-care-packages-program>
- Commonwealth of Australia. (2017b). *Aged Care Reform*. Retrieved May 15, 2017, from

<https://agedcare.health.gov.au/aged-care-reform>

Cummings, P., & McKnight, B. (2004). Analysis of matched cohort data. *The Stata Journal*, 4(3), 274–281.

Cummings, P., McKnight, B., & Greenland, S. (2003). Matched Cohort Methods for Injury Research. *Epidemiologic Reviews*, 25, 43–50. <https://doi.org/10.1093/epirev/mxg002>

Department of Health. (2011). Guidelines for streamlining pathways between ACAS and HACC assessment services. Melbourne.

Department of Health. (2013). Victorian Home and Community Care program manual 2013. Melbourne. Retrieved from http://www.health.vic.gov.au/hacc/prog_manual/index.htm

Department of Health Working Group. (2009). Living well with dementia: A National Dementia Strategy. London.

dos Santos Silva, I. (1999). Studies based on routine data. In *Cancer epidemiology: principles and methods* (pp. 231–262). Lyon: International Agency for Research on Cancer.

Eichler, T., Hoffmann, W., Hertel, J., Richter, S., Wucherer, D., Michalowsky, B., ... Thyrian, J. R. (2016). Living Alone with Dementia: Prevalence, Correlates and the Utilization of Health and Nursing Care Services. *Journal of Alzheimer's Disease*, 52(2), 619–629. <https://doi.org/10.3233/JAD-151058>

Faresjö, T., & Faresjö, Å. (2010). To match or not to match in epidemiological studies - same outcome but less power. *International Journal of Environmental Research and Public Health*, 7(1), 325–332. <https://doi.org/10.3390/ijerph7010325>

Greenland, S., & Morgenstern, H. (1990). Matching and efficiency in cohort studies. *American Journal of Epidemiology*, 131(1), 151–159. <https://doi.org/10.1093/oxfordjournals.aje.a115469>

Guidelines Adaptation Committee. (2016). Clinical Practice Guidelines and Principles of Care for People with Dementia.

Hanson, L. C., Zimmerman, S., Song, M.-K., Lin, F.-C., Rosemond, C., Carey, T. S., & Mitchell, S. L. (2017). Effect of the Goals of Care Intervention for Advanced Dementia: A Randomized Clinical Trial. *JAMA Internal Medicine*, 177(1), 24–31.

<https://doi.org/10.1001/jamainternmed.2016.7031>

- Iliffe, S., Robinson, L., Brayne, C., Goodman, C., Rait, G., Manthorpe, J., ... DeNDRoN Primary Care Clinical Studies Group. (2009). Primary care and dementia: 1. diagnosis, screening and disclosure. *International Journal of Geriatric Psychiatry*, 24, 895–901. <https://doi.org/10.1002/gps.2204>
- Jorm, L. (2015). Routinely collected data as a strategic resource for research: priorities for methods and workforce. *Public Health Research & Practice*, 25(4), 1–5. <https://doi.org/10.17061/phrp2541540>
- Kang, H. (2013). The prevention and handling of the missing data. *Korean J Anesthesiol*, 64(5), 402–406. <https://doi.org/10.4097/kjae.2013.64.5.402>
- Karmel, R., Gibson, D., Anderson, P., Wells, Y., & Duckett, S. (2012). Care trajectories through community and residential aged care services: disease effects. *Ageing and Society*, 32, 1428–1445. <https://doi.org/10.1017/S0144686X11001231>
- Lee, T. W., Yim, E., Cho, E., & Chung, J. (2014). Cognitive Function, Behavioral Problems, and Physical Function in Long-Term Care Insurance Beneficiaries with Dementia in South Korea: Comparison of Home Care and Institutional Care Services. *Journal of the American Geriatrics Society*, 62(8), 1467–1475. <https://doi.org/10.1111/jgs.12944>
- Low, L.-F., Yap, M., & Brodaty, H. (2011). A systematic review of different models of home and community care services for older persons. *BMC Health Services Research*, 11(1), 93. <https://doi.org/10.1186/1472-6963-11-93>
- Maxwell, C. J., Vu, M., Hogan, D. B., Patten, S. B., Jantzi, M., Kergoat, M.-J., ... Hirdes, J. P. (2013). Patterns and Determinants of Dementia Pharmacotherapy in a Population-Based Cohort of Home Care Clients. *Drugs and Aging*, 30(7), 569–585. <https://doi.org/10.1007/s40266-013-0083-y>
- Mukadam, N., Cooper, C., & Livingston, G. (2011). A systematic review of ethnicity and pathways to care in dementia, 26, 12–20. <https://doi.org/10.1002/gps.2484>
- Prince, Comas-Herrera, A., Knapp, M., Guerchet, M., & Karagiannidou, M. (2016). *World Alzheimer Report 2016: Improving healthcare for people with dementia*. London.
- Prince, Prina, M., & Guerchet, M. (2013). *World Alzheimer Report 2013: Journey of Caring*.

