



An Australian Government Initiative

Support Needs of People living with Dementia in Rural and Remote Australia

Report of Findings

February 2007



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Executive Summary

Executive Summary

Introduction

This report details the methodology and findings of a Commonwealth Special Project undertaken on behalf of Alzheimer's Australia by Alzheimer's Australia WA, to gain an understanding of the support needs of people with dementia and their carers in regional Australia, and their suggestions and recommendations for addressing these needs.

Three information sources on rural and remote needs relating to dementia were identified and targeted in the data gathering process: relevant publications and reports; questionnaire responses from health professionals and service providers; and, most importantly, input from carers and people with dementia attending focus groups or responding to questionnaires.

An initial scoping process included consultation with staff at the national office and regional offices of Alzheimer's Australia. The majority of the consultation process, undertaken between January and September 2006, was conducted in Western Australia with additional consultations occurring in four health regions in three other States. A total of 173 people with dementia and their carers, and 74 service providers contributed to the consultation process.

Six major themes were identified from the needs highlighted by consultation participants:

- Emotional and Social Support
- Education and Awareness Raising
- Diagnosis, Assessment and Medical Management
- Community Service Access
- Respite and Residential Care
- Distance and Travel Issues

Recommendations

The following nine recommendations address identified needs of people with dementia and their carers in rural and remote areas of Australia and are distilled from the range of suggestions made by participants in the consultation process. Although many suggestions were made by participants, the recommendations identified in this report capture those that are specific to rural and remote circumstances and people with dementia in particular.

Emotional and Social Support

- Investigate a model for the provision of local professionally facilitated counselling services to provide support, guidance and advice on effectively managing the challenging aspects of dementia.

Education and Awareness Raising

- Improve access to information and education on dementia in regional and remote areas through better utilisation of local training providers and technology-based information channels.

Community Service Access

- Explore the development of more flexible models for delivery of dementia-related community care services to overcome barriers to access created by distance and isolation.

Diagnosis, Assessment and Medical Management

- Develop strategies to increase the numbers and retention rate of health professionals with expertise in dementia in regional and remote areas.
- Investigate the provision of memory clinic services in regional centres to facilitate greater access by people with dementia living in remote and regional areas. This could include exploring the use of communication technology and visiting specialist teams to facilitate timely diagnosis, assessment and medical management.

Respite and Residential Care

- Explore processes for providing more flexible respite and residential care options in regional areas to overcome access barriers created by distance and isolation

Distance and Travel Issues

- Investigate the specific transport needs of people with dementia living in regional areas with a view to overcoming hardships created by remoteness from service providers.
- Investigate the apparent higher financial burden experienced by people with dementia and their carers living in remote and regional areas, and recommend strategies to alleviate financial hardship.

Indigenous Dementia

- Undertake a broad consultation with Indigenous people with dementia and their carers and families living in remote and regional areas in order to identify dementia support-related needs, priorities and recommendations.

Section 1

Introduction

Introduction

Dementia is one of the leading causes of chronic poor health and disability in Australia, The number of people with dementia in this country is estimated to increase from around 200,000 in 2005 to 731,030 in 2050 (Access Economics 2005a), This increase reflects an ageing Australian population where age is the greatest risk factor for developing dementia.

Although the age structure varies between regions and differs from metropolitan populations, the number of people with dementia in rural and remote areas of Australia is considerable and will also increase in the coming decades. Nearly 30% of the Australian population lives outside metropolitan areas.

The general health profile of rural and remote-dwelling Australians is both different and poorer than that of metropolitan-dwelling Australians. There is a higher rate of hospitalization, for a range of causes, and this is probably related to distance and more limited access to health care compared with metropolitan dwellers (Byles 2006). There are fewer health professionals, including general practitioners (GPs) and medical specialists, and less access to community services than in metropolitan areas (AIHW 1998),

Another crucial difference is the impact of Indigenous health on rural and remote health profiles. Two percent of Australia's population is Indigenous, however, this proportion varies across metropolitan, rural and remote areas. Indigenous people comprise up to 26% of the population in remote areas (AIHW 1998). The substantially higher proportion of Indigenous people contributes statistically to the lower health status of people in these areas compared with metropolitan and rural areas.

People with dementia need a range of health care services, including GPs, hospital care, community services and hostel and nursing homes. However access to hostel and nursing home accommodation decreases with increasing remoteness from regional

centres and this is reflected in a lower use of services compared with metropolitan areas (AIHW 1998). Their needs also affect those who support them, particularly while they are living in the community.

Representatives of Alzheimer's Australia working in regional areas have identified a number of issues for people with dementia and their carers living outside the metropolitan area, many of which are common to people and carers in metropolitan regions. They include: access to information about dementia; timely access to health specialists for diagnosis, assessment and medication management; access to health and community service personnel who are skilled in dementia; access to dementia-appropriate residential and respite services; access to informal and formal emotional and social support; and culturally appropriate services for Indigenous Australians and people from culturally and linguistically diverse groups. In addition, the high turnover of health and service personnel occurring in regional areas hinders the critical establishment of trust between provider and client. This contributes to delays in accessing services and support.

Current Initiatives

A number of initiatives to address the needs of people with dementia in rural and remote areas are currently in place. Services provided in some regions by Alzheimer's Australia include:

- a national telephone support service
- internet-accessible help sheets and other information on dementia
- teleconference and videoconference support groups
- mobile dementia resource vans
- mobile dementia respite services
- intensive counselling, education and support through live-in retreat programs for people with early stage dementia and their partners, and
- culturally-appropriate training for Indigenous careworkers.

Carers Australia also provides counselling services for carers in some rural areas, although these services are not dementia-specific.

A two-day National Indigenous Dementia Workshop held in Adelaide, 8-9th November 2006 agreed to a national framework of action for a better understanding of the prevalence and incidence of dementia in Aboriginal communities and providing better care. The proposed framework of action involves a collaborative process between key Indigenous stakeholders, Alzheimer's Australia and other Aboriginal and Torres Strait Islander focused agencies.

There are important initiatives being undertaken by medical and other health professionals to address the barriers to the health care of people with dementia. These include videoconferencing for assessment and case management, and the implementation of an assessment tool for older Indigenous Australians in remote regions. As with services provided by Alzheimer's Australia, these services are also currently limited in regional coverage.

Scope of the Project

This report details the process and findings of a Commonwealth funded special project undertaken by Alzheimer's Australia WA Ltd on behalf of Alzheimer's Australia. The objective was to identify and prioritize the support needs of people with dementia living in rural and remote Australia, and to identify suggestions for addressing these needs. The project comprised a consultation process with key stakeholders living in rural and remote areas of Australia, including people with dementia and people involved in their care and support. The consultation process was undertaken between January and September 2006. The data is derived primarily from rural and remote regions in Western Australia and, to a lesser extent, from selected health regions in other States. The scope of the project and the allocated resources precluded a comparative analysis with the needs of people with dementia in metropolitan areas, however, the findings and recommendations of this report supplement and support the findings of the National Consumer Summit on Dementia Communiqué (5-6 October 2005) and the Western Australia Communiqué Consumer Position Statement 2006.

Section 2

Methodology

Methodology

Introduction

The project aimed to consult extensively with relevant stakeholders to identify and prioritize the needs, and suggestions for addressing those needs, within resource and time limitations. For this reason the majority of consultations were undertaken within Western Australia, as the State comprises a number of diverse rural and remote regions. Other Alzheimer's Australia State offices contributed to the initial scoping exercise, and focus groups with carers were undertaken in three States in addition to WA by staff working in the nominated regions.

Procedure

Three sources of information on rural and remote needs relating to dementia were identified and targeted in the data gathering process:

- relevant publications and reports;
- questionnaire responses from health professionals and service providers; and
- input from carers and people with dementia attending focus groups or responding to questionnaires.

The project methods and questionnaire design were completed in consultation with the Centre for Research into Ageing, Curtin University.

Health professionals and service providers included general practitioners, staff from Aged Care Assessment Teams (ACATs), Aboriginal Medical Services (AMS) personnel, community health and mental health staff, community service providers and carer support services who had clients with dementia in rural and remote health regions.

Literature Search

Two search methods were undertaken for the literature review:

- an internet search of relevant databases prior to and during the project design phase; and
- analysis of reports and articles sourced from health and service providers involved in the consultation process.

The database search was focused on identifying relevant Australian information and, therefore, Australian databases were searched more extensively than international databases. The Australian databases included in the search were:

- AIATSIS (Indigenous Studies Bibliography);
- AMI (Australasian Medical Index);
- APAFT (Australian Public Affairs);
- APAIS-ATSIS (Australia Public Affairs Information Service – Aboriginal and Torres Strait Islander subset);
- APAIS-Health (Australia Public Affairs Information Service – Health);
- ATSI Health (Aboriginal and Torres Straits Islander Health);
- AusStats;
- FAMILY (Family & Society), FAMILY-ATSIS (Australian Family and Society Abstracts – Aboriginal and Torres Strait Islander subset);
- Rural (Rural and Remote Health Database).

International databases were also searched and, again, the search was focussed on Australian information. They included:

- CINAHL (Cumulative Index to Nursing & Allied Health Literature);
- Cochrane Library;
- Google Scholar;
- ProQuest 5000;
- PsychINFO; and
- PubMed.

Databases were searched using the following search terms: dementia AND Australia AND (rural OR remote OR regional).

Based on the search terms, 68 references were identified from the Australian databases. Of these, 23 were excluded, based on information in the abstract. A combined search of the international databases produced in excess of 60 references. Most of these were duplicates of the Australian database search or were deemed not relevant, based on the abstract information. Additional references, including Australian Government reports, were sourced from relevant articles.

Three additional references were provided by service providers during the consultation phase. Information from the literature review contributed to a background understanding of needs and, where appropriate, to the project design. A review of relevant literature is included in the following section of this report and a list of references is included in Appendix 6.

Health Professionals and Service Providers

Health professionals and service providers in each of the Western Australian Country Health Service (WACHS) regions who were likely to have clients with dementia were contacted by telephone (see Appendix 1). Those whose client base included people with dementia were invited to participate in the consultation process by responding to a survey of needs and recommendations (see Appendix 2) and/or by assisting in organising a focus group of carers and people with dementia from their client base and the local community.

A total of 204 health and service providers were contacted in 7 health regions in Western Australia and one health region in New South Wales. The majority provided services to people with dementia. Of these, 74 (36.3%) responded to the health and service provider questionnaire.

Carers and People with Dementia

Carers and people with dementia who were approached by a service provider were invited to participate in a focus group to discuss their needs and to suggest solutions to those needs. Appendix 3 outlines the program the facilitators followed when conducting focus groups. Carers who were unable to attend a focus group, and who wished to contribute to the project, were invited to respond to a structured questionnaire, either face-to-face or via telephone, with one of the project officers or with assistance from a nominated service provider (see Appendix 4).

In two remote regions of Western Australia, an Indigenous consultant with family and professional connections to the area and a consultant from Carer's WA with pre-established links to carers and service providers, were engaged to facilitate consultation with Indigenous and non-Indigenous carers.

