Dementia care and best practice in rural and remote settings

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Introduction
Rural and remote Australia poses many challenges for the provision of quality dementia care, including geographical isolation, sparse population distribution, ageing population, migration factors, poor socio-economic status, workforce recruitment and limited services (Henderson & Caplan 2008). Given the numerous challenges facing service provision, and by and large the poor delivery of services for people with dementia and their caregivers living in rural and remote Australia, the need to close the research gap in dementia care for people in rural and remote areas is important.

To explore the barriers to rural and remote dementia care worldwide, outline the gaps in rural and remote service provision and present the key initiatives in dementia care practice in rural and remote regions a detailed review was completed of Australian and international literature. This review informed the discussion which contains recommendations for best practice, identifies the key research gaps, provides recommendations for future research in rural and remote dementia care and tips for clinicians working in rural and remote regions.

Methodology
Information was sourced for the literature review by a number of methods. An internet search of databases and websites was conducted for the majority of Australian and all international information. For additional information on Australian service providers, a number of Alzheimer’s Australia organisations and a Dementia Training Study Centre were contacted by telephone and then when required followed up by email. Information was additionally received by post from rural agencies.

The key internet search engines used to find published articles were Medline and Pubmed. The search terms used were ‘dementia and rural’, ‘dementia and remote’. The Pubmed search on ‘dementia and rural’ identified 452 papers, and 232 papers from the terms ‘dementia and remote’. The Medline search identified 356 papers using the terms ‘dementia and rural’, and 140 papers from the terms ‘dementia and remote’.

Further papers were identified by Google Scholar. Google was used to source other reports and information.

Articles were selected for their relevance to the key areas of rural and remote: demographics, dementia service gaps, dementia care initiatives and best practice worldwide, with a particular emphasis on Australian studies. Saved papers were then reviewed in detail and, if still deemed relevant to the key areas, summarised and appraised.
Literature review

1. Demographics

Australia is a vast continent with the majority of its land mass classified as very remote and sparsely populated (Hugo 2002) (see Figure 1).

Figure 1 Accessibility/ Remoteness Index of Australia (Glover & Tennant 2003, p.5)

Rural and remote regions worldwide are generally typified by a dispersed population over a large geographical area (see Scotland Figure 2), contributing to the difficulties in providing rural and remote dementia care (Blackstock et al. 2006). However, international and national comparisons of rurality and remoteness are all relative with India being somewhat different to Australia, country Victoria being different to the vastness of Western Australia, and a large tourist town being different to a farming area or a remote Aboriginal community.
Since World War II the major proportion of the Australian population has lived in urban areas (Hugo 2002, see Figure 3) and although the decline in the rural population stabilised in the 1980’s, the rural population has once again decreased since the 1990’s (Fraser et al. 2005). This was primarily due to internal migration with the collapse of agriculture markets, a fall in land values, widespread drought and the centralisation of agricultural production to increase productivity. This led to a fewer number of farming families, a decline in the local economy and reduced employment, additionally affecting the surrounding towns which service farms and stations (Fraser et al. 2005). Remote
mining town populations, which are always vulnerable to decline, have recently been impacted by the ‘global economic crisis’ leading to a decline in local economy and employment levels.

**Figure 3. Changing distribution of population between urban and rural sectors, 1921-1996 (Hugo 2002, p.7)**

A relatively new phenomenon has lead to an increase in migration to some rural and remote areas due to the popularity of coastal and ‘tree change’ towns, with people with young families making up the majority of people migrating to these areas, although with coastal areas being a particularly popular retirement destination 21% are over 50 years of age (ABS 2004). Emigration of ‘tree change’ destinations usually balances immigration to the area (Davis & Bartlett 2008).

The rural population is ageing at a faster rate than urban Australia, lead by the emigration of younger people to urban areas for educational, employment and lifestyle opportunities (AIHW 2007; Hines & Black 1993). Twenty-five percent of the population living in small rural centres are aged over 55 years, compared to 24% of people from other rural areas, 21% of people in capital cities and 12% of people living in remote areas (ACSA & NRHA 2004).
The trend of rural emigration is occurring in many other developed nations. In the 1980’s the US had a farming crisis and in the 1990’s and 2000’s mad cow and foot-and-mouth disease in the UK resulted in a decrease in the rural population and poorer socio-economic status and health for the people that remained in the rural areas (Fraser et al 2005; Philo 2003). Developing nations are also experiencing urbanisation with many younger people, who traditionally cared for their family members, leaving rural areas to seek work in towns (Ineichen 1998).

Rural and remote populations tend to have higher levels of financial strain than urban populations (ABS 2000, Shaji et al. 2003), with the difference being particularly pronounced between very remote and urban areas (ABS 2000). Aboriginal and Torres Strait Islander peoples are the most impoverished population in rural and remote Australia, with poor access to services, employment and income opportunities (Alston 2000).

The Australian rural and remote population has poorer health than other Australians (Gibson et al. 2002). This is due to factors such as poor socio-economic status, lower levels of education, environmental risks and poor access to quality health services (Davis & Bartlett 2008). Common risk factors in rural and remote populations include obesity, smoking, drinking, environmental dangers, personal injury, hypertension, high cholesterol, asthma and diabetes (AIHW 2005; AIHW 2006).

Depression and dementia are the largest cause of disability burden for Australians (Mathers et al. 1999), including rural Australians (Walker et al. 2007) (see Table 1).

### Table 1 Health conditions by effect on quality of life (Walker et al. 2007 p.22)

<table>
<thead>
<tr>
<th>Condition</th>
<th>Occurrence Ranking</th>
<th>Mean Impact Score</th>
<th>Condition</th>
<th>Occurrence Ranking</th>
<th>Mean Impact Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychological Condition (depression, dementia)</td>
<td>13</td>
<td>3</td>
<td>Gastrointestinal Condition</td>
<td>10</td>
<td>2.3</td>
</tr>
<tr>
<td>Cancer</td>
<td>12</td>
<td>2.75</td>
<td>Osteoporosis</td>
<td>7</td>
<td>2.3</td>
</tr>
<tr>
<td>Musculoskeletal Other</td>
<td>6</td>
<td>2.7</td>
<td>Circulatory Other</td>
<td>12</td>
<td>2.25</td>
</tr>
<tr>
<td>Blood Disorder</td>
<td>11</td>
<td>2.6</td>
<td>Skin condition</td>
<td>11</td>
<td>2.2</td>
</tr>
<tr>
<td>Stroke</td>
<td>11</td>
<td>2.6</td>
<td>Auto-immune Condition</td>
<td>14</td>
<td>2</td>
</tr>
<tr>
<td>Other</td>
<td>7</td>
<td>2.5</td>
<td>Eye Condition</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Prostate Problem</td>
<td>14</td>
<td>2.5</td>
<td>Diabetes</td>
<td>4</td>
<td>1.9</td>
</tr>
<tr>
<td>Renal Disease</td>
<td>12</td>
<td>2.5</td>
<td>High Cholesterol</td>
<td>12</td>
<td>1.5</td>
</tr>
<tr>
<td>Neurological Condition</td>
<td>9</td>
<td>2.3</td>
<td>Hypertension</td>
<td>2</td>
<td>1.5</td>
</tr>
<tr>
<td>Asthma/Pulmonary Disease</td>
<td>8</td>
<td>2.3</td>
<td>Thyroid Disease</td>
<td>14</td>
<td>1.5</td>
</tr>
<tr>
<td>Arthritis</td>
<td>1</td>
<td>2.3</td>
<td>Cardiovascular Disease</td>
<td>3</td>
<td>1.4</td>
</tr>
</tbody>
</table>

There is a larger proportion of Aboriginal and Torres Strait Islander peoples living in rural and remote than urban areas (Hugo 2002). Gibson et al. (2002) report that Indigenous Australians comprise 1% of cities, 3% of rural, 13% remote centres and 26%
of people in ‘other remote areas’. Very remote areas have a higher proportion of younger people than rural and remote regions, which is influenced by the higher proportion of Indigenous Australians living in these regions (Hugo 2002). Although the population distribution of Indigenous Australians is younger than non-Indigenous Australians they access aged care services at a younger age (Gibson et al. 2002), and the prevalence of dementia in remote Indigenous Australians is approximately 5 times higher than non-Indigenous Australians (Smith et al. 2008).

Only two dementia prevalence studies in Australia have included rural or remote populations. Henderson et al. (1994) investigated the prevalence of dementia in Canberra including a nearby rural town in a sample of approximately 850 people aged 70 years and over. The prevalence of dementia in the overall sample was 7.4%. Due to a high rate of refusals, difficulties in finding informants and other biases, the authors stated that this figure is not representative of the studied population. The prevalence of dementia in the rural town was not stated. A prevalence study of dementia in remote living Indigenous Australians in the Kimberley region of Western Australia reported a prevalence of 12.4% in the sample aged over 45 years. This figure is 5.2 fold the prevalence of dementia in all Australians (Smith et al. 2008).