London.

- Prince, Wimo, A., Guerchet, M., Ali, G., Wu, Y., & Prina, M. (2015). World Alzheimer Report 2015: The Global Impact of Dementia. London.
- Rigby, A. S., & Robinson, M. B. (2000). Statistical methods in epidemiology. IV. Confounding and the matched pairs odds ratio. *Disability & Rehabilitation*, 22(6).
- Runge, C., Gilham, J., & Peut, A. (2009). Transitions in care of people with dementia: a systematic review of the literature. Canberra.
- Schwarzkopf, L., Menn, P., Leidl, R., Graessel, E., & Holle, R. (2013). Are community-living and institutionalized dementia patients cared for differently? Evidence on service utilization and costs of care from German insurance claims data. *BMC Health Services Research*, 13(1), 2. <https://doi.org/10.1186/1472-6963-13-2>
- Sinha, S., Peach, G., Poloniecki, J. D., Thompson, M. M., & Holt, P. J. (2013). Studies using English administrative data (Hospital Episode Statistics) to assess health-care outcomes - systematic review and recommendations for reporting. *European Journal of Public Health*, 23(1), 86–92. <https://doi.org/10.1093/eurpub/cks046>
- Stevnsborg, L., Jensen-Dahm, C., Nielsen, T. R., & Gasse, C. (2016). Inequalities in Access to Treatment and Care for Patients with Dementia and Immigrant Background: A Danish Nationwide Study, 54, 505–514. <https://doi.org/10.3233/JAD-160124>
- Tranmer, J. E., Croxford, R., & Coyte, P. C. (2003). Dementia in Ontario: Prevalence and Health Services Utilization. *Canadian Journal on Aging*, 22(4), 369–379.
- Turner, S., Iliffe, S., Downs, M., Wilcock, J., Bryans, M., Levin, E., ... O'Carroll, R. (2004). General practitioners' knowledge, confidence and attitudes in the diagnosis and management of dementia. *Age and Ageing*, 33(5), 461–467. <https://doi.org/10.1093/ageing/afh140>
- Vecchio, N. (2013). Gatekeepers to home and community care services: the link between client characteristics and source of referral. *Australian Health Review*, 37(3), 356–361. <https://doi.org/10.1071/AH13011>
- Vecchio, N., Fitzgerald, J. A., Radford, K., & Fisher, R. (2016). The association between cognitive impairment and community service use patterns in older people living in

Australia. *Health & Social Care in the Community*, 24(3), 321–333.

<https://doi.org/10.1111/hsc.12212>

Vu, M., Hogan, D. B., Patten, S. B., Jette, N., Bronskill, S. E., Heckman, G., ... Maxwell, C. J. (2014). A comprehensive profile of the sociodemographic, psychosocial and health characteristics of Ontario home care clients with dementia. *Chronic Diseases and Injuries in Canada*, 34(2–3), 132–144.

World Health Organization. (2016). *International Statistical Classification of Diseases and Related Health Problems 10th Revision*. <https://doi.org/10.1177/1071100715600286>

You, E. C., Dunt, D. R., White, V., Vander Hoorn, S., & Doyle, C. (2014). Risk of death or hospital admission among community-dwelling older adults living with dementia in Australia. *BMC Geriatrics*, 14(1), 71. <https://doi.org/10.1186/1471-2318-14-71>

Tables and Figures

Table 1: Description of socio-demographic characteristics of home care clients with and without dementia.