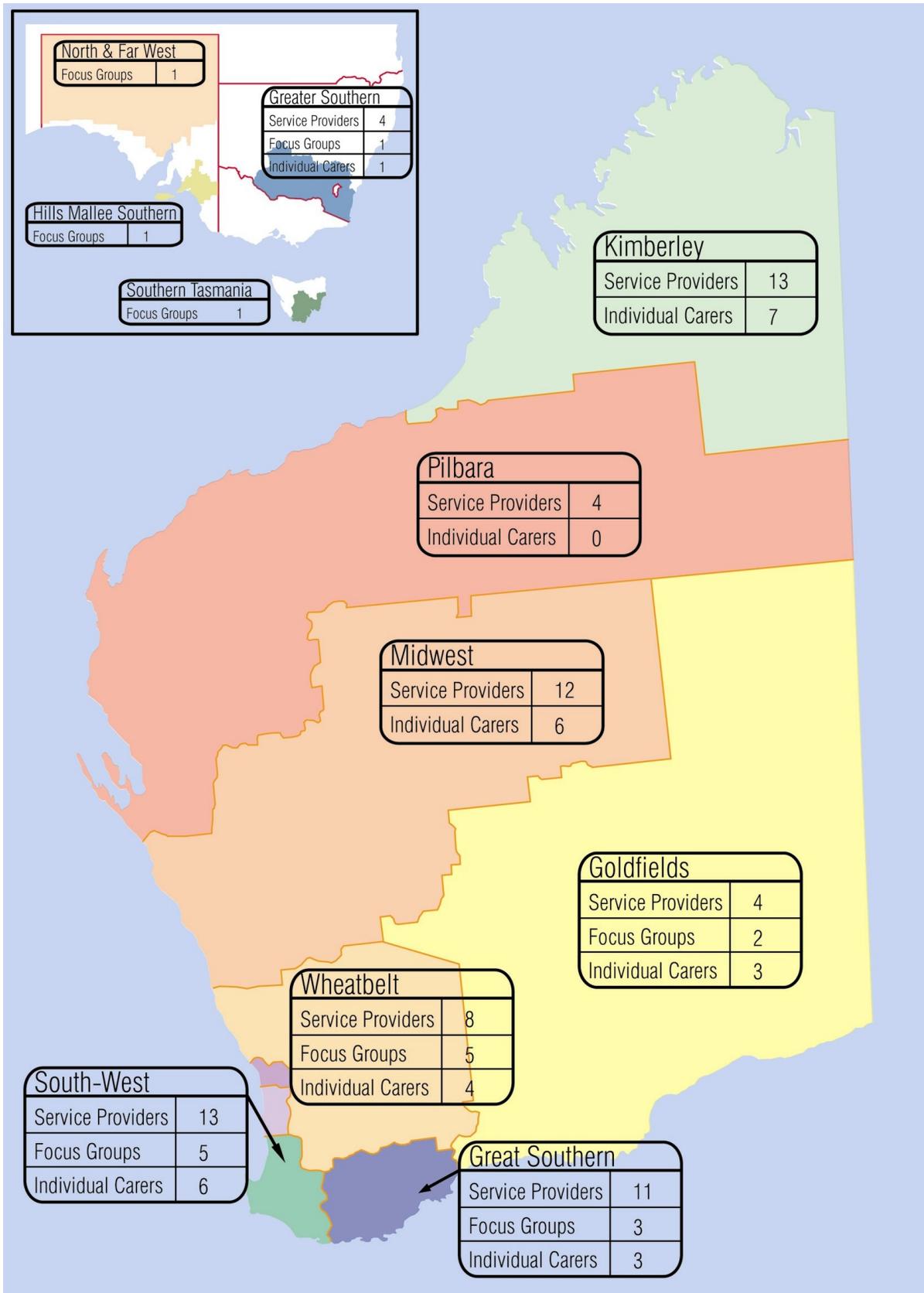
In all, 19 focus groups were conducted; 15 in Western Australia, 2 in South Australia and one each in New South Wales and Tasmania. A total of 173 carers and people with dementia participated in the project. Of these, 140 (comprising 114 carers and 26 people with dementia) participated in a focus group, and 33 people responded to 31 carer questionnaires (one family of 3 participated in an individual carer questionnaire). Seven of these respondents were sourced by the two consultants who conducted face-to-face guided conversations with three Indigenous and four non-Indigenous carers from different towns in a remote region in northern Western Australia.

The combined number of participants including service providers, carers and people with dementia was 247 (see Table 1 and Figure 1). A detailed table of focus group locations and towns where individual carer respondents reside is provided in Appendix 5.

Table 1. Participants by Type and Health Region

Region	Participants				Total
	Focus Group		Interviews/Questionnaire		
	Carers	People with Dementia	Carers	Service Providers	
Great Southern (WA)	17	8	3	11	39
Goldfields (WA)	8	2	3	4	17
Kimberley (WA)			7	13	20
Pilbara (WA)				4	4
Midwest (WA)			7	12	19
South-West (WA)	39	10	6	13	68
Wheatbelt (WA)	32	6	6	8	52
Greater Southern (NSW)	2		1	4	7
Hills Mallee Southern (SA)	9				9
Northern & Far West (SA)	2				2
Huon-Channel (Tas)	5				5
Other (region not defined)				5	5
Totals	114	26	33	74	247

Figure 1. Participant Numbers by Health Region



Data analysis

Quantitative information from focus groups and questionnaires was collated in Microsoft Excel. Where indicated, differences between variables were tested using chi-square analyses in SPSS (Version 14). Qualitative information was coded according to themes identified by the project team.

The collated and coded data was analysed to produce:

- categories of needs;
- prioritization of needs, based on frequency of occurrence;
- summaries of the impacts of unmet needs;
- representative comments and case studies to support the identified needs; and
- recommendations to address the needs.

Considerations and Limitations

The project team identified some limitations and barriers to information gathering which should be considered when interpreting the results of the project data.

- Data from individual carers would ideally have been used to inform the focus group discussions, however limitations on time and the need to work through service providers to facilitate access to individual carers made this impractical.
- Service providers who recruited participants were usually present at the focus group sessions. Their presence may have influenced the discussion and, possibly, inhibited carers and people with dementia from openly discussing some of their needs. However, feedback from participants was generally very positive towards the service providers.
- The majority of information was derived from participants from Western Australia (90.5%). However, the number and range of rural and remote regions within the State is considerable and arguably representative of the needs of regions Australia-wide.

- Participation by Indigenous carers was limited to one remote health region in Western Australia (East and West Kimberley). Their participation was facilitated by the engagement of an Indigenous consultant who interviewed them face-to-face. Two focus groups that had been organized for the Pilbara and Kimberley regions were cancelled because of a lack of attendance by participants. The Indigenous consultant spoke informally with service providers in those regions, however, and they recommended that culturally appropriate awareness-raising and education about dementia at the community-level should precede a consultation process on needs.

Section 3

Literature Review

Literature Review

Introduction

The objective of the literature review was to identify previous studies and reports on identified needs and current or past initiatives to support people with dementia and their carers in rural and remote Australia.

Discussion

There are a number of Commonwealth Government reports on aged care and aged care services which acknowledge that people with dementia, people in rural and remote areas, and Indigenous and Torres Strait Islanders have specific needs (see for example, Commonwealth Department of Health and Ageing 1998). However, there is little or no information on the cumulative impacts of rural and remote needs and dementia, or Indigenous needs and dementia. The limited information that does exist is primarily demographic (see for example, Australian Institute of Health and Welfare 1998a, 1998b), or reviews of service provision, for example, Home and Community Care services (Australia, Parliament House of Representatives, Standing Committee on Community Affairs 1994; Cooper and Jenkins 1998). More detailed information was sourced from peer-reviewed research articles and reports for non-government organisations involved in dementia-specific or general community service provision.

Needs and gaps in service provision

Although there is an extensive body of literature on the impact of caring for people with dementia, there are few Australian-based research articles with a rural and/or remote focus. O'Reilly and Strong (1997a, b) identified access and availability gaps with support services in rural communities which they found was offset, in part, by informal supports. Kirkpatrick (1991) noted differences in the provision of respite between regional centres and remote areas, and noted that respite was provided through hospitals and nursing homes. Neville *et al.* (2002) found no differences between metropolitan and regional uptake of respite services.

Some articles exist that focus on specific regions. Knapman and Waite (1993) surveyed carer needs in Northern Queensland and Hansen et al (2005) and Campbell-Smith (2003) undertook studies in regional Tasmania. A notable finding in two of these papers is a strong perception of stigma attached to dementia in smaller communities, which is reflected in a reduced uptake of available services (Hansen *et al.* 2005; Knapman and Waite 1993). Hansen *et al.* also identified distance and isolation and a lack of understanding of dementia and dementia-services as barriers to the effective provision of care and uptake of services.

The majority of articles that include rural and remote needs within a broader national focus highlight the limited access to services, particularly specialist health services and community services, compared with those who live in metropolitan regions (Brodarty *et al.* 2003; Brown n.d.).

Hines and Black (1993) question the reliability of prevalence data for dementia in rural and regional areas and suggest a need for localized estimates that account for migration patterns. More recent data on prevalence is provided by Access Economics (2005a). Estimates for regional areas throughout Australia are provided, however the reliability of data in remote areas, where there is a greater representation of Indigenous Australians, is not clear.

Some carer studies include carers of people with dementia, but do not focus specifically on their needs compared with other carers' needs (see for example, Carers Association of Western Australia 2005; Schofield 1997). Such studies are useful, however, for identifying issues, needs and initiatives that are common to people with a range of disabilities and their carers. The report for Carers Association of Western Australia (2005) is based on a research project which was undertaken to identify rural and remote experiences of caregiving, gaps in services and suggestions for improvement. The objectives and methods used in the study are similar to those employed for this project. The identified gaps included respite access, carer support, financial support and careworker training. Distance and costs associated with isolation were also identified.

Initiatives

A number of articles address specific initiatives to overcome access and availability issues. There is growing use, for example, of videoconferencing to replace some face-to-face services. Loh *et al.* (2004) and Saliari *et al.* (2002) claim high correlation between cognitive and geriatric assessment scores from face-to-face and videoconferencing. Others advocate its use as a tool for case management (Guilfoyle *et al.* 2002; Van Ast 2006) and for carer education and support (Van Ast 2006).

Other forms of carer education and support include a distance-based training package for depressed carers that comprises a self-paced video and a series of telephone counselling sessions (Steffen *et al.* 2003).

An effective solution for respite in less populated areas is the provision of mobile respite services. Wareham and Goddard (2002) and Davies and Burr (1986) provide details of two established programs. Hueke (1990) details a model for activities-based care to people with dementia in country areas with a deficit of nursing home and hostel places.

Indigenous dementia

The reliability of prevalence estimates for dementia in Indigenous communities is questioned and some studies indicate a higher prevalence amongst Indigenous Australians compared with the general population (Bruce *et al.* 1998; Pollitt 1997).

A report for Alzheimer's Australia N.T. (2002) focuses on the needs of Indigenous people with dementia. Using a similar consultation process to this project, information was sourced from service providers about needs and suggestions for reducing gaps in service provision. The report identifies issues relating to the lack of culturally appropriate assessment tools and the lack of access to appropriate assessment, diagnosis and care management for Indigenous people with dementia. These gaps are compounded in remote areas. A high level of tolerance to behaviour changes among Indigenous people contributes to late diagnosis, assessment and management. Pollitt (1997) and Lawrence and Pusemucans (n.d.) also identified tolerance and acceptance of symptoms of dementia among Indigenous people in Queensland and Central Australia.

Gaps in service provision identified in the Northern Territory report relate to respite, education and training, support for families and community services. Respite options are limited and, if available, likely to lack the provision of culturally-appropriate food, activities and Indigenous careworkers. Education and training needs relate to the lack of resources and appropriate models of education and training for careworkers with low literacy levels and little knowledge of dementia. A lack of infrastructure and availability of paid careworkers, particularly in remote areas, limits the availability of community-based support for this group. The report identifies three key strategies for improving support to Indigenous people with dementia and their carers. These are community awareness-raising, the introduction of appropriate assessment tools, and education and training of careworkers.

Other authors highlight the need for cultural sensitivity when communicating health information and seeking information from appropriate family members (Edith Cowan University 2004; McGrath and Holewa 2005; Sheldon 2001). Lawrence and Pasmucans (n.d.) stress the importance to Indigenous Australians of being connected to their country. They identified a stoic attitude to poor health and a low expectation of health care services among desert-dwelling Indigenous Australians, linked to a fear of culturally inappropriate services, such as attendance by health careworkers who are wrong gender and wrong skin.