Jorm et al. (1987) reported in a review of Scandinavian dementia studies that the three rural studies reviewed had significantly lower rates of dementia than urban or mixed studies. This comparison may have been biased due to the difference in sampling methods, as the rural studies assessed the total populations, whereas urban studies reviewed a sample of the population. Other studies have found no difference in risk of dementia between rural and urban sites (Yip et al. 2006) and Hall et al. (2000) reported an association between rural residence in childhood and low education and Alzheimer’s disease.

Although further investigation of the extent of dementia in rural areas is required, the ageing demographic of rural areas and the high prevalence of dementia in remote Indigenous Australians highlights the necessity of developing and implementing quality aged care services that address the needs of people living with dementia in rural and remote Australia.
2. Service Gaps

There are many positive initiatives for people with dementia and their caregivers living in rural and remote Australia, and some of these key initiatives will be outlined in section 3. Nevertheless people living with dementia in country regions are largely disadvantaged in terms of having available, accessible and acceptable services to address their specific needs. As John Anderson, the previous leader of the Australian National Party observed “The sense of alienation, of being left behind, of no longer being recognised and respected for the contribution to the nation being made, is deep and palpable in much of rural and regional Australia today” (Anderson 1999).

a) Service co-ordination

Across Australia a complex community service structure has originated from a number of community services being set up independently from one another to service the same area and clients (O’Reilly & Strong 1997a). This structure has often led to poor service coordination and communication. Dispersed populations create particular difficulties for the organisation and co-ordination of services (Innes et al. 2006). In rural and remote settings ‘possessiveness’ of clients or personal differences can be more visible and further inhibit service co-ordination (O’Reilly & Strong 1997a).

The informal networks existing in rural and remote communities can assist service co-ordination and aid formal communication (George & Bradshaw 2006; Blackstock et al. 2006). As a caregiver in rural Scotland notes “Here we meet each other, you know, you bump into Iona (service provider) or Helen or whoever in the shop. Here it is different you are always in contact” (Blackstock et al. 2006 p.168).

To overcome service co-ordination issues Innes et al. (2006) recommends forming partnerships with other agencies to provide joint services in rural and remote areas, the flexible use of the wider generalist health care team, use of technology e.g. telehealth, and effective transport.

b) Service funding

The majority of aged care funding from the Australian government is spent on residential care subsidies and approximately 9% of federal government ageing expenditure is spent on community care (Henderson & Caplan 2008), with state governments co-funding this area.

Many rural and remote aged care services face high levels of financial burden due to the higher costs of consumables, infrastructure, staffing, need for outreach services, travel costs and small service size (ACSA & NRHA 2004). Services are often funded by population size without distances to be covered by these services or population need being taken into account (O’Reilly and Strong 1997a). This results in rural and remote services having to stretch resources and personnel over vast distances, inhibiting case management (Philo et al. 2003). For example in remote areas Aged Care Assessment Teams (ACAT) have to travel large distances to see clients, with resulting assessments
often being based on one visit without the time to build rapport with the client, family and local services (Hansen et al. 2005).

As rural and remote areas for the most part have adopted urban models of health care and workforce measures, service design and funding must change (Davis & Bartlett 2008; Innes et al. 2006; Philo et al. 2003). Hines & Black (1993) recommend using a combination of population size, level of disease burden, and demand methods to determine service requirements in rural areas.

c) Specialist services
Services in rural and remote areas for people with dementia and their caregivers are limited. Most towns with a population less than 10,000 have only generic services, with limited dementia diagnostic, management, respite and support services and poor access to appropriate facilities (Brodaty et al. 2003; Hansen et al. 2005). HK Training and Consultancy (2002) identified a lack of specialist geriatric services such as psychogeriatricians, geriatricians and neuropsychological assessment or services in rural and remote areas. A lack of specialists with dementia expertise in rural and remote areas is reported in the literature in developing and developed countries worldwide (Innes et al. 2005; Shaji et al. 2003).

General practitioners are central to the care of people with dementia and their carers but due to a number of factors, including competing demands and lack of dementia training this role may not be fulfilled (Brodaty et al. 1990). As a service provider states “Mental health issues in aged care, especially in dementia, very often it’s in the too hard basket. No one wants to deal with it” (Eley et al. 2006 p. 28). In addition social worker contact is important in service referrals for dementia care however social worker positions are not often funded in remote areas (Brodaty et al. 2005).

Competing demands often lead to dementia care being a low priority for generalist health care providers in rural and remote areas, particularly for health professionals working in developing countries or with Aboriginal and Torres Strait Islander peoples with ‘fourth world’ health problems. In rural India, similar to Indigenous Australia, the primary care service focuses on child, maternal health and control of infectious diseases and little training or priority is given regarding aged care to primary health care workers (Shaji et al. 2003).

d) Workforce Shortages
Recruitment and retention of staff are issues in rural and remote areas worldwide (Henderson & Caplan 2008; Shaji et al. 2003; Turyn 2001). Some reasons identified for the aged care and health professional workforce shortages in rural and remote Australia are low salaries, lack of training, insufficient Aboriginal and Torres Strait Islander recruitment, use of private transport, lack of housing and housing costs, poor career recognition, and ageing of the aged care workforce (Henderson & Caplan 2008; Davis & Bartlett 2008). The isolation, lack of staff support and distance from family and friends
leads to stressful work conditions and when staff members are not replaced immediately local information and possible support networks are not handed over (O’Neill et al. 2004).

The general shortage of qualified and experienced health professionals and aged care workers and frequent staff turnover can compromise client care. A key concern of many Aboriginal and Torres Strait Islander rural and remote communities is the lack of residential care options within their communities. "We need funding for an old people's home in the community, because when old people are taken into town they get really homesick" (Senior 2000 pg.19). Australian government flexible aged care service grants are available to establish residential care in Aboriginal and Torres Strait Islander communities however workforce expertise and training options are lacking, putting residents at risk, such as the distressing death of an elder in a fire pit at the remote Docker River community aged care in 2007. As the Aged Care Commissioner Rhonda Parker detailed in a review into the incident "Throughout the life of the (aged care) Service, staffing has been a significant issue and continues to be so. During one 12-month period, there was a turnover of 40 staff. At the time of my visit to the Service, the longest serving clinical staff member had been employed for six months. There was a new Care Coordinator who had only been employed for a matter of weeks, and a new carer for the same period, who came to work at Docker River during her long service leave. The difficulty in recruiting staff to the Service has had a flow on effect, one of which is a lack of coverage overnight at the Service. I understand the Shire is focussing on this overnight issue as a matter of priority.”(Parker 2008, p.11).

Since this incident Australian Government funding for staff accommodation, better facilities, training and support of staff and management, and provision of emergency staff relief has become available through the Remote and Indigenous Service Support Programme (Elliot 2008).

e) Diminishing pool of informal caregivers

With a shortage of formal services in many rural areas and failure of services in many remote areas for people with dementia and their families, informal caregivers provide the majority of care to people with dementia in these settings (Brodaty et al 2005; Hayes et al. 2006).

A rural Tasmanian study reported that most participants (95%) could identify a family or friend who would provide some level of support to them on a regular basis with children being the primary source of contact and support for participants (Walker et al. 2007). Senior (2000, p.19) reports on a caregiver experience of the cultural responsibilities of rural and remote Aboriginal and Torres Strait Islander peoples to provide informal care to their family members. "If you have a family, you care for all of your family, and all your in-laws too. All this looking after them makes you stressed out. In our way we must look after old people".
The strong informal support network in rural and remote areas is reported in literature worldwide. A Scottish study reported the important role of family and friends in providing social and emotional support to caregivers and people with dementia and also being there in times of crisis. As one caregiver stated “Here in the Highlands and Islands as I understand it there has always been strong kinship ties...there is a strong affinity towards clanship and that is still a significant factor for people who live in the Highlands and Islands, that they are close together or have extended families that are supportive of one another” (Blackstock et al. 2006, p.169).

Due to these strong support networks people with dementia and caregivers living in rural and remote areas are often supported and cared for at home longer than in urban areas (Hansen et al. 2005), although informal networks may not always be preferred over formal services. As outlined by William and McHugh (1993, p.4) “Although rural communities are famed for their spirit of independence and self-reliance, it cannot be concluded that an apparent willingness to rely on informal assistance would be actually preferred if formal services were readily available as an alternative. Country people may well make a virtue of necessity.”

Although rural and remote areas are known for their closer family networks (Hayes et al. 2006) there are signs that this pool of informal caregivers is diminishing, increasing the need for quality services and infrastructure aimed at supporting people with dementia at home in rural and remote communities, and supporting those caregivers that remain in the role (Davis & Bartlett 2008).

While extended family do often fulfil their family and cultural obligations and provide support for people with dementia and their caregivers, family support can often be absent, particularly given the worldwide trend of the breaking down of traditional ways and families. A study in rural India reported that while some extended family members do fulfil their responsibilities, often family social support is absent resulting in caregiver stress, isolation and family disputes (Shaji et al. 2003).