Characteristic	Dementia (n=2307)		Matched group (n=9224)		Sig
	%	(95% CI)	%	(95% CI)	
Age, mean (SD) years	84.01	(6.49)	84.01	(6.49)	
65-69	2.4%	(1.8%-3.1%)	2.4%	(2.1%-2.7%)	
70-74	6.2%	(5.3%-7.3%)	6.2%	(5.7%-6.7%)	
75-79	14.8%	(13.4%-16.3%)	14.8%	(14.1%-15.5%)	
80-84	25.5%	(23.8%-27.3%)	25.5%	(24.6%-26.4%)	
85-89	31.1%	(29.2%-33.0%)	31.1%	(30.2%-32.1%)	
90-94	16.2%	(14.8%-17.8%)	16.2%	(15.5%-17.0%)	
95+	3.7%	(3.0%-4.5%)	3.7%	(3.3%-4.1%)	
Sex, female	63.2%	(61.2%-65.1%)	63.2%	(62.2%-64.2%)	
Country of birth					
Australia	51.2%	(49.2%-53.2%)	55.8%	(54.8%-56.8%)	*

	Other	48.8% (46.8%-50.9%)	44.2% (43.2%-45.2%)	*
Interpreter required				
	No	84.1% (82.5%-85.5%)	88.7% (88.0%-89.3%)	*
	Yes	15.9% (14.4%-17.4%)	11.3% (10.7%-12.0%)	*
Living situation				
	Lives alone	39.9% (37.9%-41.9%)	44.6% (43.6%-45.6%)	*
	Lives with family	53.3% (51.3%-55.4%)	48.9% (47.9%-49.9%)	*
	Other	6.8% (5.9%-7.9%)	6.5% (6.0%-7.0%)	
Socioeconomic status				
	1	9.9% (8.7%-11.2%)	9.9% (9.3%-10.5%)	
	2	2.5% (2.0%-3.2%)	3.3% (3.0%-3.7%)	
	3	8.9% (7.8%-10.1%)	8.8% (8.2%-9.4%)	
	4	9.5% (8.4%-10.8%)	9.9% (9.3%-10.5%)	
	5	3.2% (2.6%-4.0%)	2.9% (2.6%-3.3%)	
	6	4.6% (3.8%-5.5%)	5.4% (5.0%-5.9%)	
	7	7.8% (6.8%-9.0%)	10.1% (9.5%-10.7%)	*
	8	17.3% (15.8%-18.9%)	18.6% (17.8%-19.4%)	
	9	21.0% (19.4%-22.7%)	19.6% (18.8%-20.4%)	
	10	15.3% (13.9%-16.8%)	11.6% (11.0%-12.3%)	*
Accommodation				
	Private residence	85.6% (84.1%-87.0%)	85.2% (84.5%-85.9%)	
	Retirement village	9.9% (8.7%-11.2%)	10.2% (9.6%-10.8%)	
	Other	4.6% (3.8%-5.5%)	4.6% (4.2%-5.1%)	
CI, confidence interval; SD, standard deviation; Sig, denotes statistical significance				

Table 2: Description of home care service utilisation for clients with and without dementia.

Variable	Dementia (n=2307)		Matched group (n=9224)		Sig
	%	(95% CI)	%	(95% CI)	
Admission					
Referral source					