Initiatives for Indigenous Dementia Care

The Kimberley Indigenous Cognitive Assessment (KICA) tool which was developed with assistance from Indigenous and non-Indigenous health professionals is a valid and reliable tool for assessing dementia among older, remote-dwelling Indigenous people (LoGuidice 2006; Smith 2005). It is being adapted and evaluated in the Northern Territory (Smith 2006). The tool will be applied in a dementia prevalence study of the Indigenous population in the Kimberley.

Summary of Literature Review

The articles and reports discussed in the literature review generally support the findings of this project and highlight a number of issues related to dementia and some specific gaps in care and management for people in rural and remote areas which are tied to isolation and distance. The most consistently reported gaps are access to services, including respite and support services, and access to trained careworkers. Australian-based initiatives for rural and remote healthcare include the use of technology to overcome issues of distance and isolation. The literature includes reports on the evaluation of videoconferencing for clinical assessment, case management, education and support and provision of support to carers.

The limited literature on dementia in Indigenous communities is focused on the lack of information about prevalence and barriers to care which is linked to isolation, lack of awareness and culturally inappropriate services.

Section 4

Findings

Findings

Introduction

The information from focus groups, the questionnaires from interviews with carers, and questionnaires completed by health professionals and service providers, provide three comparable sources of data.

Six major themes were developed from the needs identified by the participants. The themes are ordered according to the issues most frequently raised in the focus groups, being the participant category that provided the greatest number of responses.

- Emotional and Social Support
- Education and Awareness Raising
- Diagnosis, Assessment and Medical Management
- Community Service Access
- Respite and Residential Care
- Distance and Travel Issues

Data relating to the needs of Indigenous people with dementia and their carers is included in the six themes.

Details of Themes

Each of the six major themes comprises two or more related issues, and encompasses:

- a definition based on the issues assigned to each theme;
- figures prioritizing the relative importance of the theme according to each participant type;
- a summary of the impacts of the needs on carers and people with dementia, including comments and case studies to illustrate the needs, and regional differences where relevant ; and
- a summary of suggestions for addressing the needs.

Discussion

There were some differences in the ranking of issues between the three sources of data but overall, the discussion from focus groups and individual responses from carer questionnaires generated a consistent trend (Figures 2-4). Issues relating to the themes Emotional and Social Support and Education and Awareness Raising, were the most frequently raised in the largest source (focus groups). No differences in ranking of issues were apparent across the major regional focus groups; however, some regions with smaller representation in focus group participation did not address all themes. Individual carers raised issues about Respite and Residential Care more often than focus group participants, but the number of individual carer respondents was small relative to the number of focus group participants. Unsurprisingly given the nature of their work, health professionals and service providers listed issues relating to Respite and Residential Care and Community Service Access more frequently.

As indicated above, data relating to Indigenous needs has been included in the six major themes and referred to when applicable. This data was provided by three Indigenous carers from one remote health region and 13 service providers from five different health regions in Western Australia; although the majority are from the remote Kimberley region. One Indigenous service provider working for an Aboriginal Medical Service just two hours by road from a capital city, provided information that was consistent with the other needs and suggestions for Indigenous dementia.

However, given the small sample commenting directly on Indigenous issues, the data should be read with this limitation in mind.

Figure 2: Identified Needs from Focus Groups

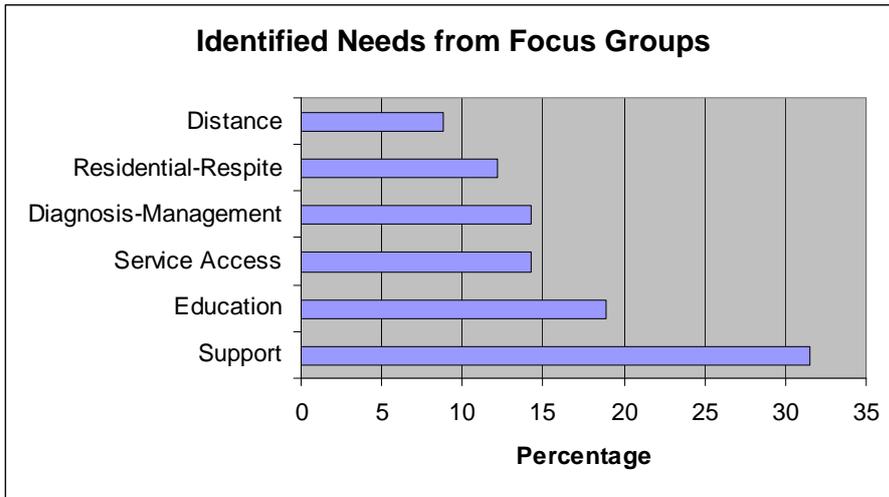


Figure 3: Identified Needs from Individual Carers

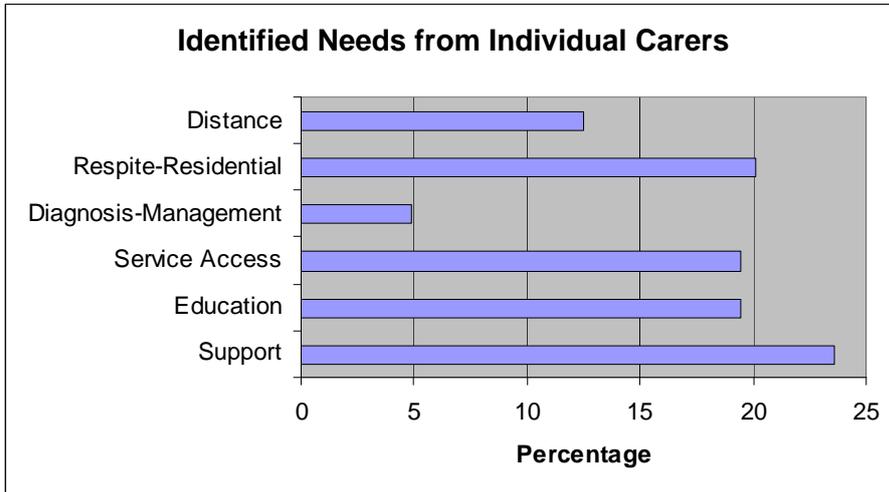
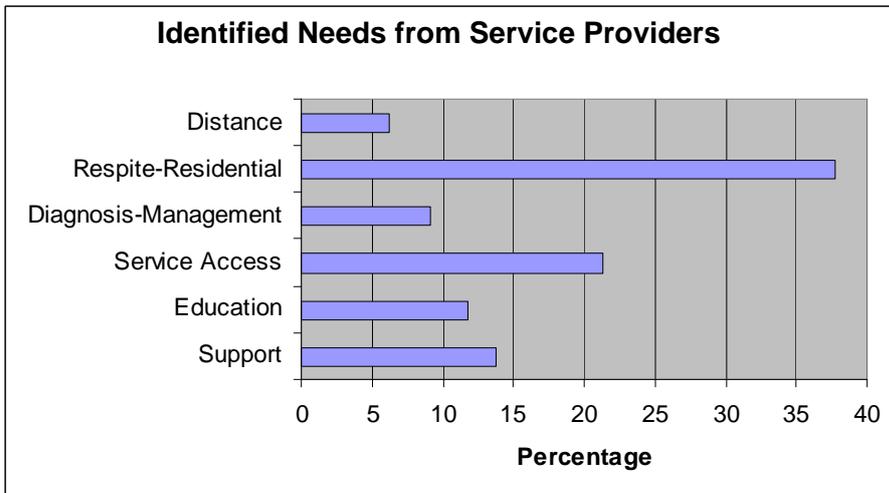


Figure 4: Identified Needs from Service Providers

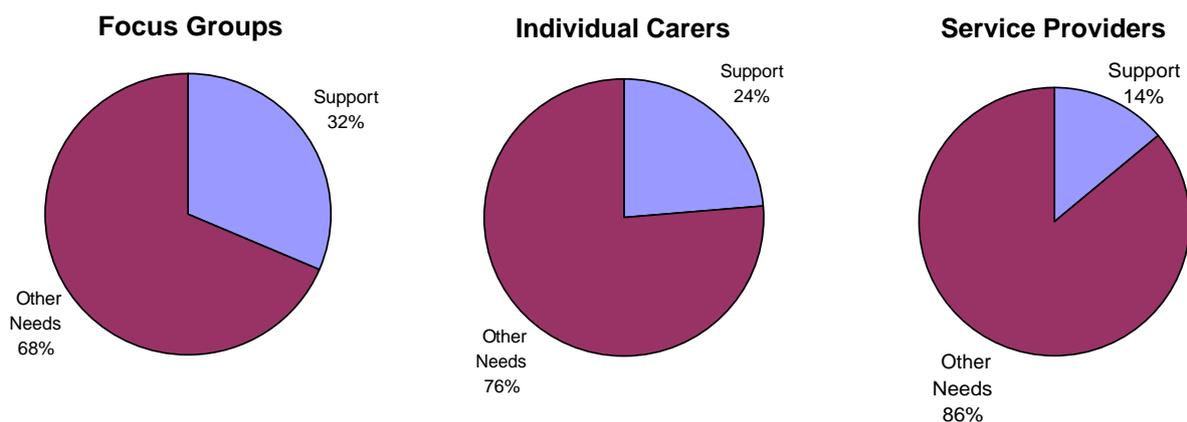


Emotional and Social Support

Description

Needs identified as relating to social and emotional support included: coping with accepting the diagnosis of dementia, managing changing roles, decision-making for the future, and strategies for managing symptoms of dementia. These needs are compounded by limited access to formal and structured support such as appropriate counselling, advocacy and carer support groups. They are also compounded, for some people, by distance issues or lack of understanding from extended family or social networks, resulting in limited informal support.

Figure 5: Emotional and Social Support Needs as a Percentage of All Needs per Participant Type



Impact

Carers recalled the impact of learning of the diagnosis, of feeling lost and frightened and in need of immediate support.

The diagnosis comes like a bomb shell.

When you are going through it I don't think anything can help, it changes your life.

Both carers and service providers commented on the impact of caring leading to feeling “burnt out”, depressed, stressed, fatigued and unable to control their emotions.

Your nerves are raw, stressed and shattered.

Carers describe coming to terms with and managing the physiological and behavioural changes of the person with dementia. These changes include dealing with incontinence, disturbed sleep, wandering, suspicious behaviours, resisting assistance with personal care, apathy, shadowing, insecurity and anxiety. The repercussions of changes like incontinence included an increased work-load, mopping floors and washing, which increased exhaustion.

I can cope with the Alzheimer's disease but it's the [in]continence that gets me.

She wanders, looking for the toilet.

She becomes agitated when she is unable to sort out what is going on.

Carers indicated that when they become stressed and impatient, they “feel awful afterwards”. Their role is often made more difficult when the person for whom they are caring lacks insight into their condition and resists help from the carer.

I want to organize respite but [the person with dementia] is very resistant and doesn't realize anything is wrong and wants to stay at home.

These feelings are often compounded by the pain of “letting go” which, according to some service providers, results in a reluctance by carers to accept help.

I found the first time of using respite very hard, I cried a lot.

Carers described the loneliness and feelings of isolation as their care responsibilities reduce their ability to maintain previous social activities. Some carers said they were embarrassed for the person with dementia and some of their behaviours, and that they avoided going on outings with them.

Friends tend to drop away, to respect your privacy.

Both carers and service providers observed a lack of support by family which they contributed to distance issues in some cases and a lack of understanding of the effects of dementia in others.

Carers reported experiencing feelings of loss and grief. They struggled with the prospect of 'losing' their relative, of losing companionship, a partner and communication. One carer described:

The difficulty of no longer being able to share ordinary things with [the person with dementia], the excitements, sadness, problems He's not the man you married.

You feel like you're losing a bit of the person every day.

I think it is like a grieving process. I think once [the person with dementia] dies I will have shed all my tears, but whenever the phone rings, my heart stops.

Carers reported feeling anxious about coping with changes and about the future. They struggle with role change and having to take on chores previously done by the person with dementia.