Emigration is a key factor diminishing the pool of informal carers with younger people leaving rural and remote areas due to economic, employment and other socio-economic reasons (O’Reilly & Strong 1997b), and in some cases older people are retiring to regional centres without their families living in close proximity. Instead of family, friends and neighbours are often relied upon to fill the service gap (Buckwalter 2002). Other factors diminishing the pool of informal caregivers are the trend towards smaller families, relationship breakdowns, the ageing of carers and more women entering the workforce (Henderson & Caplan 2008).

f) Caregiver support services

O’Reilly and Strong (1997a) identified education and respite as the most important services for caregivers of people with dementia living in rural areas. Alzheimer’s Australia WA (2007) state that emotional and social support was the most important issue
for rural and remote carers of PWD, followed by respite/residential care availability, education and access to community services (see Figure 4).

**Figure 4** Identified caregiver needs (Alzheimer’s Australia WA 2007 p. 28)

![Identified Needs from Individual Carers](image)

Other services that are not provided to the extent required in rural and remote areas are therapy services, Aboriginal health workers, home help, personal care, respite and residential care (O’Neill et al. 2004). The main gaps of service provision for Indigenous caregivers of people with dementia include respite, education, training and support for families and community services (HK Training and Consultancy 2002).

Carer respite services are particularly limited in remote areas, with respite organisations based only in the largest towns. Alzheimer’s Australia WA (2007) reported that respite was more likely to be provided through hospitals and nursing homes in regional areas, reflecting the lack of in-home or community-based respite options in regional areas. *The only respite available is in hospital. Carers are made to feel this is not appropriate and also that ‘it's your job’* (Alzheimer’s Australia WA 2007 p.46).

Hansen et al. (2005) noted that while it is of benefit that the rural area studied in Tasmania often has an emergency hospital respite bed available, it is a safety concern that people with dementia are placed in this non-secure bed at the hospital. Rural and remote caregivers from other countries also have difficulties accessing respite services (Innes 2006), with an identified need for locally based respite to support caregivers in caring for their relatives in the community (Innes et al. 2005). A Scottish study of rural caregivers identified in-home respite as the preferred respite option for people with dementia and their caregivers “*Ideally, what I would like would be if somebody could come and stay here with her ... that would be best, that would mean there was almost no distress and disruption*” (Innes et al. 2005 p.358).

In a study of young onset dementia (<65 years) around Australia Luscombe et al. (1998) found that there were no differences in the use of community support services, respite
services or carer support services in metropolitan versus rural areas. Sampling bias would have affected this finding as the ‘convenience’ rural sample was recruited through referrals and support groups it was comprised of people who already accessed services in those areas.

A Scottish study of caregivers reported that home and personal care provision was influenced by the availability of paid carers (particularly poor in remote areas) and distance. Often travel time would take longer than the care task, such as to put someone to bed or assistance with showering (Innes et al. 2005). Day care service gaps were related to inappropriate venues and activities offered and the poor availability of places (Innes et al. 2005).

The provision of aids and home care are a real need for rural caregivers in India, where the most distressing issue resulting from dementia is incontinence (Shaji et al. 2003). Houses in rural areas without attached bathrooms, high number of inhabitants and floors that are difficult to clean would become almost inhabitable for the residents. This issue also impacts on other components of the families lives. As one caregiver reported “As long as she is here and is like this, we cannot think of our son’s marriage. Who will want to send their daughter to a house like this?” (Shaji et al. 2003, p.3).

Rural and remote living people with dementia who have challenging behaviours, and cannot be managed at home or in generic residential care, are sent to a larger town away from their local community (Alzheimer’s Australia WA 2007). As an Australian service provider stated “There is always a chronic shortage of aged care facilities, particular dementia-specific units for dementia care. It’s very rare in rural areas. We do not have one and we desperately require one and we’re not going to get one” (Eley et al 2006, p.28).

For those rural communities that are fortunate enough to have services available to them, lack of choice is often identified as a problem, with the service perhaps not being suitable for people with dementia. As a Scottish caregiver noted “[It] All links with choice. It’s a rural community and people don’t have a choice of five or six different services, they have the one that is closest to them” (Innes et al. 2006 p.257).

g) Financial support

The higher cost of living, particularly for fuel, transport and food creates financial burden for the rural and remote caregivers looking after people with dementia (O’Reilly and Strong 1997a). As one remote caregiver stated “Pensioners in remote areas should get an allowance to compensate for higher fuel and groceries [costs]” (Alzheimer’s Australia WA 2007 p.50).

Cost may prevent rural and remote caregivers from seeking residential respite and care (Hansen et al. 2005). In a report by Alzheimer’s Australia WA (2007) caregivers reported that the carer’s allowance and payment are insufficient given the higher cost of transport, medications, continence aids and special equipment in rural and remote areas.
Financial difficulties are of course more pronounced in developing countries. Family caregivers in rural India are often unable to find a regular job, particularly when their family member has behavioural symptoms of dementia. This reduces the family income at a time when they often have to face increased medical expenses (Shaji et al. 2003). Government financial support for caregivers is not usually provided. As Shaji et al. (2003 p.2) report “One family member applied for financial assistance from the government, he had not received a reply after many months and said that he did not expect any response before his mother died.”

The requirement to pay for services may lead rural and remote caregivers to reject support. Morgan et al. (2002) reported that for Canadian caregivers this was not only related to the high cost of services and financial hardship but also attitudes, where after a lifetime of hard work people believed that they should not have to pay for support, or a lifetime of frugality may make them reluctant to pay for services. “We have a large number of elderly people in our district, and there are lots of them that will not pay for home care, no matter what. They worked hard all their lives for that money and they’re not giving it to anybody” (Morgan et al. 2002 p. 1137).

h) Caregiver training
Caregiver education needs identified by Hansen et al. (2005) and O’Reilly & Strong (1997b) include the dementia disease process, the legal position of people with dementia and carers, available dementia specific services, and the role of doctors and other health professionals. Hansen et al. (2005 p.77) reported that caregivers requested training on behavioural changes associated with dementia and management techniques, “I do think there should be something, someone with a knowledge of dementia who can come and tell you what to expect.”

A lack of awareness of the existence of services or understanding of how the services can assist caregivers has influenced the rate of service provision (Brodaty et al. 2005). Studies in rural areas of developed and developing countries have identified that the most important information required for caregivers is on dementia as a disease and practical strategies to support people with this condition (Innes et al. 2005; Shaji et al. 2003).

i) Workforce Training
Training is required for health professionals such as general practitioners, nurses and Aboriginal health workers, hospital staff, community aged care staff and aged care facility staff (Alzheimer’s Australia WA 2007). Dementia training is not currently included in Aboriginal health worker courses. Some of the key areas for training are dementia symptoms, progression, stages, caring for a person with dementia, challenging behaviours, guardianship and legal issues, services and resources available for people with dementia and cultural awareness training (Alzheimer’s Australia WA 2007).
Government scholarships are available for aged care workers in rural and remote areas to access training opportunities, however education options within the regions are limited and there are high costs involved with accessing training outside their communities. (Older people and aged care 2004). Health managers require training in financial management, staffing and cultural awareness (ACSA & NRHA 2004).

Certificate III in aged care, which is recommended for aged care workers can be difficult to obtain in rural and remote areas (ACSA & NRHA 2004), and can be difficult for people with low literacy levels such as people from remote Aboriginal communities to obtain without ongoing support.

Generic health professionals may have poor dementia awareness leading to a lack of quality health care for people with dementia and their families (Alzheimers Aust WA 2007; Davis & Bartlett 2008). As one rural Canadian caregiver stated “I would say that our problem was mostly the fact that you knew the person was not well, was having a lot of problems, but when you take them to the doctor, the doctor would say, ‘Oh, they’re just getting old—everybody gets forgetful.’ And you would have no help from that.” (Morgan et al. 2002, p.1136).

An Australian study found that general practitioners had difficulties with dementia diagnosis and management, even though they were aware of diagnostic features and carer needs (Brodaty et al. 1994). General practitioners have an important role in the diagnosis and management of dementia, particularly in rural and remote areas, and support and training through videoconferencing and other methods may increase their confidence in their role (Downs et al. 2000).

Caregivers of people with dementia in rural Tasmania identified community nurses as being an important carer resource in rural areas (Hansen et al. 2005). The community nurses were concerned about their own lack of dementia knowledge and reported that they required dementia training to improve the quality of care provided (Hansen et al. 2005).

Identified health provider training gaps include dementia diagnosis, management strategies, medication, legal issues and structure of the aged care system (Hansen et al. 2005; Davis & Bartlett 2008). While the barriers to training for service providers include cost, time and travel, the benefits of training for service providers include increased job satisfaction, improved job security and sense of professional worth in addition to the obvious benefits for people with dementia and their caregivers (Innes et al. 2006; Innes et al. 2005).

j) Transport
The distance to key services limits access to specialist and community services, and impacts on the level of health care resources available to the older population in rural and remote areas worldwide (Hansen et al. 2005; Blackstock et al. 2006). A nurse reported “If they’re (a person with dementia) in a local area they (a carer) can often pop in every
Caregivers in rural and remote areas are more likely to report that distance is a problem for accessing dementia assessment and diagnoses for younger people with dementia compared to people living in urban centres (44% versus 13%, Luscombe et al 1998).