	Hospital	30.3%	(28.5%-32.2%)	40.1%	(39.1%-41.1%)	*
	ACAS	8.1%	(7.1%-9.3%)	4.8%	(4.4%-5.3%)	*
	Community health service	12.9%	(11.6%-14.4%)	9.4%	(8.8%-10.0%)	*
	Local Medical Officer	11.6%	(10.4%-13.0%)	10.2%	(9.6%-10.8%)	
	Family/friend/neighbour	13.2%	(11.9%-14.7%)	6.3%	(5.8%-6.8%)	*
	Self	1.2%	(0.8%-1.7%)	3.3%	(3.0%-3.7%)	*
	Other	22.7%	(21.1%-24.5%)	25.8%	(24.9%-26.7%)	*
Service Provision						
Nursing intervention						
	Assessment only	4.5%	(3.7%-5.4%)	3.2%	(2.9%-3.6%)	*
	Care coordination	8.8%	(7.7%-10.0%)	9.6%	(9.0%-10.2%)	
	Counselling	12.7%	(11.4%-14.1%)	13.3%	(12.6%-14.0%)	
	General nursing	5.3%	(4.5%-6.3%)	4.4%	(4.0%-4.8%)	
	Monitoring and surveillance	24.4%	(22.7%-26.2%)	21.2%	(20.4%-22.0%)	*
	Supporting informal carers	5.8%	(4.9%-6.8%)	4.6%	(4.2%-5.1%)	
	Nursing procedure	24.6%	(22.9%-26.4%)	29.6%	(28.7%-30.5%)	*
	Teaching/education	12.4%	(11.1%-13.8%)	13.2%	(12.5%-13.9%)	
	Other	1.5%	(1.1%-2.1%)	0.9%	(0.7%-1.1%)	
Outcome						
	Goals achieved	60.3%	(58.3%-62.3%)	67.6%	(66.6%-68.6%)	*
	Change in capacity	1.4%	(1.0%-2.0%)	1.1%	(0.9%-1.3%)	
	Deterioration	23.8%	(22.1%-25.6%)	19.1%	(18.3%-19.9%)	*
	Failure to adhere to regime	0.6%	(0.4%-1.0%)	0.5%	(0.4%-0.7%)	
	Unexpected improvement	0.6%	(0.4%-1.0%)	0.6%	(0.5%-0.8%)	
	Other	13.2%	(11.9%-14.7%)	11.1%	(10.5%-11.8%)	*
Discharge						
Discharge status						
	Planned	61.0%	(59.0%-63.0%)	67.7%	(66.7%-68.7%)	*
	Unplanned	39.0%	(37.0%-41.0%)	32.3%	(31.4%-33.3%)	*
Discharge reason						
	Acute care	26.4%	(24.6%-28.2%)	23.2%	(22.4%-24.1%)	*
	Death	3.2%	(2.6%-4.0%)	3.5%	(3.1%-3.9%)	

	Informal care	8.0%	(7.0%-9.2%)	3.1%	(2.8%-3.5%)	*
	Permanent care	5.7%	(4.8%-6.7%)	2.5%	(2.2%-2.8%)	*
	Problem resolved	17.5%	(16.0%-19.1%)	27.7%	(26.8%-28.6%)	*
	Respite care	9.9%	(8.7%-11.2%)	2.6%	(2.3%-3.0%)	*
	Internal service transfer	8.5%	(7.4%-9.7%)	12.5%	(11.8%-13.2%)	*
	Self care	7.2%	(6.2%-8.3%)	11.2%	(10.6%-11.9%)	*
	Client terminated care	1.5%	(1.1%-2.1%)	1.6%	(1.4%-1.9%)	
	Other	12.1%	(10.8%-13.5%)	11.9%	(11.3%-12.6%)	
Discharge location						
	Home	57.9%	(55.9%-59.9%)	68.5%	(67.5%-69.4%)	*
	Hospital	26.2%	(24.4%-28.0%)	23.5%	(22.7%-24.4%)	
	Nursing home	7.4%	(6.4%-8.6%)	2.9%	(2.6%-3.3%)	*
	Other	8.5%	(7.4%-9.7%)	5.2%	(4.8%-5.7%)	*
Services on discharge						
	No service required	27.5%	(25.7%-29.3%)	29.2%	(28.3%-30.1%)	
	Other health care professional	28.4%	(26.6%-30.3%)	30.1%	(29.2%-31.0%)	
	Community health service	6.8%	(5.9%-7.9%)	7.3%	(6.8%-7.9%)	
	Non-health community service	7.1%	(6.1%-8.2%)	6.3%	(5.8%-6.8%)	
	Personal care	6.9%	(5.9%-8.0%)	4.2%	(3.8%-4.6%)	*
	Other	23.4%	(21.7%-25.2%)	22.8%	(22.0%-23.7%)	
Other services						
	Medical practitioner	45.7%	(43.7%-47.7%)	47.7%	(46.7%-48.7%)	
	Home help	8.8%	(7.7%-10.0%)	7.3%	(6.8%-7.9%)	
	Aged care assessment team	4.5%	(3.7%-5.4%)	2.4%	(2.1%-2.7%)	*
	Other	41.0%	(39.0%-43.0%)	43.0%	(42.0%-44.0%)	
CI, confidence interval; ACAS, aged care assessment service; Sig, denotes statistical significance

Figure 1: Reported relative risks and 95% confidence intervals for select variables for people with dementia compared to those without.

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