When they have to go into care you think "I should have been able to cope". You feel mean when in their own mind they can leave [the facility].

Service providers in remote regions expressed concern that Aboriginal people do not recognize behaviour changes in people with dementia; rather, they accept these changes as part of normal ageing. This leads to delays in seeking appropriate assessment and support.

Limits to Services

Service providers described a lack of advocacy and support for people with dementia and their carers. Many smaller towns and regional areas have limited access to counselling services and those services that are available are not dementia-specific. Support groups for carers are usually limited to the larger centres. Service providers in remote regions identified a lack of culturally-appropriate counselling to assist Indigenous families to cope with behaviours such as anger and aggression

Participant Suggestions

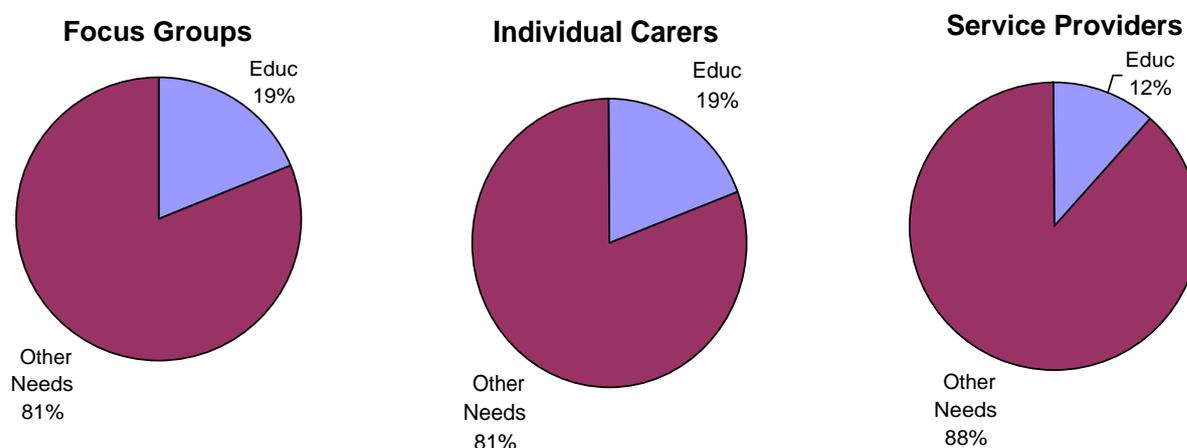
- Access to face-to-face counselling services for guidance with advice on effectively managing the challenging aspects of dementia. One carer stated a preference for a local person that knows rural needs.
- Provision of (preferably) dementia-specific support groups, set up and facilitated by professional people, in those areas where such support groups do not already exist.
- Access to practical suggestions, through a package of information for example, on how to manage symptoms such as incontinence, or keeping the person calm, as well as information about services.
- Locally-based training and education for families, carers and community people to learn skills to ease the challenges of care giving. Training could be provided locally through guest presentations, radio, TV and DVD, to overcome the problem of inability to access courses in metropolitan areas. Alternatively, access to support online might be appropriate for some carers.
- Provision of support for people with dementia and carers for the transition phase from home to residential care.
- Access to and sharing of information and support for Indigenous carers through carers' meetings and through social gatherings with service providers

Education and Awareness Raising

Description

Education and awareness needs included: knowledge and understanding of dementia for carers; training for health professionals and service providers; and awareness and understanding of dementia in the broader community, including those working in financial and legal areas relevant to people with dementia and their carers.

Figure 6: Education and Awareness Needs as a Percentage of All Needs per Participant Type



Impact

Carers felt they lacked access to information about dementia and did not know where to access information. Specifically, they lacked information about early stage dementia and were uncertain about what was going to happen and how they would cope with the stages of dementia. Service providers felt this lack of information put extra pressure on families who do not understand behaviours and did not have the ability to manage them. They believed a lack of understanding increased the likelihood of accidents in the home, and that better access to information can help to overcome this.

Once families have knowledge of dementia they find the situation easier to cope with.

Service providers also suggested the lack of knowledge about dementia resulted in delays in presenting to health services. Carers stated they have little understanding of treatments and lack information about services, as well as information on the legal and financial implications for the person with dementia and for themselves.

Who do I ring if the person with dementia falls?

If I become ill, what happens to the person with dementia?

I have a problem; I don't know about assessment services, my [relative with dementia] is getting worse

What would I do in an emergency?

Carers indicated that a lack of knowledge about dementia among extended family is the reason for a lack of informal support. Service providers also felt this lack of knowledge prevented families making plans for the future.

Both carers and service providers identified distance as a barrier to family members being able to attend courses. For example, participants of one focus group knew of a course run by Alzheimer's Australia for people with early stage dementia and their carers, but stated they were unable to access it because the number of people in their area with dementia was not sufficient to justify running a course.

Carers identified a lack of knowledge about dementia among some health professionals, including hospital staff. Many service providers also identified a lack of dementia education and training for themselves.

We do not have proper training in working with clients with dementia

Carers and service providers identified a lack of knowledge and understanding about dementia in the community and the stigma and lack of acceptance of symptoms of dementia.

There is a fear of dementia in the elderly community.

He is not crazy, he can't help it!

The person with dementia is still very special to us; the rest of society needs to realize this.

Service providers and Indigenous carers also identified a lack of understanding about dementia by carers, families and the broader Indigenous community. This contributes to the stress of providing care and being unable to cope with behaviour changes. Low levels of literacy and the provision of inappropriate resources, in some communities, adds to this problem.

Participant Suggestions

- Carers and service providers suggested a range of ways for families to access information and education, including:
 - local courses that are suitable both for carers and for the person with dementia in the early stages. Service providers suggested the information needed to be appropriate without being overwhelming;
 - printed information (books, packages providing information about dementia and about local services including Carelink services, help sheets, and regular newsletters on events);
 - access to Telecentres (video conference) and Internet information for younger carers;
 - guest speakers;
 - GPs for discussing information at the time of diagnosis and afterwards;
 - Family information sessions and sessions with care workers to enable sharing of information.
- Information on other topics to assist in caring, such as first aid, human rights, legal information and information about safe environments.
- More government-funded education for people working with people with dementia. The information should be “hands-on” as well as theoretical. Service providers recommended greater provision of dementia specific information in Aged Care Certificate III and IV for care workers, and in the training and professional development of acute care staff.

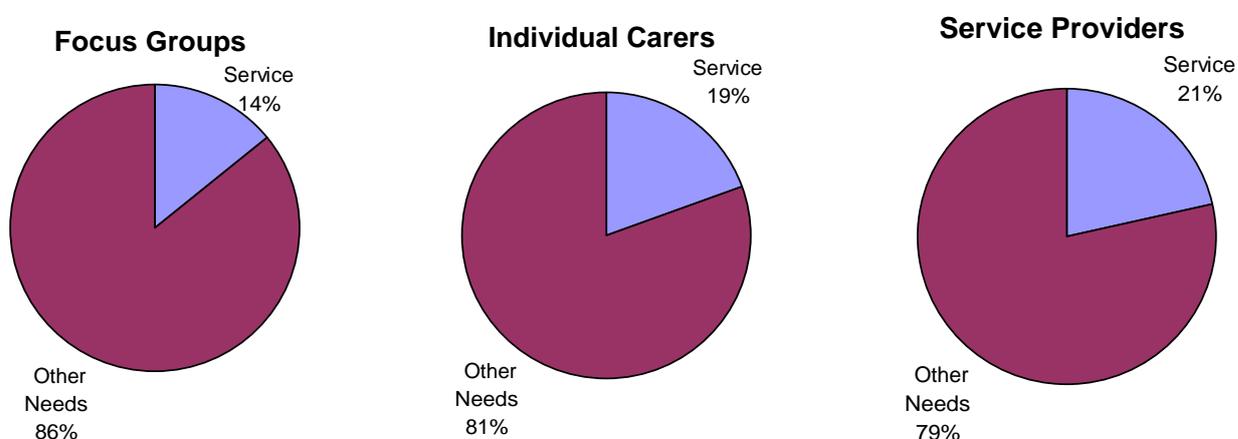
- Community education and awareness-raising via local papers, regional TV stations and other media; pamphlets and packages in medical practice; and the promotion of services such as respite through community forums and advertisements. High school students were seen as an important target group, as the prevalence of dementia is projected to increase and many will become carers themselves.
- Development of appropriate resources for Indigenous family carers and clients; including pictorial information and the use of radio, DVD and television.

Community Service Access

Description

Needs relating to service access included: access to appropriate community services, including personal care and domestic services; access to activities for people with dementia and carers; and satisfaction with service provision.

Figure 7: Service Access Needs as a Percentage of All Needs per Participant Type



Impact

Carers providing assistance to family members with dementia, particularly as they become more dependent, struggle with the extra load, often at the expense of their own health. They may be trying to cope with a person who is refusing assistance and is at risk.

I worry something will happen to me.

Often, carers reported that they were unaware of the services that are available, such as transport assistance, respite options, domestic assistance and equipment to support mobility, comfort and manual handling.

Service providers noted that a lack of services and provision of safety features in the home increased the likelihood of carer “burn-out” and hospitalization and early admission of the client to residential care.

Carers discussed their dissatisfaction with the move, in some regions, to centralization of community service provision that was previously local. The impact is perceived as creating more paperwork and longer waiting lists for services. There are also waiting lists for equipment hire, which puts an added strain on people waiting.

Many carers identified a lack of dementia knowledge and sensitivity among service providers, which results in a lack of consistency and continuity of service provision. They feel uncomfortable complaining about poor service, however, as there are few options in remote places.

Providers of a range of community services identified a lack of funding to provide the required services and to enable them to be flexible to suit the needs of people with dementia. Many argue they are struggling to provide basic needs and care packages (Community Aged Care Package and Extended Aged Care at Home Packages) are limited. Remoteness and isolation also adds to the cost of providing services and thus limits service availability.

Both carers and service providers highlighted the need for provision of, and access to, appropriate activities and opportunities for stimulation and for socialising with others with dementia and/or with family carers. Activities needed to be relevant to the person’s background and interests. Carers found it difficult to keep the person with dementia motivated and active and may have little time to devote to activities and strategies to engage the person.

She is always at home; she doesn’t want to go out ... she is always with us.

[He] misses farm interaction and interaction with local people.

There’s not much for men to do.

Activities provide a change and a break [from daily routine] and give the carer a break.

An Indigenous carer identified a need for more support from agencies to help with understanding and providing care. She felt isolated from services that provide in-home support. Service providers supported this perception, claiming town-based HACC services did not extend to Aboriginal communities and people who could benefit from supports such as meals on wheels cannot access them. In some regions, local Aboriginal care workers provide HACC services, but they lack knowledge about dementia

Service providers also identified a need for both male and female Aboriginal care-workers. They noted that Aboriginal people in remote regions won't accept care that is culturally inappropriate; from care workers who are not from the same skin group, for example. Culturally inappropriate services cause stress to this client group.

Participant Suggestions

- Increase the funding and availability of services, including EACH and CACP packages.
- Make the provision of services more flexible to recognise the longer travel time that is often involved.
- Provide greater flexibility in the types of services available including, for example, access to handyman services and laundry services for people with continence issues.
- Improve wages and work conditions to assist in attracting people to community care work in regional areas.
- Improve monitoring and accountability of service provision.
- Ensure local services, such as HACC agencies, become informed about dementia.
- Provide training to improve understanding and empathy for community service providers.