The most commonly cited barrier to accessing services is the lack of transport available in rural and remote communities (Walker et al. 2005; Williams &McHugh 1993; Innes et al. 2005). At a time when walking and driving are less accessible, there is an associated loss of independence, a problem greatly magnified when public or community care transport is not available (Walker et al. 2005). This leads to isolation of the caregiver and person with dementia, creates difficulties in accessing supports and services and is a barrier to visiting their friends or family members, and people living in residential care (O’Reilly & Strong 1997a; ACSA & NRHA 2004).

Walker et al. (2007) reported that a loss of social contact and informal support from transport problems may be more significant for the health of community members than the difficulties it creates in accessing health services. As reported by a caregiver in a remote Aboriginal community "Old people are not used to sitting around camp, they are used to walking in the bush. People could take them to the billabong and get them to talk about their childhood. But there is so little transport and in the wet it gets harder" (Senior 2000, p.20).

Driving long distances can be tiring for caregivers and the person with dementia, which is compounded by the effort it may take to get their family member in and out of the car. As a Canadian caregiver reported “In the first place it was difficult to get my husband into the car, but ... well I might be able to get him into the car, but when I got him home, it would take several hours of persuasion [to get him out] that’s practically impossible, so it wasn’t worth it.” (Morgan et al. 2002, p.137).

When there are long distances to drive to access services the free time gained by taking their family member to day care or respite is often offset by the time spent in the car (Buckwalter 2002).

Rural and remote roads are often in poor condition which can be risky for the person with dementia and their caregiver (Innes et al. 2005), even when only short distances are involved. “The roads are dirt and deeply corrugated causing great difficulties for those in wheelchairs or who are unsteady on their feet. In the wet season the roads are often flooded and always boggy.” (Senior 2000, p.10).

Racism and stigma can also lead to less transport being available in remote communities compounding difficulties in accessing health and community services “Taxi drivers do not like entering the community (there is a perception that the people from the community will not pay the fares) and therefore such transport is often very unreliable... Buses do not come into the community - they do stop on the main road outside the community, but
this is a long walk for many people. Both communities are a considerable distance from the nearest shop, post-office, medical service and school.” (Senior 2000, p.10).

Without transport the elderly are reliant on family or friends with personal transport for activities such as healthcare appointments, collecting mail, picking up medication and socialising, with funding for transport by community services often falling short of meeting the needs of the elderly in rural and remote areas (ACSA & NRHA 2004). Due to distances and high fuel prices in rural and remote areas transport can be costly, which may prohibit its use by service providers, people with dementia or caregivers. As noted by a Scottish service provider “Transport is costly. These costs need to be taken into account when providing a service. This is not the same in the city centre.” (Innes et al. 2006, p.256).

k) Culturally and linguistically diverse groups living in rural and remote areas

Mainstream health and community services are not meeting the needs of people from culturally and linguistically diverse backgrounds living in rural and remote areas, particularly Aboriginal and Torres Strait Islander peoples (Brodaty et al. 2005).

Aboriginal and Torres Strait Islander caregivers have a perceived high level of tolerance for the behavioural symptoms of dementia (HK Training & Consultancy 2002). This perception of high tolerance may be due to lack of service use resulting from a lack of culturally appropriate services and facilities, poor utilisation of Indigenous staff, interpreters and culturally appropriate assessments and resources and a lack of cultural and dementia education and training (Pollitt 1997; HK Training & Consultancy 2002; O’Neill et al. 2004).

Staying in country (the territory of one’s own language group) is of utmost importance to older Indigenous Australians and is imperative to health and well-being (Brown 2001; McLennan 2003). Some of the fears older people may face when leaving their country are being separated from country and family, a foreign language and culture, and dying away from their country (Bennett et al. 1995). As an Aboriginal caregiver reported in Senior (2000) "old people want to die at home, not in hospital. They have to see important people before they go" (p.19). Non-Indigenous Australians from rural and remote areas also feel strongly connected to their communities. As one carer reported “I would be very concerned at mum having to leave the area. She would feel so insecure and lost” (Hansen et al. 2005, p.75).

Language barriers often exist with people from linguistically diverse backgrounds. In 2002 40% of Aboriginal and Torres Strait Islander adults in remote areas spoke an Indigenous language as their main language at home, compared with 2% in non-remote areas (ABS 2002). A Northern Territory study by Cass et al (2002) found that shared understanding of concepts rarely occurred between Yolgnu patients and renal staff, although neither the health professionals nor the patients realised that language problems had occurred. Interpreters should be utilised a shared understanding of key health concepts developed and the use of jargon by service providers decreased to improve
service provision in rural and remote areas (O’Neill et al 2004; Cass et al 2002). Non Indigenous staff members should not only participate in cultural training but also put new knowledge into practice, behave in a culturally appropriate way and adjust services to reflect cultural preferences (Mungabareena Aboriginal Corporation 2008). The formation of shared partnerships would assist in the development of appropriate services for Aboriginal and Torres Strait Islander people.

The stigma of dementia and the stigma of seeking assistance from people you know socially may lead to reluctance by rural and remote caregivers to access services or to ask informal supports for assistance (Hansen et al. 2005; Alzheimer’s Australia WA 2007). This could mean that the familiarity of the local service provider with community members may actually be a barrier to service uptake (Mason et al. 2005). The stigma of dementia in some rural and remote areas may also lead to a decrease in the availability of informal supports. As reported by a Canadian caregiver “it’s still very much a stigma someone can have a heart attack and everyone is desperately concerned. Someone is obviously slipping into dementia and people will just race as far away from them as they can get, as if they’ve got some dreaded communicable disease. And yet, if you’ve got a stroke or heart attack victim, people will come to visit you” (Morgan et al. 2002, p.1133).

Japan is the most rapidly ageing country in the world (Arai et al. 2000). In rural Japan there is great reluctance to utilise support services, with 42% of the elderly surveyed not wanting their family members to use formal services, even if they develop dementia (Arai et al. 1998). This sentiment may be due to a pre-World War II law requiring that the wife of the eldest son had to provide care to her in-laws (Arai et al. 2000). A reason identified for low service use in rural Japan is caregivers feeling they will not be seen as a dutiful daughter-in-law, “A daughter-in-law who had once used respite care because she wanted to go on holiday with her family members, was accused of running off to have a good time, abandoning her mother-in-law” (Arai et al. 2000, p.965). Stigma is attached to public services, which are seen as only there for people whose family will not look after them. “Caregiving is too much for me anyway. But I don’t want to be isolated among family members so I cannot use these services, can I?” (Arai et al. 2000, p.966). Invasion of privacy was another identified cause of low service use “My family members do not want home-helpers to come into our house, they may think that our house is a mess” (Arai et al. 2000, p.966).

The caregiver may feel guilty when asking for formal assistance and may be concerned about the care that their family member will receive. Caregivers may require support from service providers to accept assistance, particularly nursing home respite or care and reassurance that they are not misusing the system (Morgan et al. 2002; Blackstock et al. 2006).

Public education and community based and inclusive programmes are required to break down the stereotypes of dementia and reduce stigma. As a Canadian aged care worker states “Oh it [stigma] is still there. So I think even educating right from the early, early grades that this is a disease, this is why your grandpa is like this, or this is why your grandma’s like this. It’s public awareness, you know how they’re stressing you to have
Home Care—they have to get more knowledge out, even to our kids. We need to get more awareness to the public." (Morgan et al. 2002, p.1139).

3. Dementia care initiatives in rural and remote areas
Despite these service gaps some positive Australian initiatives exist for people living with dementia in rural and remote areas.

a) Regular Government community care services
The majority of community home based services in rural and remote areas are provided by Home and Community Care (HACC), which is jointly funded by Australian, state and territory governments. A HACC survey in Victoria reported that 5.2% of HACC clients had dementia (Victorian Dementia Reference Group 2004). The HACC programme is funded and has the potential to include home nursing services, meal delivery, home help and home maintenance, transport and shopping, allied health, home and centre based respite care, advice and other assistance (AIHW 2007), although the degree that these services are provided in rural and remote areas is varied. A report on services for Indigenous Australians with dementia reported that in remote areas services are limited, with meals often being the only service offered in these communities. There is a lack of care planning and employment of paid carers to assist families (HK Training and Consultancy 2002).

Community Aged Care Packages (CACP), funded by the Australian government, provides additional support to people who are eligible for residential aged care, with care coordinated by the provider (AIHW2007a). Due to the relatively poorer health and resulting disability in Indigenous Australians the level of CACP use is higher as compared to the rate of non Indigenous Australians and recipients are younger, particularly in remote areas (AIHW 2007b; Henderson & Caplan 2008). In remote regions distance can make it difficult for the provider to coordinate and access care.

