# DementiaCare Research Focus

This section aims to provide a channel of two-way communication between researchers and practitioners in the expanding field of social, psychological and nursing research in dementia care, including all aspects of nursing and care practice, communication and the environment.

The Research Focus section of the Australian Journal of Dementia Care aims to keep readers up to date with the fast expanding field of social, psychological and nursing research in dementia care. By this we mean every aspect of person-to-person communication, nursing and care practice and organisation, and the influence of all aspects of the environment. The aim is to provide a channel of two-way communication between researchers and practitioners, to ensure that research findings influence practice and that practitioners' concerns are fed into the research agenda. We would like to hear from you, specifically with:

notice of the publication (recent or imminent) of peer reviewed papers with practical relevance to dementia care;

- research reports available for interested readers;
- requests or offers for sharing information and experience in particular fields of interest.

# Lack of dementia services may contribute to retrievals

**Fergus Gardiner**, **Noel Collins**, **Mathew Coleman** and **Frank Quinlan** report on a cross-sectional review of data for patients with dementia requiring aeromedical retrieval by the Royal Flying Doctor Service of Australia

verall, the Australian population enjoys relatively good health. However, rates of potentially avoidable morbidity and mortality increase with remoteness, to more than 2.5fold higher in populations living in very remote areas compared to those living in major cities (Gardiner et al 2018a). The causes of lower life expectancies in rural and remote populations are multifactorial (van Gaans & Dent 2018), however in part appear to be associated with reduced access to essential services, such as healthcare (Gardiner et al 2018a). Whilst rurality is associated with lower life expectancy, rural and remote populations are likely to experience growing rates of dementia, due to high comorbidity rates and an ageing population.

While the exact number of people living with dementia in Australia is unknown, it is estimated that in the year 2020 400,000-459,000 Australians have dementia, with Alzheimer's disease making up the majority (up to 70%) of cases (AIHW 2020). This figure is expected to grow, due to the



Herb, a Royal Flying Doctor Service (RFDS) patient in Tilpa, far west NSW. As well as providing aeromedical emergency services to country Australia, the RFDS is also the GP for hundreds of communities in the bush. Photos courtesy RFDS

ageing Australian population, with median age increasing in rural and remote populations due to many younger people leaving for work and study (Bauer *et al* 2019).

Dementia is also likely to grow at a faster rate in rural and remote areas, as compared to major city areas, due to the higher rates of modifiable risk factors in rural and remote areas, including (although not limited to) smoking, type two diabetes, hypertension, and obesity (AIHW 2020). Additional risk factors that may be more prevalent in rural settings include lower levels of education, depression, excessive alcohol consumption, geographical isolation and infrequent social contact (Livingston *et al* 2020). There is no cure for dementia which remains the leading cause of dependency and disability among older people (Morgan, Innes & Kosteniuk 2011), which is worrying given the ageing rural and remote population (Gardiner *et al* 2018b), coupled with high rates of vascular disease (Gardiner *et al* 2019a). While dementia can affect younger people, it is mainly associated with advancing age occurring in those aged 65, or 55 years old if Aboriginal and Torres Strait Islander (hereafter referred to as Indigenous) (Gardiner *et al* 2019b).

## **Review of patient data**

While there has been some research concerning older people's health and access to services in rural and remote Australia (Gardiner *et al* 2019b), there has been little research aimed at determining the characteristics of patients with dementia requiring aeromedical retrieval to innerregional and major city areas for ongoing care.

We undertook a crosssectional review of prospectively collected routine patient data for patients retrieved for dementia by the Royal Flying Doctor Service (RFDS) from anywhere in Australia between 1 July 2016 and 31 June 2020 (four years). Patient diagnostic data was coded to the International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10) (WHO 2020).

During the study period, the RFDS conducted 449 patient episodes of care for people experiencing a dementia, as



A RFDS primary health consultation in Tasmania. RFDS provides regular fly-in-fly-out GP, nursing and allied health clinics

highlighted in Table 1 (see below). This included 272 (60.6%) males and 177 (39.4%) females, with the median age being 71 years old (interquartile range (IQR) 52.75-79.0). The majority of patients were non-Indigenous (n=347; 77.3%), however there was an overrepresentation of Indigenous patients (n=102; 23.0%). Indigenous patients were significantly younger, with a median age of 53.0 (IQR 30.5-67.0), as compared to non-Indigenous patients, with a median age of 74.0 years

(IQR 62.0-80.0). **Reasons for retrieval** The leading retrieval reasons were for delirium (n=134; 29.8%), unspecified dementia (n=93; 20.7%), and unspecified organic or symptomatic mental disorder (n=60; 13.4%) (see Table 1 which details patient aeromedical retrieval characteristics).