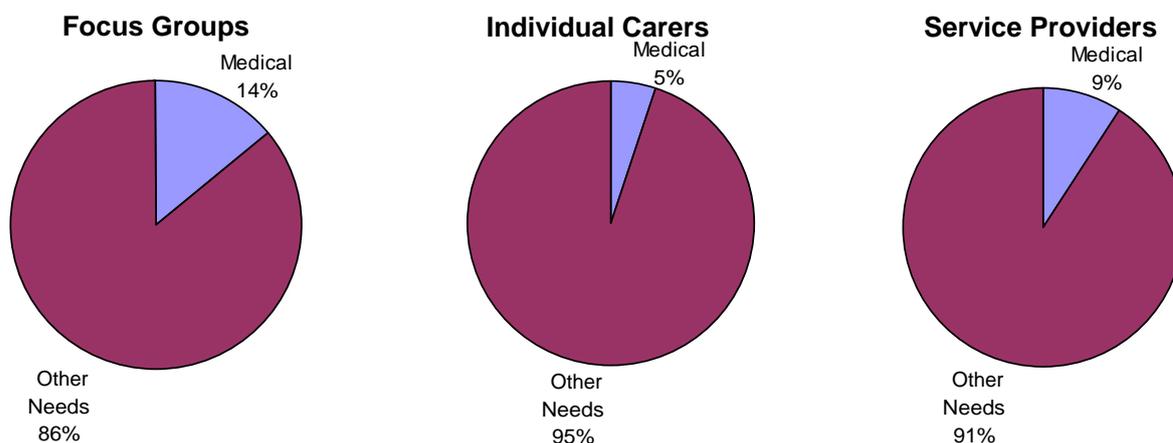
- Provide opportunities and promote careers in care-provision for young Aboriginal people, which would increase local employment opportunities and could contribute to maintaining Indigenous culture by providing opportunities for older clients to pass on their oral stories.
- Promote culture-appropriate care for Indigenous clients by appointing region-based dementia educators to provide practical support to Indigenous care workers and families.
- Provide access to risk reduction (assistive) technologies such as temperature-controlled taps and tracking devices for people with dementia.
- Offer access to intergenerational activities to provide opportunities for people with dementia to mix with a range of age groups.
- Develop access to activities that are gender-relevant, age-relevant and interest and ability relevant; such as farm visits and fishing for men.
- Provide access to places and events that can be attended by the person with dementia and their carer, such as coffee mornings and weekend retreats.

Diagnosis, Assessment and Medical Management

Description

Diagnosis, assessment and medical management needs identified included: access to general practitioner (GP) and specialist medical services such as geriatricians and mental health professionals; access to appropriate assessment tools and processes; and skilled medication and medical management in the community and in the acute hospital setting.

Figure 8: Diagnosis, Assessment and Medical Management Needs as a Percentage of All Needs per Participant Type



Impact

A lack of GPs and a high turnover of GPs in regional areas limits ready access to general medical care as well as up-to-date dementia management. In one region, carers reported difficulties accessing GPs in their local area because they had closed their books to further patients. The high turnover of GPs leads to a lack of consistency in management of their clients.

We were not happy with how the doctor told us.

The GP discussed the diagnosis but hasn't spoken about it since.

The medication caused gastro side-effects and the GP didn't suggest another type.

In remote health regions, geriatricians only visit once every three months. This leads to delays in early and timely diagnosis and commencement and monitoring of medications. The only other option is to travel to a major city for tests rather than waiting. In some regions, travel to a major centre is required to access some of the diagnostic procedures, such as scans.

The GP is good but the opportunity to see a specialist is rare. We will have to travel to Perth.

Service providers noted that delays in diagnosis place stress on people with dementia and carers. Delays in diagnosis can also affect decisions about driving and other issues of competence. The limited access to specialists means limited professional support for behaviour symptoms such as aggression.

Specialists cannot see behaviour in the usual setting. They only get a snapshot and hence wrongly treat [the] client.

Early diagnosis and treatment can assist in clients staying in the community.

Some carers were concerned about the way assessments were administered. They felt that the questions were demeaning and, in some cases, lacking in cultural relevance. Another group commented on the lack of appropriateness of the MMSE for some cultural groups. Service providers also commented that a lack of culturally appropriate assessment tools and process for Aboriginal clients contributed to delays in supporting both the person and their families.

The tests are inappropriate. [They should] ask about family information eg “Your daughter has had a baby recently – what did she have?” – use more conversational questions.

Carers whose relative had been in hospital for treatment or respite commented on the lack of understanding, skills and empathy shown by staff in the provision of care to this client group. Carers felt they had to be present at all times to supervise the person and prevent them from removing tubes and to assist the person with eating. They felt there was little communication from staff and health professionals.

The hospital staff did not seem to know how to manage my husband.

My brother-in-law and I felt we had to be present to feed my husband while he was in hospital.

My husband was given anaesthetic and discharged too soon ... He took days to recover and hasn't been the same since.

Service providers were more likely to comment on the inappropriateness of the hospital environment for people with dementia. They also felt that the lack of understanding among staff exacerbated symptoms in patients, particularly aggression.

Participant Suggestions

- Provision of incentives to attract GPs to work in rural and remote areas.
- Greater dementia education for GPs and mental health staff through the regional Divisions of General Practice or via videoconferencing, to increase their abilities to diagnose early dementia.
- Longer appointments with GPs to enable more time for discussion of the diagnosis or progress and availability of support and services.
- Provision of assessment and dementia management education for community nurses, in the absence of GPs.
- Training for health professionals in the use of the Kimberley indigenous Cognitive Assessment tool.
- Inclusion of a broad family needs assessment in the assessment process, particularly for Indigenous people.
- More frequent visits from geriatricians and, in regions with older populations, the establishment of memory clinics and incentives to attract full-time geriatricians.

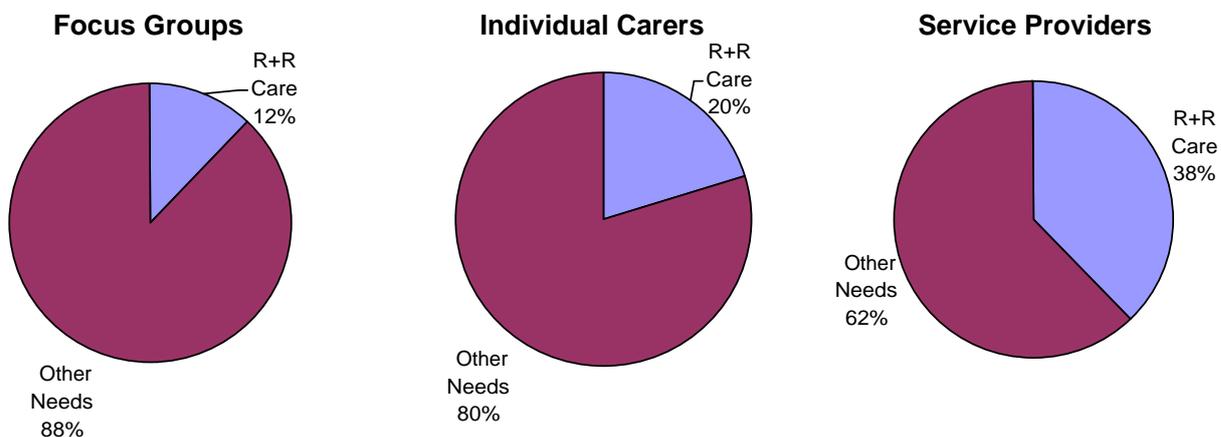
- Greater use of videoconference (Telehealth) access to geriatricians and psycho-geriatricians for GPs, ACAT staff and service providers to support ongoing medical and medication management.
- Dementia education for hospital staff to improve their management of patients with dementia and to improve communication with families and community service providers while they are in hospital and as part of the discharge plan.
- The provision of dementia-appropriate wards or units that are secure for acute care and for respite use.

Respite and Residential Care

Description

Needs identified relating to respite and residential care were of a similar nature. Respite needs included: access to flexible respite options such as in-home respite and home clubs (including farm-based), after hours respite, respite options that were gender and culturally relevant and emergency respite. Residential care needs included access to low and high care residential facilities and dementia-specific and secure facilities within the local community.

Figure 9: Respite and Residential Care Needs as a Percentage of All Needs per Participant Type



Impact

Carers recognised the need for “time-out” from their caring role. Many indicated they have little or no time for themselves. Many also understood the benefits to the person with dementia that respite can provide. However distance issues and lack of flexibility of respite services were identified as limiting their access to respite.

Lack of sleep, exhausted [it is the] ‘biggest relief to sleep all night’

The majority of carers and many service providers, including those whose main service is respite, highlighted a shortage in supply of respite services, although one region which is adjacent to a metropolitan region reported unused respite hours in their day centres and in-home respite. The travel time required for some clients to access respite in day centres was identified a barrier and in-home day respite in remote and isolated locations, including farms, was seen to be in short-supply.

The lack of available respite in some regions means carers cannot plan their respite. If a respite bed becomes available at short notice, the timing may not be suitable for the carer

You need a break when you need a break and not when it is convenient for the service.

Service providers identified a lack of culture-appropriate respite for Indigenous families. The burden of care is often placed on one main carer who may also be responsible for the care of extended family members.

Both carers and service providers in most regions identified a shortage of overnight and long-term respite options. In a number of places the hospital was the only available place for respite. Hospitals are rarely secure, there is a lack of continuity and staff are not skilled in managing people with dementia.

The only respite available is in hospital. Carers are made to feel this is not appropriate and also that 'it's your job'.

Indigenous carers also identified resistance by their family member to being admitted to the local hospital as many older Aboriginal people associate these facilities with deceased relatives.

In most regions, the distance to both low and high-care respite services was reported to be considerable, which limited family access to people in long-term respite care, particularly for Indigenous families.

Service providers also noted a number of deficits in respite service, including access to appropriate activities, sufficient numbers of trained staff and lack of access for people with dementia who are living alone.

People with dementia living alone are ineligible for in-home respite, however, [they] pose risks to themselves and [are] unable to [take] care of themselves.

Carers and service providers identified a lack of low and high-care residential facilities. Service providers highlighted insufficient government funding provided for facilities. They noted that the current shortage of appropriate residential care will increase as the population ages.

Carers commented on long waiting lists for the nearest facilities which are often located in a different town. Many carers felt they did not know what was available or how to access information. The shortage of facilities meant some carers had to relocate to access appropriate facilities, leaving other family members and friends, or had to travel long distances to visit their relative once they were in permanent care.

I am thinking of placing my husband in Perth when the time comes as he has a daughter there.

One carer is looking for a facility that can accommodate his wife with dementia and himself, as he is aged and frail. No such facility exists in his town or in nearby towns.

There is a perceived lack of dementia-specific and secure facilities in regional communities. In many regional towns nursing homes and hostels are attached to the local hospital and staff move between the different types of facility. One family noted that the hostel is no longer staffed 24 hours a day - that hospital staff check on residents frequently but are not located on-site.

Participants also highlighted that entry to permanent care also excluded the person with dementia from eligibility for community-based programs. This was seen to contribute to a sense of being cut-off from the wider community.