The primary role for Aged Care Assessment Teams (ACAT) is to assess and approve people for complex community packages such as CACPs to help people with dementia stay in their community for longer and for Commonwealth funded residential care (Henderson & Caplan 2008). The Dementia Education and Support programme was developed for rural ACATs to access advice and training on dementia. (Bishop 2005).

The Extended Aged Care at Home (EACH) packages support people at home who would otherwise be in nursing homes (Henderson & Caplan 2008). EACH Dementia (EACHD) packages were developed for people with behavioural and psychological symptoms of dementia, with services similar to those available to CACP clients (AIHW 2007a). No EACH or EACH Dementia packages are available in remote areas of Australia (see Table 2).
Table 2. Australian use of aged care services by age and geographic area (AIHW 2007a, p.152)

<table>
<thead>
<tr>
<th>Age</th>
<th>Major cities</th>
<th>Inner regional</th>
<th>Outer regional</th>
<th>Remote(n)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Per 1,000 population(n)</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Residential aged care residents in Australia (30 June 2006)</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>65–74</td>
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<td>0.0</td>
<td>8.1</td>
<td>7.2</td>
</tr>
<tr>
<td>75–84</td>
<td>56.5</td>
<td>65.8</td>
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<td>241.5</td>
<td>263.9</td>
<td>210.7</td>
<td>106.5</td>
</tr>
<tr>
<td>65+</td>
<td>56.4</td>
<td>54.7</td>
<td>44.1</td>
<td>29.5</td>
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<tr>
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<td>12,856</td>
<td>1,657</td>
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<tr>
<td>Community Aged Care Packages recipients (30 June 2004)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>65–74</td>
<td>2.0</td>
<td>2.1</td>
<td>3.1</td>
<td>3.0</td>
</tr>
<tr>
<td>75–84</td>
<td>14.0</td>
<td>13.4</td>
<td>11.6</td>
<td>22.5</td>
</tr>
<tr>
<td>85+</td>
<td>36.7</td>
<td>36.6</td>
<td>27.2</td>
<td>38.1</td>
</tr>
<tr>
<td>65+</td>
<td>11.3</td>
<td>10.7</td>
<td>8.5</td>
<td>17.0</td>
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<tr>
<td>Clients 65+ (number)</td>
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<td>6,019</td>
<td>2,492</td>
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<tr>
<td>Extended Aged Care at Home recipients (30 June 2006)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>65–74</td>
<td>0.4</td>
<td>0.4</td>
<td>0.3</td>
<td>..</td>
</tr>
<tr>
<td>75–84</td>
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<td>1.0</td>
<td>1.1</td>
<td>..</td>
</tr>
<tr>
<td>85+</td>
<td>2.2</td>
<td>2.1</td>
<td>2.1</td>
<td>..</td>
</tr>
<tr>
<td>65+</td>
<td>0.9</td>
<td>0.8</td>
<td>0.8</td>
<td>..</td>
</tr>
<tr>
<td>Clients 65+ (number)</td>
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<td>..</td>
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<td>Home and Community Care clients (1 July 2004 to 30 June 2005)</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>65–74</td>
<td>95.0</td>
<td>107.3</td>
<td>123.4</td>
<td>156.2</td>
</tr>
<tr>
<td>75–84</td>
<td>291.1</td>
<td>300.7</td>
<td>326.6</td>
<td>354.5</td>
</tr>
<tr>
<td>85+</td>
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<td>518.1</td>
<td>553.3</td>
<td>520.1</td>
</tr>
<tr>
<td>65+</td>
<td>198.0</td>
<td>220.8</td>
<td>238.3</td>
<td>253.9</td>
</tr>
<tr>
<td>Clients 65+ (number)</td>
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<td>339,985</td>
<td>68,011</td>
<td>11,129</td>
</tr>
</tbody>
</table>

(n) Remote and Very remote categories have been combined.
(1) Population denominators relate to the year reported.
(2) Excludes Dementia recipients.

Note: The data are classified according to the remoteness area of the service except for HACC which uses the client location.
Source: AIHW analysis of DoHA Aged and Community Care management Information System (ACMIS) data and AIHW analysis of HACC/HCIS.

b) Joint working

‘Joint working’ is a term used in Scottish literature regarding the formation of partnerships to co-manage and co-fund resource integrated services to improve service provision, access to services and the efficient use of resources (Mason et al. 2005). Premises, staff and budgets can be shared. The emphasis on the creation of partnerships across government, community and private organisations is in line with current Australian Government policy priorities (Department of Health and Ageing 2008a), and is a key component of the Way Forward, a new strategy for community care in Australia, which states “Strengthening and improving community care and achieving the expected benefits will only be realised if everyone works together in a collaborative and constructive manner. A partnership approach between all interest groups will help achieve the best results for older people, people with disabilities, special needs groups, their carers, for service providers and for governments” (Department of Health and Ageing 2008b, p.1).

The Way Forward (Department of Health and Ageing 2008c) is designed to improve service coordination for people with disabilities and their caregivers (Henderson & Caplan 2008). The changes identified in The Way Forward regarding people with
dementia in rural and remote areas include the trialling of Access point demonstration projects which aim to streamline client entry into community care; the merging of funding for the Dementia Support Assessment programme for dementia assessments in rural and remote areas with ACAT; and the development of a national contract for the National Dementia Behaviour Advisory Service, the Carer Education and Workplace Training Project, the Early Stage Dementia, Support and Respite Project, and the Dementia Education and Support Programme (Department of Health and Ageing 2008c).

In Australia flexible aged care services can be developed in rural and remote communities through Multi Purpose Services (MPS). MPS are jointly funded by the Commonwealth and State Governments to enable the integration of hospital, aged care and community services under single management in smaller rural and remote communities whose population cannot support individual services (Neumayer et al. 2003; AIHW et al. 2006). In 2006-2007 there were 78 different MPS operating and 1,233 aged care beds across rural and remote Australia, with 37 MPS and 530 beds in WA, 18 MPS and 407 beds in NSW, 9 MPS and 110 beds in Queensland, 9 MPS and 91 beds in Vic, 3 MPS and 85 beds in SA, 2 MPS and 10 beds in Tasmania and no MPS operating in NT or ACT (AIHW 2008). The integration of services allows greater flexibility of service delivery including allowing meals to be provided from one site, hospital nurses can take on community and domiciliary roles and hospital gardeners can additionally provide home gardening support. It also encourages training of staff in multifaceted roles which may improve service delivery across all areas (WA Country Health Service 2009).

Innes et al. (2006) completed a survey on dementia care with 86 service provider organisations in rural and remote Scotland, and followed up with 11 telephone qualitative interviews. Eighty percent of the original respondents worked with other organisations. Partnerships involved the service providers from health, social services and voluntary services co-funding, assessing and managing service provision. Community networks, local knowledge and transport were also shared. Innes et al. (2006) state that a multi-disciplinary and multi-partner approach where community-based and specialist services are better integrated is critical for the provision of dementia care in rural and remote areas.

Le Mesurier & Duncan (2000 p.33) outlined in a review of a mobile service in rural England the need for flexible approaches to the delivery of care and the importance of service providers partnering with existing local networks, “Bringing services to people in sparsely populated areas requires innovative approaches which, if they are to reflect local needs and draw upon local support, depend on a thorough understanding of the way particular local communities are structured and perceive themselves...Voluntary-sector organisations have an advantage, in that they function on the strength of local support and integration, and are more independent of the strict eligibility criteria imposed by many local authorities. They also have a degree of flexibility in their working practices which accords with the need for providers to disseminate responsibility to a variety of locations in order to respond sensitively to a range of local circumstances and changing local needs.”
As outlined in Philo et al. (2003), areas where rural partnerships can become problematic include ensuring client confidentiality, negotiation of interagency relations, and maintaining appropriate standards of conduct by staff with different professional backgrounds and co-managed by different agencies.

c) Rural and remote Aboriginal and Torres Strait Islander models

The Aboriginal and Torres Strait Islander Flexible Aged Care Strategy was developed in 1994 to establish combined residential and community care services in rural and remote communities for Aboriginal and Torres Strait Islander peoples. In 2008 there were about 30 services and 700 flexible places under this programme (Elliott 2008). In September 2008 the Federal government announced that quality standards will be set for the National Aboriginal and Torres Strait Flexible Aged Care programme, grants will be established to improve facilities for clients and staff, and provide a peer and professional support programme for Aboriginal aged care and an emergency assistance programme for short term help in crisis (Elliott 2008).