# Discussion

It is unclear from this inflight clinical coding what the exact reasons for retrieval were. However, if retrieval is assumed to be a proxy for the need for acute medical treatment, then studies looking at the reasons for acute hospital admission for people with dementia may provide some clues.

People with dementia are often admitted for co-morbid medical problems such as pneumonia, UTI or dehydration, consistent with the finding that 30% of retrievals were in response to delirium (Natalwala et al 2008). Other research reports suggest that the presence of responsive behaviours such as agitation, aggression as well as increasing functional dependency also increase the risk of acute admission (Toot et al 2013). Given that responsive behaviours significantly increase carer burden in home, residential care and medical settings (Sampson et al 2014), this is likely to contribute to local care or placement failure and a subsequent request for medical escalation and retrieval.

In rural and remote areas there is a shortage of local dementia services and due to geographical and social isolation many patients are required to travel long distances to access services (Bauer *et al* 2019). This puts

(ICD-10 code) In-flight working diagnosis	Male (%)	Female (%)	Total (%)	Median age (IQR)
F00 Dementia in Alzheimer disease	14 (5.1)	13 (7.3)	27 (6.0)	74 (71-78.5)
F01 Vascular dementia	16 (5.9)	4 (2.3)	20 (4.5)	75 (67.75-80.0)
F02 Dementia in other diseases classified elsewhere	11 (4.0)	4 (2.3)	15 (3.3)	75 (62.5-78.5)
F03 Unspecified dementia	58 (21.3)	35 (19.8)	93 (20.7)	77 (73.0-85.0)
F04 Organic amnesic syndrome, not induced by alcohol and other psychoactive substances	1 (0.4)	2 (1.1)	3 (0.7)	71 (71.0-76.0)
F05 Delirium, not induced by alcohol and other psychoactive substances	77 (28.3)	57 (32.2)	134 (29.8)	68.5 (54.5-78.0)
F06 Other mental disorders due to brain damage and dysfunction and to physical disease	22 (8.1)	8 (4.5)	30 (6.7)	51 (34.75-64.0)
F07 Personality and behavioural disorders due to brain disease, damage and dysfunction	10 (3.7)	7 (4.0)	17 (3.8)	57 (49.0-67.0)
F09 Unspecified organic or symptomatic mental disorder	36 (13.2)	24 (13.6)	60 (13.4)	43.5 (28.0-68.0)
G30 Alzheimer disease	7 (2.6)	10 (5.6)	17 (3.8)	75.5 (71.25-77.0)
G31 Other degenerative diseases of nervous system (such as circumscribed brain atrophy; senile degeneration; degeneration due to alcohol)	20 (7.4)	13 (7.3)	33 (7.3)	68 (59.0-76.0)
Total	272	177	449	71 (52.75-79.0)

Table 1: Characteristics of patients who received an aeromedical retrieval for dementia, from the years 2016 to 2020, throughout rural and remote Australia

much pressure on friends, family and carers of people with dementia (Papastavrou et al 2015), who are required to escort loved ones, often due to the person with dementia not being able to, or allowed to, drive; or due to the inaccessibility of suitable public transport. Other obstacles to local care include fewer local specialist providers (and culturally appropriate services), limited clinical dementia training for local health care workers, and limited geriatric and diagnostic service (Kendig & Phillipson 2014; Morgan et al 2015).

The lack of commissioned memory assessment pathways and models of care in rural settings make post-diagnostic care and signposting to local non-government support organisations such as Dementia Australia difficult. Splits between the national funding of aged and geriatric care, primary care, social care and state-based older adult mental health or neurological services further complicates the provision of integrated care (Chase et al 2020).

Furthermore, many of the patients are from small towns, where the stigma of having dementia can be experienced, with carers avoiding accessing support services for fear of being ostracised (Phillipson et al 2015). Combined with the additional challenges of navigating complex health and social care systems, these challenges may result in people waiting until a crisis point before seeking any help. As such, sustained policy initiatives that support the commissioning and investment in local integrated dementia diagnostic and support services are likely to reduce the need for sudden escalation and aeromedical retrieval.

Improving the capacity and capabilities of local hospitals to detect and manage delirium, as well as specialist support to manage responsive behaviours in local care settings are also likely to reduce the dependency on RFDS services by people living with dementia.

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A patient is transferred on to an RFDS aircraft for transport to hospital