Participant Suggestions

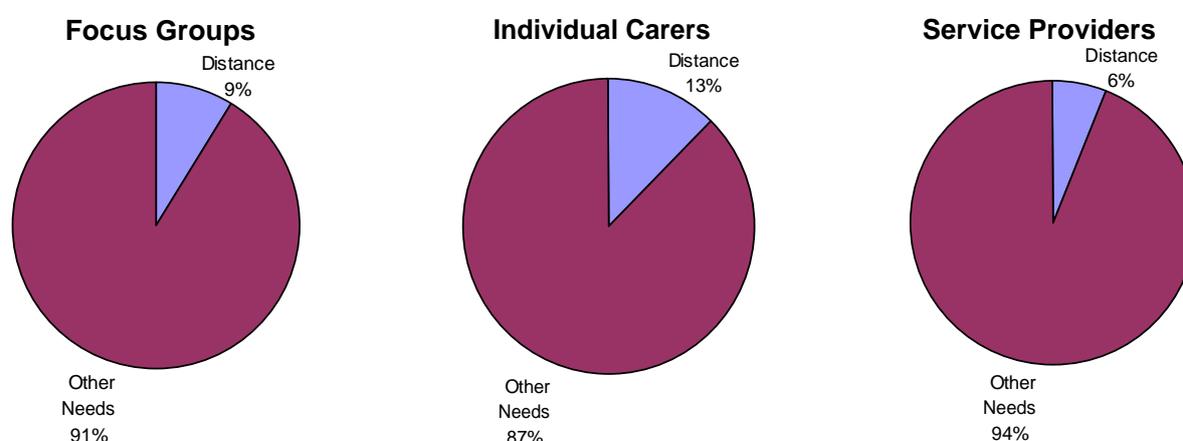
- Increased funding for in-home, day centre and residential respite, including more funding for wages and other costs associated with travel.
- Access to more respite hours for clients to accommodate travel and distance barriers.
- Access to culture-appropriate respite with Aboriginal carers, so that Aboriginal families can meet their cultural obligations.
- Provision of more flexible respite options to accommodate the interests and need for familiarity of the clients, such as farm-based host clubs, fishing trips etc.
- Greater access to mobile respite services.
- Access to locally-based facilities that provide overnight and long-term respite as well as residential care.
- Appropriately designed accommodation that allows for graduated needs, from independent living, to small group housing for low care, to high care in the same facility.
- Hostel-type accommodation for people in hospitals waiting for residential accommodation.

Distance and Travel Issues

Description

Distance and travel issues incorporated those needs that were specifically linked to issues of isolation, distance from major service centres and the financial costs associated with remoteness.

Figure 10: Distance Needs as a Percentage of All Needs per Participant Type



Impact

A major impact highlighted by carers in rural and remote areas was the isolation they experienced because family have moved away or are busy working. Those who live on farms feel particularly isolated, especially if their friends and family stop visiting because they feel uncomfortable with the person's dementia.

Carers find distance significantly affects their access to services, including access to health services, respite and access to support groups. When locally-based health professionals take holidays or personal leave, they are usually not replaced. One carer spoke of her need to travel to the city for specialist treatment:

The treatment was delayed for some time until suitable respite could be organised, which affected my physical and emotional health.

Transport issues were also of major concern. Public transport in rural and remote areas is limited and older carers are often dependent on busy adult children for transport. Carers were generally aware of the Patient Assisted Transport Scheme (PATs) which provides travel support for medical reasons, but they find it difficult to access as it requires forward planning to access PATs funds for their fuel or public transport costs.

Home and Community Care (HACC) services provide limited transport support, but only within the region. The cost of air travel is expensive and security regulations can be disruptive to the person with dementia. Many carers who are elderly reported concerns about losing their driver's licence and fear they will have to move if this happens.

Those who live on farms worried that relocation into a town, even a local town, would be disruptive to the person with dementia. In some cases, adult children have relocated their parent with dementia closer to where they reside and have only become aware of how much support is required once they are closer to them.

I'm handling it better now that I know he's in care and I know he's safe and I'm not a two-hour drive away.

Carers and service providers identified the extra financial burden of caring for a person with dementia in a regional area. Those receiving a carer's allowance or carer payment claim it is insufficient to cover the higher cost of transport, medications, continence appliances and special equipment that they are advised to purchase to assist them with their care. Self-funded retirees report struggling to cope with the extra costs as they are not eligible for the Seniors' Health Card. One carer stated:

Pensioners in remote areas should get an allowance to compensate for higher fuel and groceries [costs].

A service provider noted that because of the high cost:

The [continence] pads are left on too long leading to infections and hospitalization.

Participant Suggestions

- Provide senior's buses, school buses or volunteer drivers in rural areas for access to appointments and services.
- Establish partnerships with fly-in services, such as the Royal Flying Doctors' Service, for long-distance transport.
- Increase the carer allowance and carer payment and provide Senior's Health Cards to carers living in regional areas, regardless of income or age.
- Increase Medicare rebates for pensioners and carers.
- Provide incentives to service providers to encourage greater provision of local services.
- Provide incentives to service providers to better coordinate and share service delivery in a town or region.

Section 5

Case Studies

Case Studies

Three case studies are provided to illustrate the circumstances and difficulties under which carers and service providers in remote and regional areas may often operate. The first two case studies highlighting carers' experiences are based on face-to-face interviews undertaken with those carers. The third service provider case study is based on information provided in a returned questionnaire and a subsequent phone interview with the service provider. No real names are used in the case studies and details of the regions involved have been modified slightly to maintain anonymity.

Rural-dwelling Family Carers

Background

Retired farmers "Ron" and "Joan" moved from the Wheatbelt region to Perth. However Joan was diagnosed with dementia a few years later and Ron's health had also deteriorated. Their adult children who are still farming encouraged them to return to their country town so that they could support them.

The family describes the rural town as typical of many in the area, the population is ageing and the young people are moving to the city for education and work. As with other such towns, sporting organisations are being discontinued as the demographic changes.

Joan's condition has deteriorated in the past few years and she is unable to do anything for herself. She has suffered a number of falls. Ron is limited in his ability to provide care and does not sleep at night, worrying about his wife's safety. He is unwilling to accept community help and, according to his son and daughter, is in denial about his wife's condition. The couple receive meals on wheels three times a week and the local hospital has been providing two hours per week community support; one hour for cleaning and one for assistance with showering once a week. The main personal care and shopping is provided by the couple's daughter and daughter-in-law, both of whom live up to 30 minutes away and have farming commitments.

Needs

A major community support service has recently withdrawn its services from the town, resulting in difficulties providing continuity of care to clients. The small client population means there is insufficient work to attract careworkers and cleaners to this sphere of employment.

The couple have had a home assessment and the installation of rails and the hire of other equipment to assist was recommended. However some time has passed and the rails that were promised have not been installed. Other equipment, including an electronic bed and chair, has been purchased privately by family because they could only be hired for short periods of time. Some of this equipment has not been useful as the recipient has been unable to adapt to using it. The family believe the assessors did not grasp the difficulties their mother was having learning how to adapt to new procedures.

Joan is currently in the hostel section of the hospital for respite. However, the hospital has recently reduced staffing in the hostel from twenty-four hour staffing to hourly checks by a patient care attendant. The family believes the hospital and hostel staff do not know how to manage their mother. They say she is not given enough fluids and the staff are unwilling to persist with care when she resists. They were concerned when staff did not mobilise her for more than week after she “had a turn”.

Suggestions

The family feels that an increased presence of community care staff in the town would assist older people to live in their homes longer.

From their experience, they recommend that careworkers and assessors should be trained to understand the changes that occur with dementia. They also feel that access to a careworker who was able to engage their mother in activities would have been of benefit to her.

Remote-dwelling Daughter Carer

Background

“Margaret” lives in a Kimberley town and cares for her mother “Nancy” who has dementia. Margaret, who is Aboriginal, also has school-aged children living at home and often cares for her grandchildren.

Her family refers to Nancy’s dementia as a “sickness”. Nancy’s husband passed away a long time ago. He and Nancy spent all their working life on the cattle stations in the area. The family noticed changes in their mother as she would go over and over the same thing. She would constantly talk about people who had died; particularly her husband and a son who had also passed away. She reminisced about the station life and would ask to go back to those places.

The family has difficulty understanding their mother’s behaviour. Margaret finds it extremely hard, as the burden is primarily on her as the main carer. She feels that she needs a break sometimes to help keep caring for her mother. Caring for her other family members adds to this situation.

Margaret has given up her job, which she enjoyed, to care for her mother. Her job made her feel she had a really important role in the community and she was financially independent. Margaret is now on Centrelink benefits and finds it hard to manage financially, as the cost of living in the remote Kimberley is very high.

Margaret has recently moved into town, 100km from her community, to have access to better services. Margaret’s extended family remains in the community. Margaret feels she misses out on family, cultural and community obligations by being the main carer for her mother. When family members look after Nancy, Margaret spends her time worrying, as she feels they don’t know her as well as she does and can’t provide the care needed. Nancy keeps asking to go back to her. The only formal respite available is in the hospital, which Nancy refuses to go to. There is stigma attached to the hospital in the Aboriginal community.

The services provided by the Commonwealth Respite Service and Home and Community Care (HACC) are valued by Margaret. The staff in both places are caring and supportive. Many activities are arranged for carers, including fishing trips. HACC provides activities three days a week. Margaret can get a break for a full day and Nancy is involved in activities with other older people. Activities are also provided that Margaret and Nancy can do together. HACC have provided Margaret with information on Alzheimer's disease and she sees them as a good resource.

Needs

Margaret finds it is hard to access overnight respite as the options are limited and families have to plan for it months ahead. Carers can't get it when they need it.

She believes that her family needs to know more about Alzheimer's disease and where to get information about it. It is hard when the burden is on one family member who then has to educate the whole family. Margaret does not know other people in the same situation and feels isolated in her town.

Suggestions

Margaret suggested there be more opportunities made available for families to access respite. She believes that if families had more information it may help with caring for their family member in the future and help them to prepare for changes. She suggests training be made accessible for all family members to share the information and to have a better understanding of Alzheimer's disease. This training must be appropriate for Aboriginal people. Margaret suggested that one of the service agencies in the town, such as HACC for example, could be the key agency that families go to obtain information on Alzheimer's disease.

In addition to providing information, Margaret believes a carers' network needs to be set up so that carers can share information and ideas with others in the same situation and thereby reduce the sense of isolation.

Margaret also suggests that appropriate training should be provided to HACC workers.

Rural Service Provider

Background

“Bronwyn” works for a hospital-based Home and Community Care Service in a small town in the Midwest health region. She coordinates a social group for carers in the area. The town and surrounding area has a population of about 1200, two-thirds of whom live in the town. Approximately 400 people live in outlying farms or settlements and a high percentage of this group is Aboriginal. Public transport is available just twice weekly to the major town in the region, which is 100kms away. Many health services are provided on a visiting basis, by rotating staff.

Needs

Bronwyn notes that families don't always recognise dementia or know enough about it or the help that might be available. Aboriginal families often accept behaviour changes in relatives with dementia and try to deal with it within their own family. These carers can become overwhelmed by the burden of care, particularly when they have other family members, including grandchildren, to care for. They are unlikely to take up offers of respite as the restrictive guidelines for respite are not appropriate for Aboriginal clients.

The lack of local essential services such as regular transport and access to continence products, and the added cost of heating and cooling of houses to maintain basic comfort for elderly people with dementia, prompts people to consider moving to more suitable accommodation. However, legal difficulties can emerge if the property is jointly owned with the person with dementia.

Bronwyn believes these carers will only seek help from people they can trust and they will avoid medical/clinical people who lack understanding and knowledge of their ways. Frequent staff changes result in a loss of continuity of services, knowledge and trust that is built up over time.

She notes that assessments rarely take into account the full impact of care for some families. Many health service staff lack understanding about the complex problems confronting a family caring for a person with dementia, particular Aboriginal families who may have extended family commitments.

Suggestions

Bronwyn suggests that basic domestic support, such as assistance with laundry when the person with dementia is incontinent or transport to services, would provide more practical service to these carers than the current limited services that are offered.

She suggests health service staff need to gain knowledge of and empathy for the complex social issues that many Aboriginal families have to deal with. Assessments should be family-oriented and take into account the full impact of care. They should also be conducted by a person who has the trust of the client and family. Bronwyn also suggests that families need information about dementia in a language they can understand and from a person they trust.

Bronwyn believes incentives to attract local Indigenous people to become community careworkers would provide skills and employment opportunities for local Aboriginal people, and would address the need for culturally appropriate care. She believes young people could be encouraged to undertake careworker training through the Community Development Education Program.

Section 6

Discussion and Recommendations

Discussion

Overall, the information from focus groups and responses from carer and service provider questionnaires generated a clear picture of the needs of people with dementia in rural and remote Australia.

As noted in the results section, there were some differences in the ranking of issues between combined focus groups and combined individual carers and service providers questionnaires; but, overall, the issues raised were consistent.