The WA Centre for Health and Ageing, University of Western Australia in collaboration with Kimberley Aboriginal communities, Kimberley Aged and Community Services and Kimberley Aboriginal Medical Services Council conducted a qualitative study to determine service gaps for Aboriginal people with dementia and their families and to address these unmet needs by developing and trialling models of care (Ralph 2008). The key unmet needs identified in the Kimberley study were community consultation, communication and coordination of services, Indigenous employment, workforce training, caregiver and community education, activities, respite, home help, housing, transport, accountability and advocacy (personal communication, Kate Smith). A new holistic model of care is being trialled in the remote Kimberley Aboriginal community of Looma. The project is co-funded and co-managed by the Aboriginal community council, key government services and non-government organisations in a partnership model. The model, although having a particular focus on dementia, is inclusive of all community members with disabilities and mental illness and their caregivers. The shared objective of the project is to optimise the health and well-being of this target group. The project partners have jointly employed and identified training opportunities for Aboriginal community staff to address the key unmet needs outlined above. A project coordinator provides hands on supervision and feedback to staff and is the contact person for community members and outside agencies regarding aged, mental health and disability care. A local action group of local health and community care professionals and community members meet with project staff monthly to provide operational guidance and support. A blueprint of the model of care is being developed to be transferable to other remote Aboriginal communities (personal communication, Kate Smith).
**d) Training and education**

Dementia Training Study Centres for Health Professionals (DTSCs) are a new dementia initiative developed to provide career and training opportunities to health professionals in the field of dementia, including those working in rural and remote areas. They receive a proportion of the $320.6 million of Australian Government funding over 5 years for dementia care (Rampatige et al. 2009).

Four DTSCs operate nationally (Doyle 2009). In Western Australia dementia training is provided through ‘scholarship workshops’ in rural areas for rural and remote health professionals. Each workshop participant is then granted a scholarship to undertake a small project on dementia over a six month period and supported by DTSC staff. An Indigenous dementia training workshop was additionally run for health professionals and aged care workers working with Indigenous people living with dementia (personal communication, Nina Graham 21.04.2009).

Caregiver and service provider education on the behavioural and psychological symptoms of dementia (BPSD) is provided through the Dementia Behaviour Management Advisory Services (DBMAS). DBMAS is an Australian government initiative to deliver clinical support to caregivers and people with moderate to severe BPSD, including those living in rural and remote areas). DBMAS service delivery varies slightly in each state, but some examples of the services that are available through the programme are clinical support and advice, assessment, clinical supervision, mentoring and training on behaviour management techniques, short term case management and care planning, referrals to other support services and information and education workshops. In some areas such as the Northern Territory an outreach service visits the client, completes a behavioural assessment and develops a behavioural management plan (Department of Health and Ageing 2008d).

A trial of a distance dementia caregiving skills programme in the United States, comprising of a video focussing on behavioural strategies and telephone counselling sessions, was successful in lowering levels of depression, stress and frustration in depressed caregivers of people with dementia living in rural and remote areas (Steffen & Mangum 2003).

Hepburn et al. (2003) and Smith et al. (2005) outlined a portable research-based programme for caregivers which involved specialists initially ‘training the trainers’ at a workshop. The new trainers (consisting of educators, aged care workers and health professionals) then conducted the programme in their rural towns. The resources consisted of a trainers manual, caregiver manual and CD-ROM. Following evaluation the CD-ROM was changed to a video as not all caregivers had access to a computer.

A twelve week telephone based caregiver skills programme in the United States was developed to reduce caregiver stress and improve the ability of caregivers to look after their family member with dementia (Davis 1998). After 12 weeks of weekly telephone based skill building there was a noticeable improvement in the caregiver’s sense of life satisfaction, social support, and a reduction in their depressive symptoms. However there
was no significant change in the caregiver’s response to behavioural changes or their problem solving styles, which may indicate that more content was required on these areas, and that home visits may enable the health professional to better understand the environment and the specific needs of the caregiver and the person with dementia.

Link2Care is a Californian internet based programme that provides support and information to caregivers of people with dementia. The program was created in 1999 after a caregiver support network noticed a decline in phone calls for support and an increase in caregivers in the workforce (Kelly 2003). The programme is a joint partnership between Family Caregiver Alliance (a research and advocacy group), the University of Wisconsin and the Californian Caregiver Resource Centre. Caregivers are first screened by the caregiver resource centre, and a password is required to take part. It includes related news and research, online discussions, articles and factsheets, “Ask the expert” which includes being able to ask questions to researchers about the latest findings and local education session listings. The caregiver can also communicate to their Caregiver resource centre consultant via email and will receive email updates. Client surveys found that 66% of caregivers said it increased their knowledge on caregiving issues, 60% said it reduced feelings of isolation and improved their ability to cope, and 86% said they would recommend the programme to other caregivers of people with dementia (Kelly 2003). Although Kelly (2003) states that there are over 700 caregivers enrolled in the programme the number of caregivers surveyed is not given.

The Rural Alzheimer’s Physician Education Project is a successful programme in the US that involves trainers (including a doctor, social worker and a nurse) visiting rural health centres to train rural health staff (Turyn 2001). Education includes information on behaviour management strategies and resources for caregivers of people with dementia and at times a patient is assessed by the education team for the rural staff to observe. The organisers put some of the success of the programme, where demand exceeds supply, down to the fact that one of the trainers also was a medical lecturer of many of the doctors now working in rural areas (Turyn 2001).

The University of Bradford in the U.K. offers accredited undergraduate and postgraduate qualifications in dementia, including a Certificate of Higher Education in Dementia Studies, BSc in dementia studies and MSc in dementia studies (Downs et al. 2009). These courses are offered as distance learning, so are ideal for health professionals working in rural and remote areas. Distance learning is conducted through the internet with a ‘virtual’ classroom including online discussions and blogs, an electronic notice board for information and an electronic ‘file cabinet’ for course documents. Individual support is offered through different media such as email, telephone, web cams and skype (Downs et al 2009).

e) Memory clinics
Memory clinics are multidisciplinary diagnostic, educational and referral clinics for people with memory loss and their caregivers. Memory clinics are operating in a number of rural areas around Australia. The Cognitive, Dementia and Memory Service Clinics
(CDAMS) are successfully operating throughout Victoria including Mildura (George & Bradshaw 2006) and five other regional areas in Victoria (Foreman et al. 2003). Dementia outreach memory clinics operate in regional areas in New South Wales to provide a uniform approach to assessments and an outreach memory clinic is practicing in rural South Australia (Whitehead 2006). However the majority of rural areas have little access to such services.

A memory clinic that services rural and remote areas in Canada utilises videoconferencing facilities for a pre-clinic assessment which involves obtaining a brief medical history, interviewing the person with dementia and their caregiver about the referring problem, to send a request for blood results and to give details on the upcoming clinic visit. A few weeks later the patient and their caregiver must then travel to the urban centre for multidisciplinary assessments that include a neuropsychologist, geriatrician and a neuroradiologist. A case conference is then held and a management plan developed. Post-clinic assessments are initially conducted over videoconference but then alternated between telehealth and face-to-face (Morgan et al. 2005). Telehealth for follow up was often preferred by patients and their families. Some patients would not visit the memory clinic at all or had great difficulty in getting there due to financial or cultural barriers. It was identified that culturally appropriate assessments should be developed for Canadian Aboriginal elders (Morgan et al. 2009).

f) Telecommunication
One of the most useful recent initiatives for rural and remote dementia care is the introduction of telehealth. Videoconference facilities are utilised in areas that either have no specialist services or very limited access to services, allowing health professionals and families to connect to specialists in urban areas (Saligari et al. 2002). Loh et al (2004) report that in West Australia alone there are 40 sites in operation. Telehealth has been used for remote and rural areas for assessment, management, caregiver, health professional and residential care staff education, support and networking opportunities (O’Reilly & Strong 1997a; Van Ast 2005; Van Ast & Larson 2007). Loh et al. (2007) developed protocol for the diagnosis of Alzheimer’s disease via telehealth and demonstrated that the use of the Standardised Mini Mental Examination (SMMSE) and Geriatric Depression Scale over telehealth is valid and reliable (Loh et al 2004.).

Martin-Khan et al (2008) demonstrated that dementia assessment is suited to telehealth when they found that the exclusion of physical examination (apart from gait analysis) from geriatrician reviews did not significantly alter dementia diagnoses in 30 participants, as long as laboratory examination and brain imaging results were available prior to the assessment. Two of the 30 diagnoses changed with the inclusion of a physical examination, one from Alzheimer’s disease to mixed dementia and the other from vascular dementia to dementia of unknown aetiology.

A Chinese study compared cognitive intervention outcomes between videoconferencing and face-to-face. Improvements in cognitive functioning were noted in both groups, with
the only notable difference being that the face-to-face group improved in the spatial construction task whereas the videoconferencing group did not. Hands on assistance during the intervention phase would have assisted the face to face group with this task (Poon et al. 2005).

Helgesson et al. (2004) conducted multidisciplinary co-ordinated care planning over telehealth for elderly people and their caregivers in Sweden. Staff participation was higher for telehealth than in face-to-face care planning as the transport time and the actual case conference time was less. This improved the co-ordination of care for the elderly patients.

Johnston and Jones (2001) in the US reported that telepsychiatry allowed the consultant to provide more continuous and regular contact with rural and remote staff and patients, and enabled the consultant to follow through on recommendations. The necessary presence of a local health staff member during the videoconference enables training opportunities and greater likelihood of recommendations being follow through, families were positive about being included during the videoconference, and both families and patients were glad that they did not have to travel a long distance to see the consultant. It also saves time for the staff where “using telemedicine travel time is eliminated, and the 4 hours can be put to maximum clinical use of the course of the month” (p.74). A key challenge in using telehealth was the high turnover of staff at the remote site, so that for a period of time new employees often had less knowledge and enthusiasm for the medium (Johnston & Jones 2001).

Reviews of telemedicine literature suggest that some of the limitations of telemedicine are that caregivers feel uncomfortable with new technology and have difficulty learning how to use it, they find it difficult to talk to people via a television, there is an emotional distance between the caregiver and the service provider, and that there is a tendency to be less open in providing information over telehealth (Botsis & Hartvigsen 2008; Buckwalter et al. 2002).

Caregivers, aged care and health workers in a study by Leong et al. (2001) identified that a dementia telephone helpline could assist with support, advice, referral to services and in mobilising assistance in emergency or crisis situations. The federally funded Dementia Education and Support Programme delivered by Alzheimer’s Australia provides a free 24 hour Dementia 1800 helpline (1800 100 500) for caregivers and health professionals and includes confidential telephone based counselling, practical information about dementia and referral services (AIHW et al. 2006).

**g) High level case management**

In rural and remote settings the role of ACAT is often broader than in urban areas, and case management is often required. An example of this is the Dementia Rehabilitation at Home (DRAH) pilot model of high level case management used by the ACAT in rural NSW. Intensive case management includes organising telehealth for specialist cognitive assessment, diagnoses and multidisciplinary support, assistance with accessing services
and following up that care is established. Clients and caregivers identify rehabilitation goals such as education, counselling, in-home services and behavioural management. An evaluation of the model estimated that the 15 packages of DRAH produced an annual saving of 200 hospital patient days (AIHW et al. 2006).

**h) Assessment**
Some cognitive assessments are not suitable for people living in rural and remote areas or are urban-centric. For example the RUDAS safety question of “how would you cross a road if there were no traffic lights or pedestrian crossing?” (Storey et al. 2004) is not appropriate in many regions as most remote regions do not contain any traffic lights and pedestrian crossings only exist in main towns.

The Kimberley Indigenous Cognitive Assessment (KICA) is the only cognitive assessment tool developed specifically for people living in rural and remote Australia, although as mentioned previously, Loh et al. (2007) have developed protocols for cognitive assessment with telehealth. The KICA was developed and validated in the Kimberley region of Western Australia in 2003 for Aboriginal and Torres Strait Islander peoples aged over 45 years (LoGiudice et al. 2006; Smith et al. 2007). The KICA has since been additionally validated with Aboriginal and Torres Strait Islander populations in the Northern Territory and Far North Queensland and is being utilised by health professionals and care workers in rural and remote regions of Australia (Smith et al. 2009). The KICA was used to screen participants to discover the high prevalence of dementia in Aboriginal people in the remote Kimberley region of Western Australia (12.4% of over 45 year olds) (Smith et al. 2008).

**i) Transport**
Flexible funding models are required to address the key priority area of transport for older people living in rural and remote areas. A flexible funding initiative in Central Queensland is funding a free community bus for older people to attend medical appointments. The local government houses the bus and funds ongoing maintenance. The local casino funded the purchase of the bus and the costs associated with staff and other service costs (ACSA & NRHA 2004).

Age pensioners in Australia receive discounts for travel on public transport. However due to the scarcity of public transport in rural and remote areas this concession can not be utilised day-to-day by rural and remote pensioners. A Government of Western Australia initiative ensures that from 1st May 2009 aged pensioners living in rural and remote areas will receive a $500 Country Age Pension Fuel Card to put towards transport costs every year for the next four years. The fuel card can be used towards fuel for private vehicles or taxi fares (Department of Local Government and Regional Development 2009). As stated by the WA Minister for Regional Development, Brendon Grylls “Age pensioners in regional areas generally do not have access to extensive public transport and fuel is usually more expensive than in the metropolitan area. The fuel card will help country age pensioners meet the additional cost of travel.
using their own vehicles or taxis. It will also help those who rely on transport from their family, friends or carers to get to appointments, shopping and other essential engagements. We recognise that in some cases, an age pensioner may not have a driver’s licence, but still has the same transport needs. Those age pensioners will be able to use the card to pay for taxi fares or for petrol for the vehicles of the people helping them with their transport needs.” (Grylls 2009).

In a review of Scottish organisations providing care to people with dementia in rural and remote areas, Innes et al. (2006) reported that to overcome transport difficulties service providers used a combination of local transport schemes, volunteer drivers, taxis, ambulances and staff member’s cars. 41% of service providers provided their own transport for clients, 9% used another organisation and 23% used a combination of sources.

j) Mobile respite services
Mobile respite services are becoming increasingly available in rural and remote settings. The mobile respite team visits different areas of the region at a time and offers services such as one to one respite, carer support, one to one and group education (Shanley 2006), or bringing clients into a central point for day care (Bird & Parslow 2001). Mobile respite is viewed as best practice for respite services in rural and remote areas, “We need innovative, flexible models of mobile respite that can respond [to the needs of people in country areas].” (Eley et al. 2006 p.32).

Mobile dementia regional teams operate in regional areas through Alzheimer’s Australia, and are funded by the Commonwealth National Respite for Carers Programme and the Home and Community Care programme. The team provides family support and referrals to appropriate services. In-home, community-based or host family respite is offered. Host family respite is a social club of approximately three people with dementia organised by a care worker (personal communication Elizabeth Barnes, Program Manager, Great Southern Alzheimer’s Australia WA).

k) Safe return programme
The safe return programme is a National government initiative in liaison with Alzheimer’s Association, the police and local agencies. The safe return programme involves the use of a bracelet and police database. The caregiver must notify the police once they notice the person with dementia is missing and quote the number on the bracelet. The police then look at their database on the person which includes physical characteristics and familiar places a person would visit. If a member of the public comes across a person with dementia who seems lost they can call the police and give the details on the bracelet to them so that they can assist the person to get home (Alzheimer’s Australia 2009).

Electronic tracking is another system that may be implemented to assist in locating people with dementia who are lost in rural and remote areas. Different forms of electronic
tracking have been trialled over the years, with GPS being a more recent tracking method, such as the use of GPS enabled mobile phones (Miskelly 2005). Ethical concerns have been raised over the tracking of people with dementia, with the possible restrictions to freedom and dignity needing to be weighed up against the safety and welfare of the person with dementia (Welsh et al 2003).

1) Mobile resource vans
Alzheimer’s Australia Associations run a number of mobile memory resource vans in metropolitan and rural areas to increase community awareness of dementia, through provision of brochures, memory testing, web-based information and educational sessions. They regularly attend regional community events such as expos, festivals and agricultural shows (Sherwood 2007).

Le Mesurier and Duncan (2000) outline the development of a successful mobile aged care programme that provides specialist services through partnerships created with local non-government organisations in rural England. Local organisations support and/or provide a range of services through a mobile caravan service, such as the delivery of counselling and support to caregivers, and hairdressing and foot-care.

4. Discussion

a) Summary of themes
The needs of Australians with dementia and their caregivers living in rural and remote areas differ from those of people living in urban areas. Rural and remote Australia has a particularly dispersed population that is ageing at a faster rate than its urban counterpart, primarily due to the emigration of the younger population. They have substantially poorer access to health and community services, education, employment, income and transport than their urban counterparts, which is resulting in poor health outcomes. Workforce shortages, instability and poor access to staff training are a major contributor to the poor availability of services in rural and remote regions.

Aboriginal and Torres Strait Islander peoples tend to have more barriers to quality dementia care than other people living in rural and remote areas. This is primarily due to the poor utilisation of Indigenous staff, interpreters, culturally appropriate assessments and resources and cultural and dementia training, resulting in often culturally inappropriate service provision and facilities.

International literature, particularly Scottish literature, identifies joint partnerships as a key initiative in the successful provision of services to people with dementia in rural and remote areas. The formation of partnerships with local communities and other stakeholders is repeatedly identified as a method to overcome many of the financial, workforce, communication and distance related barriers to providing quality and flexible services in rural and remote regions.
b) Recommendations

Service models
People with dementia and their caregivers living in rural and remote communities require improved access to aged care programmes that suit their needs. Many rural and remote communities do not have an aged care service let alone dementia specific programmes. Improving access to and coordination of general aged care services in these regions is a priority, with dementia specific needs such as dementia training for aged care staff and local health professionals being additional measures to improve the quality of care for people with dementia and their caregivers.

Collaboration between services and resulting flexible funding arrangements are required to improve service access and coordination (HK Training and Consultancy; Henderson & Caplan 2008). There needs to be an approach towards decentralisation with increased focus on community management (Williams & McHugh 1993) and community-based research should be funded to plan and trial alternative models of service delivery for people in rural and remote communities. The community, including potential clients of the service, local agencies and service providers and local government should be involved in planning and developing services (ACSA & NRHA 2004). The strengths of the community should be built upon, for example local counselling and training providers could collaborate with community services to improve service quality. People with a track record in successfully developing aged care/dementia programmes in rural and remote communities should be sourced and consulted.