Focus groups consistently ranked Emotional and Social Support, and Education and Awareness Raising as the most important needs. There was no difference in the ranking of issues within the major regional focus groups. Some regions with smaller representation in focus group participation did not address all themes.

Individual carers also ranked Emotional and Social Support as the most important need and Respite and Residential Care was ranked just above Education and Awareness Raising. However, the number of individual carer respondents was small relative to the number of focus group participants. The two most frequently occurring needs raised by Indigenous carers were: Emotional and Social Support needs (sharing information with other carers), and Education and Awareness Raising (for carers and the extended family).

Unsurprisingly given the nature of their work, health professionals and service providers listed issues relating to Respite and Residential Care and Service Access more frequently than other needs. The 13 service providers who commented specifically on Indigenous dementia ranked culturally-appropriate Education and Awareness Raising and Access to Community Services as high needs. They also identified a need for understanding and respect for Indigenous culture by non-Indigenous health and service providers, and recommended a broad consultation and planning process with Indigenous stakeholders to obtain a comprehensive picture of Indigenous needs relating to dementia.

Recommendations

The following recommendations are based on suggestions made by all participant types that are directly relevant to the rural and remote context. Other issues that are common to all people with dementia and carers have been identified in other reports.

Emotional and Social Support

1. Investigate a model for the provision of local professionally facilitated counselling services to provide support, guidance and advice on effectively managing the challenging aspects dementia

Both carers and service providers recommended access to local, professionally facilitated counselling services for appropriate guidance and advice on effectively managing the challenging aspects of dementia.

Education and Awareness Raising

2. Improve access to information and education on dementia in regional and remote areas through better utilisation of local training providers and technology-based information channels

Both carers and service providers recommended increased access to information and education on dementia, dementia care, and related topics. Suggested vehicles for education delivery included local family and careworker courses; printed information; videoconferencing; information provided via the internet and through local general practitioners.

Community Service Access

3. Explore the development of more flexible models for delivery of dementia-related community care services to overcome barriers to access created by distance and isolation.

Both carers and service providers recommended more flexible provision of community services, for example better coordination and sharing of resources and services, to overcome problems associated with distance and travel,

Diagnosis, Assessment and Medical Management

4. Develop strategies to increase numbers and retention rate of health professionals who have expertise in dementia in regional and remote areas

Carers and service providers recommended incentives to attract general practitioners, community nurses and allied health staff to work in rural and remote areas (problem is this is for all health needs not just dementia), and that ongoing professional education programs be delivered to this group when working in these regions.

- Investigate the provision of memory clinic services in regional centres to facilitate greater access by people with dementia living in remote and regional areas. This could include exploring the use of communication technology and visiting specialist teams to facilitate timely diagnosis, assessment and medical management.

Service providers *recommended* increased access to geriatricians and gerontology services through the establishment of memory clinics in regional areas

Respite and Residential Care

5. Explore the provision of more flexible respite care options in regional areas to overcome access barriers created by distance and isolation.

Both carers and service providers recommended more flexible provision of respite (such as mobile respite services) to overcome problems associated with distance and travel, and to meet the specific interests/needs of people in rural and remote areas (such as farm-style accommodation and gender-relevant activities).

Distance and Travel Issues

6. Investigate the medically-related transport needs of people with dementia living in regional areas with a view to overcoming hardships created by remoteness from service providers.

Carers recommended that more flexible transport options be available for people with dementia in regional areas who require transport for appointments and services. Suggestions included access to seniors' buses and volunteers for local trips, and fly-in/fly-out services with the Flying Doctors' Service for long-distance transport.

7. Undertake further investigation of the apparent higher financial burden experienced by people with dementia and their carers living in remote and regional areas, and recommend strategies to alleviate hardship

Carers recommended that Government recognizes the greater financial cost incurred by carers in regional areas. Suggestions included subsidies through increased: carer allowance and carer payment; Medicare rebate; and access to Senior's health card, regardless of income and age. Service providers recommended increased funding to cover the additional costs associated with providing respite and community services in rural and remote areas, and to attract staff to work in the regional community service sector

Indigenous Dementia

8. Undertake a broad consultation with Indigenous people with dementia and their carers and families living in remote and regional areas in order to identify dementia support-related needs, priorities and recommendations

Service providers working with Indigenous clients with dementia recommended that a broad consultation process be undertaken with Indigenous communities to find out their needs, priorities and recommendations.

Section 7

Appendices

Appendix 1: Outline of Initial Contact with Service Providers

PHONE PROGRAM FOR HEALTH PROFESSIONALS AND SERVICE PROVIDERS

Introduction

My name is [_____] from Alzheimer's Australia WA Ltd. Alzheimer's Australia, WA is the peak not for profit organization providing advocacy support, counselling, information, education and respite services to people with dementia throughout Western Australia.

Services provided for PWD

Does your organization provide support and/or services to people with dementia or to their families and carers?

Yes No

Background of Project

I am working on a project to identify and prioritize the needs of people with dementia who live in rural and remote Australia. The project is being undertaken by Alzheimer's Australia for the Commonwealth Government.

In order to achieve this we are seeking support in three ways:

- We are inviting people with dementia and/or families and support networks living in these areas to contribute by taking part in a focused-discussion with us; and
- We would also like to include feedback from health professionals and service providers who are working with people with dementia.
- Lastly, we are presenting an overview of the existing literature or reports completed on this issue.

(If the service does not have access to PWD)

Do you know of any health professionals or service providers who are working with people with dementia in your area?

Please provide name and contact details of appropriate service below

.....

.....
.....
.....

Thank you for your time.

Confidentiality

Any information collected/provided will be treated confidentiality. The report to the Commonwealth Government will not include any identifying details.

Survey

Would you be interested in responding to a short 6-question questionnaire on the unmet needs of people with dementia in your area, on behalf of your organization?

Yes No

(If no) Is there someone else in the organization who would be more appropriate to talk to?

(Name/position of person).....

(If Yes) We can send the questionnaire to you by post, email, fax or we can complete it over the phone, which would you prefer?

Post Fax Email Phone

Details

Postal address:

Name/Position:

.....
Address

Email:

Fax:

Phone: *(If phone)* When would you like to do it?

Date Time

Focus Group

Another avenue that we are hoping to gather this information is from focus groups of people with dementia, families and support people, where these groups represent the needs of people with dementia in (name of region). Would you be interested in organising a focus group of people with dementia and/or their support people to discuss these issues with us?

Yes No

If no:

Reason if given:
.....
.....
.....

Discuss possibility of individual questionnaires via phone contact or face-to-face

If yes:

Explain outline of focus group

Recruitment: Advertising within existing cliental base

Do you foresee any issues with recruiting participants?
.....
.....
.....

We are likely to be in the (region) in (month). Would this be a good time to have the focus group?

Date:

Time:

Location:

Discuss materials needs especially whiteboard facilities

- Collect details for sending information/advertisement

Previous Research

We are also compiling a list of previous studies or reports on this topic. Do you know of any existing information on the needs of people with dementia, in your area or other remote areas, which could be relevant to this project?

Yes No

(If yes) Please provide details of relevant documents

.....
.....
.....
.....

Report

We would also like to forward you a draft copy of the report in mid August for your to review it and respond with any comments/feedback before the final report is presented to the Commonwealth in late August, early September. Would this be okay?

Yes No

Other service providers or health professionals

Do you know of any other services in your region that may be interested in supporting this project?

(If yes) Name and contact details

.....
.....

Give your contact details

Thank you for your support

Appendix 2: Service Providers' Questionnaire

HEALTHPROFESSIONAL AND SERVICE PROVIDER QUESTIONNAIRE

'Needs of People with Dementia living in Rural and Remote Australia'

Alzheimer's Australia is the peak body for people living with dementia and their support systems. We are responsible for providing advocacy, support, counselling, information and education to people throughout rural and metropolitan Australia. The Commonwealth Government has asked us to identify the needs of people with dementia who live in rural and remote Australia. We invite you to participate in this brief questionnaire on the needs of people with dementia living in rural and remote Australia and how these needs can be addressed. The information you supply will remain confidential and your anonymity upheld when reporting the findings to the Commonwealth. We anticipate and appreciate your support in our quest to advocate for the needs of people with dementia in rural and remote Australia.

Question 1. Please list the 5 most important 'unmet' needs of people with dementia in your area?

- 1.
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- 2.
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- 3.
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- 4.
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- 5.
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Question 2. Please describe briefly how these needs affect the person with dementia, their family, friends and/or community.

- 1.
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- 2.
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- 3.
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- 4.
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- 5.
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Question 3. What solutions can you suggest for each of the needs you have identified?

- 1.
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- 2.
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- 3.
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- 4.
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- 5.
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Question 4. Do you feel your service meets or partially meets the needs you have identified?

Yes **No**

Please briefly explain how your service does or does not meet these needs.

1.
.....
2.
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3.
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4.
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5.
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Question 5. Do you have any other comments?

.....
.....
.....

Question 6. Demographic Details

Name of organization:

Your position:

Health region:

**Please Return Questionnaire to Alzheimer's WA in the Reply Paid Envelope
Provided
THANK YOU**

Appendix 3: Focus Group Structure

PROGRAM FOR FOCUS GROUPS: Facilitators Guide

Welcome participants and supply name tags and information sheet.

Time allocated (minutes)	Activity	Materials
10	<ol style="list-style-type: none"> 1. Welcome/Thanks for coming 2. Introduce facilitators 3. Provide background and explanation for focus groups including our aim 	<ul style="list-style-type: none"> • Introduce focus groups as a way of answering the Commonwealth's initiative of wanting to recognize the different needs of people with dementia living in RRR Australia. • <i>Aim:</i> 'Gaining a greater understanding of what your specific needs are and reporting the needs you identify to the Commonwealth'. • Answer any questions • <i>Caution:</i> Ensure discussion does not become a 'support group' or focused on any one issue • <i>Limit of focus group:</i> the structure of the focus group does not allow for specific discussion on one issue, unless this is the wish of the whole group. If specific personal issues arise, the facilitators will provide information on support options after the discussion.
5	<p><u>Ice breaker</u> Go round the group and ask each person to introduce themselves and where they live</p>	<ul style="list-style-type: none"> • This will give the group/facilitators an opportunity to understand why needs may differ
20	<p><u>Phase 1: Identify Needs</u></p> <p>Allow participants to identify needs of people with dementia living in RRR Australia (either met or unmet)</p>	<ul style="list-style-type: none"> • Ask participants to just state the issue – in one sentence or less • Clarify the issues as they are identified indicating whether these needs are currently met or unmet • Summarise the essence of what has been said (for verification)

		<p>before scribing on the whiteboard</p> <ul style="list-style-type: none"> • <u>Materials:</u> Write each issue on whiteboard or butchers paper
20	<p><u>Phase 2: Prioritising Needs</u></p> <p>Assign 5 'dots' to each participant to allocate to the issues he/she considers the most important (completed individually)</p> <p><i>Break</i></p>	<ul style="list-style-type: none"> • Ask participants to prioritise needs based on severity and frequency of need • Show where to place dots (below the stated need, in a box) • Instruct participants to only use as many of the 5 dots allocated to rank those needs that affect them • <i>Break</i> whilst participants decide their priorities individually • <u>Materials:</u> Distribute red dots (5 x participants)
5	<p>Prioritise the issues, and pick the issues with the most dots</p>	<ul style="list-style-type: none"> • Calculate the issues with the most dots
20	<p><u>Phase 3: Impact of Needs</u></p> <p>Write each issue on a separate sheet of paper and allow participants the freedom to move between issues and discuss how each issue impacts on the person with dementia</p>	<ul style="list-style-type: none"> • If necessary, write a statement clarifying the issue before dividing into groups • Allow a maximum of 5 minutes to each issue depending whether time permits • Groups to appoint a scribe • <i>How does the issue impact on the participant and/or person with dementia?</i> • <u>Materials:</u> Need butchers paper and markers
10	<p>Groups to report back on the impact of issues</p>	<ul style="list-style-type: none"> • Allocate spokesperson for each small group • Large group discussion • Facilitators to scribe clarifying statements on existing paper • <u>Materials:</u> Collect paper
20	<p><u>Phase 4: Recommendations</u></p> <p>Again, write each issue on a separate sheet of paper and allow participants the freedom to move between issues and discuss possible solutions/strategies</p>	<ul style="list-style-type: none"> • Divide priority issues between groups • Instruct participants to give specific and detailed strategies to meet needs as well as general recommendations • Allocate spokesperson for each small group • Allow a maximum of 5 minutes