To improve the availability and quality of dementia care in rural and remote areas service design and funding needs to take into account geographical distances, demand and level of disease burden. For example the viability supplement received by some rural and remote residential care services is based on the remoteness of the location, the size of the facility and whether 50% or more of the facilities residents are people who have special needs (ACSA & NHRA 2004).

Training and education
Videoconferencing for specialist assessments and education would be beneficial for dementia care. Telehealth has been shown to be a reliable method of dementia assessment (Loh et al. 2007), although further research is required on its validity as compared to face to face assessment. Telehealth may be more useful as a tool to providing regular support, advice and training to generalist health professionals and local training providers, who in turn can provide locally relevant training to caregivers and the community and conduct face-to-face assessments (ACSA & NRHA 2004). Best practice guidelines on dementia for health professionals working in rural and remote areas also need to be developed. Grants and scholarships to attend training and conferences such as those provided by the Dementia Training Study Centres are very important as travel costs often prohibit rural and remote service providers from accessing professional development to update their knowledge of current best practice.
Training for rural and remote caregivers should include not only disease-related information on dementia and behavioural management strategies, but also stress management and information on available supports for the caregiver including relatively new initiatives such as DBMAS. Community awareness programmes and resources with the continued aim to decrease the stigma of dementia and service use, need to be developed with, and inclusive of, people from rural and remote areas and cultural and linguistically diverse backgrounds. This includes emphasising the crucial role that family and friends play in the support of primary caregiver, the confidentiality of client information and the benefits of accessing formal supports (Innes et al. 2006; Shaji et al. 2003; Arai et al. 2000).

Incentives should be given for urban-based specialists who provide services via telecommunication to visit rural and remote areas and complete cultural education to gain a better understanding of the socio-cultural and environmental context of the region. This will enable them to conduct better quality assessments, provide more meaningful management strategies to families and more relevant training to local health and community workers (ACSA & NHRA 2004; Cass et al. 2002).

Recruitment
There is a need for an aged care workforce strategy to recruit and retain workers with dementia knowledge and experience. This may involve investigating the wages and conditions for aged care workers, the differences in wages between aged care and acute nursing, improve undergraduate, postgraduate and aged care training and professional development (National Rural Health Alliance 2006). As previously discussed the Dementia Training Study Centres have developed some positive dementia training initiatives for rural and remote health professionals (Rampitage et al. 2009).

Financial support
There is a need to ensure services are not cost prohibitive to the client and their families. Australian caregivers are eligible to receive government financial support; however the carer allowance and payment are minimal. It has been suggested in a report by Alzheimer’s Australia WA (2007) that the Medicare rebate be increased for caregivers and seniors, and carer support payments are increased. In other countries such as India there is no government financial support for caregivers, greatly reducing access to services and medications (Shaji et al. 2003).

Transport
Obtaining transport for caregivers and related organisations should be a priority in rural and remote areas. Some initiatives already discussed include sharing transport between local agencies, vehicle grants specific to rural and remote areas and seeking shared funding from local businesses and government agencies for aged care vehicles (Innes et al. 2006; ACSA & NHRA 2004). The new Country Age Pension Fuel Card programme available to rural and remote aged pensioners in Western Australia should be implemented by other states and territories around Australia (DLGRD 2009).

Aboriginal and Torres Strait Islander peoples
Rural and remote areas have a higher proportion of Aboriginal and Torres Strait Islander peoples than urban areas, and Aboriginal people in remote areas have a high prevalence of dementia (Smith et al. 2008). Cultural training for staff, employment of interpreters, the improvement of services to meet cultural preferences and the development of partnerships with rural and remote Aboriginal and Torres Strait Islander communities are important cultural safety principles to improve the quality of dementia care for Aboriginal and Torres Strait Islander peoples living in rural and remote regions.

Access to professional Indigenous interpreter services is vital, with communication issues a common cause of poor health outcomes (McDonald 2006). This is particularly important with dementia care as cognitive screening involves the assessment of language skills and people with dementia often lose their ability to speak a second language such as English. Interpreters should be trained to work with health care workers, and health care workers should complete cultural training courses to decrease the risk of communication errors (Cass et al. 2002).

**Research**

Recommendations for future research for dementia care in rural and remote Australia as determined from the review of the literature are outlined in Table 3 below.

**Table 3 Recommendations for future research**

<table>
<thead>
<tr>
<th>Research gaps</th>
<th>Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>The extent of dementia in rural and remote areas</td>
<td>Comprehensive Australian studies are required to address the extent of dementia in rural and remote Australia.</td>
</tr>
<tr>
<td></td>
<td>Comparisons between urban, rural and remote regions may also provide further information on the environmental and endogenous causes of dementia, including the effect of the economic, social, environmental and socio-cultural components of rural and remote regions.</td>
</tr>
<tr>
<td>Unmet needs of caregivers</td>
<td>Research to determine the unmet needs of rural and remote dementia caregivers. Rural and remote areas are very diverse for example farming areas, stations, Aboriginal communities etc, and so a variety of studies to encompass the diversity would be required.</td>
</tr>
<tr>
<td>Service use</td>
<td>The current service use of people with dementia and their caregivers in rural and remote areas should be further investigated.</td>
</tr>
<tr>
<td>Flexible models of care</td>
<td>The attributes and resources of rural and remote communities to support people with dementia need to be identified. Studies are also required to investigate, develop, trial and evaluate flexible and sustainable models of care in rural and remote communities using the partnership model.</td>
</tr>
<tr>
<td>Training</td>
<td>Dementia training for health and community care workers in rural and remote areas is required to maximise ‘on the ground’ capacity.</td>
</tr>
<tr>
<td></td>
<td>Research to determine the current level of knowledge of dementia in health and aged care workers, to determine best practice in dementia</td>
</tr>
</tbody>
</table>
training for rural and remote areas (e.g. telehealth, e-learning, local training providers), and the efficacy of health professional training for positive outcomes for people with dementia and their caregivers.

Caregiver and community awareness and support programmes need to be similarly evaluated.

<table>
<thead>
<tr>
<th>Cognitive assessments</th>
<th>Cognitive assessments should be reviewed, and if needed adapted and validated for people living in rural and remote areas.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support services</td>
<td>Research to investigate how to best support caregivers of people with dementia in rural and remote areas.</td>
</tr>
<tr>
<td></td>
<td>This may include determining the natural supports that exist in families and communities and how best to build on them, investigating creative care options such as flexible respite and local recreation opportunities for people with dementia and their caregivers.</td>
</tr>
<tr>
<td>Cultural barriers to care</td>
<td>The cultural reasons for not accessing care and reasons for becoming caregivers should be investigated in rural and remote areas. Culturally specific needs should be identified and strategies developed to meet these needs.</td>
</tr>
<tr>
<td>Transport</td>
<td>Isolation and distance from services and supports are a major concern for people living in rural and remote areas. Research on the transport needs of caregivers and service providers and the impact of different methods and costs of transport in rural and remote areas is required.</td>
</tr>
<tr>
<td>Telehealth</td>
<td>Further research as to the validity of telehealth dementia assessments as compared to face to face assessments. Local service provider and caregiver perception of the usefulness of telehealth should be investigated.</td>
</tr>
<tr>
<td></td>
<td>Research on the use of telehealth for dementia assessments of people from diverse cultural and linguistic backgrounds and the reliability of interpreter use over telehealth.</td>
</tr>
<tr>
<td>Financial barriers</td>
<td>The financial cost of living in rural and remote areas, including the cost of transport, food, accessing support, resources and services for people with dementia should be determined and strategies developed to assist people with financial burden.</td>
</tr>
</tbody>
</table>

c) Tips for clinicians

- Partner with other services including local private industry, community representatives (e.g. local council), government and non-government stakeholders to co-manage projects, share resources and skills to improve supports available to local people with dementia and their caregivers.
- Consult with consumer representative /advocacy groups to identify what their priority and ideas are for your service and ask for input to improve practices.
• Set up network meetings, videoconference, attend and present at conferences to find out best practice in other services and share your ideas.
• Conduct formal and informal evaluations of your practice e.g. feedback form, discussion with clients, family. Use this information to improve practice.
• Sign up to library and ask them to put you on a list to email you the contents of relevant journals and read articles.
• Attend cultural training and use this information to improve your work practices to suit the needs of the particular cultural group. Seek assistance from a local agency representing that group and form partnerships as required.
• Review cognitive assessments with local representatives and only use assessment tools appropriate for people living in the region and their particular cultural group.
• Offer an interpreter to Aboriginal and Torres Strait Islander peoples and other CALD groups and organise through an interpreter service as required.
• Access training available in other regions through videoconference facilities.
• Access specialist assessments, management advice and ongoing support through telehealth.
• Organise caregivers and people with dementia to link into support groups and community education via videoconference facilities.

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