		<p>to each issue depending whether time permits</p> <ul style="list-style-type: none"> • <u>Materials:</u> Need butchers paper and markers
10	Group to report back on possible strategies/recommendations	<ul style="list-style-type: none"> • Allocate spokesperson for each small group • Large group discussion • Facilitators to scribe recommendations on board/paper • <u>Materials:</u> Collect paper •
10	Close/Thank you	<ul style="list-style-type: none"> • Ask for any closing comments that participants would like included in report: messages to the Commonwealth can be either verbal or written comments • Identify participants who would like or need a follow up contact • Inform participants that they can obtain copy of report at completion, collect postal details • Ensure all paper/materials is collected • Consider any individual case studies that may be appropriate

LIST OF MATERIALS

Materials needed to conduct focus groups:

- Copy of program
- Participant information sheet
- Butcher's Paper Activity
 - Butcher's Paper
 - Various coloured markers/pens
 - Blue tack
 - Large clips
- Whiteboard Activity or butchers paper
 - Whiteboard markers and duster; or
 - Butchers paper hanging with blue tac or clips and string

- Sticky dots (5 x participant)
- List of participants attending
- Name labels for participants and facilitators
- Envelope for completed sheets
- Paper and pens for facilitator comments
- Paper for follow up contacts

Appendix 4: Individual Carers' Questionnaire

INDIVIDUAL CARER/PERSON WITH DEMENTIA QUESTIONNAIRE

'Needs of People with Dementia living in Rural and Remote Australia'

Alzheimer's Australia is the peak body for people living with dementia and for their family and support system. We are responsible for providing advocacy, support, counselling, information, education and respite services to people throughout rural and metropolitan Australia. The Commonwealth Government has asked us to identify the needs of people with dementia who live in rural and remote Australia. We invite you to participate in this brief questionnaire on the needs of people with dementia living in rural and remote Australia and how these needs can be addressed. The information you supply will remain confidential and your anonymity upheld when reporting the findings to the Government. We anticipate and appreciate your support in our quest to advocate for people with dementia in rural and remote Australia.

Question 1. Please list the 5 most important 'unmet' needs of people with dementia in your area?

- 1.
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- 2.
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- 3.
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- 4.
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- 5.
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Question 2. Please describe briefly how these needs affect the person with dementia, their family, friends and/or community.

- 1.
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- 2.
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- 4.
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Question 3. What solutions can you suggest for each of the needs you have identified?

- 1.
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- 2.
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Question 4. Do you have any other comments?

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Question 5. Demographic Details

How are you related to the Person with Dementia (wife, husband, daughter, son, friend etc):

.....

Health region:

.....

Please Return Questionnaire to Alzheimer’s WA in the Reply Paid Envelope Provided

THANK YOU

Appendix 5: Participants by Type, Location and Health Region

Region	Location	Participants			
		Focus Group		Interview/Questionnaire	
		Carers	People with Dementia	Carers	Service Providers
Great Southern (WA)		17	8	3	11
	Albany	7	3		
	Denmark			2	
	Gnowangerup			1	
	Katanning	6	4		
	Mount Barker	4	1		
Goldfields (WA)		8	2	3	4
	Esperance	6	2		
	Kalgoorlie	2		2	
	Kambalda			1	
Kimberley (WA)		0	0	7	13
	Broome			2	
	Derby			1	
	Kununurra			4	
Pilbara (WA)		0	0	0	4
Midwest (WA)		0	0	7	12
	Dongara			1	
	Kalbarri			2	
	Geraldton			1	
	Morawa			1	
	Mullewa			1	
	Northampton			1	
South-West (WA)		39	10	6	13
	Bridgetown	3			
	Bunbury	9			
	Brunswick Jctn			1	
	Collie	12	2		
	Manjimup	9	8	4	
	Margaret River.	6			
	Waroona			1	
Wheatbelt (WA)		32	6	6	8

	Corrigan	4			
	Dalwallinu	5	4		
	Jurien	11			
	Narrogin	7			
	Northam	5	2		
	Quairading			1	
	Southern Cross			3	
	Other (undefined)			2	
	Greater Southern (NSW)		2	1	4
	Braidwood			1	
	Yass	2			
	Hills Mallee Southern (SA)		9		
	Kangaroo Isl.	9			
	Northern & Far West (SA)		2		
	Port Augusta	2			
	Huon (Tas)		5		
	Huonville	5			
	Other (region not defined)				5
	Totals		114	26	33
					74

Appendix 6: References

Access Economics, 2005(a). *Dementia Estimates and Projections: Australian States and Territories*. Report for Alzheimer's Australia, Canberra, ACT, February. Available on www.alzheimers.org.au

Access Economics, 2005(b). *Dementia Estimates and Projections: Western Australia and its Regions*. Report for Alzheimer's Australia WA, February. Available on www.alzheimers.org.au

Alzheimer's Association of Australia, 2001. *Diagnosing Dementia: A Reference Paper*. Report undertaken by K. Black, D. LoGiudice, D. Ames, B. Barber and R. Smith. Alzheimer's Association of Australia.

Alzheimer's Australia NT, 2002. *Indigenous Dementia Project Report*. Report undertaken by consultants for Alzheimer's Australia NT. Darwin: Alzheimer's Australia NT.,

Australia, Department of Health and Ageing, 1998. *Aged Care: Make the Choices that are Right for You*. Canberra, ACT: Aged and Community Care Division, Department of Health and Family Services, 1998.

Australia, Parliament House of Representatives, Standing Committee on Community Affairs, 1994. *Home but not Alone: A report on the Home and Community Care Program*. Canberra, ACT: Australian Government Publishing Service.

Australian Institute of Health and Welfare, 1998a. *Health in Rural and Remote Australia*. The first report of the Australian Institute of Health and Welfare on rural health. (PHE 6).

Australian Institute of Health and Welfare, 1998. *The health of subpopulations*. *Australian Health*, **6**, 28-74.

Barber, J.G., 1998. Rural disadvantage in the distribution of South Australian Home and Community Care funding. *Australian Journal of Social Issues*, **3** (3), 231-239.

Boldy, D., Davey, M., Crouchley, K. and Lilly, E., 2005. Host family respite: description and assessment of a program. *Australasian Journal on Ageing*, **24** (2), 94-97.

Brodaty, H.; Draper, B. M. and Low, L., 2003 Behavioural and psychological symptoms of dementia: a seven tiered model of service delivery. *Medical Journal of Australia*, **178**, 231-234.

Brodaty, H., Thomson, C., Thompson, C. and Fine, M., 2005. Why caregivers of people with dementia and memory loss don't use services. *International Journal of Geriatric Psychiatry*, **20** (6), 537-546.

Brown, Judith (n.d.). *To investigate community programs which provide respite and support services to carers of people who are frail aged or have dementia in rural and remote localities – Canada, Sweden, Norway*. Report to the Winston Churchill Memorial Trust for Churchill Fellowship, 2004.

Bruce, D.G., Baird, M. Saddler, A.H. and Goldswain, P., 1998. A preliminary survey of patients seen by the Kimberley Aged Care Assessment Team. *Australasian Journal on Ageing*, **17** (2), 95-97.

Byles, J., Powers, J., Chojenta, C., and Warner-Smith P., 2006. Older women in Australia: ageing in urban, rural and remote environments. *Australasian Journal on Ageing*, **25** (3), 151-157.

Carers Association of Western Australia, 2005. *Roughing it in the Bush: Carers in Rural and Remote Western Australia: Their Needs and Experiences*. Report by Thomas Barrett, Social Work and Social Policy, UWA. Perth: Carers Association of Western Australia.

Cooper, D., and Jenkins, A., 1998. *Obtaining consumer feedback from clients of homebased care services: a review of the literature*. Canberra, ACT: Australian Institute of Health and Welfare..

Campbell-Smith, M. 2003. Rural Tasmanian dementia health care model. *In 7th National Rural Health Conference, March 2003, Hobart.*

Davies, M. and Burr, M., 1986. The mobile day care program. *Proc Annu Conf Aust Assoc Gerontology* , **21**, 78.

Davison, B., Kendig, H., Jordan, F., Misso, V. and McLaren, M., 1991. What is quality of care? Evaluating day care for people with dementia. *Proc Annu Conf Aust Assoc Gerontology*, **26**, 58-62.

Edith Cowan University, 2004. *Guidelines for a Palliative Approach in Residential Aged Care*. Canberra, ACT: Rural Health and Palliative Care Branch, Department of Health and Aging.

Hansen, E., Robinson, A., Mudge, P. and Crack, G., 2005. Barriers to the provision of care for people with dementia and their carers in a rural community. *Aust J Prim Health* **11** (1), 72-7.

Harvey, D., Webb-Pullman, J. and Strasser R., 1999. Rural Health Support, Education and Training Program (RHSET): Where to now? *Australian Journal of Rural Health* **7**(4), 240-248.

Hines, J., 1993. *Dementia in Rural Australia: A Study of Expressed Demand for Health Services*. Thesis (Masters). University of New South Wales.

Hines, J. and Black, D., 1993. Dementia: a challenge for rural health planning. *In A fair go for rural health – forward together: 2nd National Rural Health Conference, 12-14 February 1993 Armidale, N.S.W.* Armidale: University of New England, 207-12.

Hines, J., and Black, D., 1993. Health Administration for rural health planning. *In A fair go for rural health – forward together: 2nd National Rural Health Conference, 12-14 February 1993 Armidale, N.S.W.* Armidale: University of New England, 207-12.

Home and Community Care National Service Standards Consumer Survey 2002 Western Australia, 2003. Final Report, Perth.

Hueke, M., 1990. A Model for the management of people with diagnosed dementia in country areas. *Australasian Journal on Ageing*, **9** (4), 33-5.

Jorm, A.F., Dear, K.B.G., and Nicole, M., 2005. Projections of future numbers of dementia cases in Australia with and without prevention. *Australian and New Zealand Journal of Psychiatry* **39** (11-12), 959-963.

Killer, G. and Medza, S., 1998. Building preventive health policies for Australia's veterans. In 2nd National Men's Health Conference, 1997 Perth. Perth: Curtin University of Technology, 451-6.

Kirkpatrick, K., 1991. Support for the aged in non-urban areas: the experience of the South West Queensland Geriatric Assessment Team. *Proc Annu Conf Aust Assoc Gerontol* **26**, 179-81.

Knapman, C., 1998. Repositioning dementia: from a private trouble to a public issue. *Northern Radius* **4** (3):14-15.

Knapman, C. and Waite, H., 1997. Rights, relationships and dementia care. In *Achieving Inclusion: Exploring Issues in Disability*. M.L. Caltabiano, R. Hill, and R. Frangos, eds.. Townsville, Qld: Centre for Social and Welfare Research, James Cook University, p199-219.

Knapman, C. and Waite, H., 1993. Missing persons in scientific discourse: carers for people with dementia. *Proc Annu Conf Aust Assoc Gerontol* **28**, 65-8.

Lawrence, J. and Pasmucans, M., (n.d.) Nganampa Health Council as a Multi Purpose Service. In *3rd National Rural Health Conference 3-5 February 1999 Mt Beauty*.

Lawrence, C., 1994. The role of government in the care of frail older people: keynote address. *Proc Annu Conf Aust Assoc Gerotol* **29**, 55-64.

Loh, P.K., Ramesh, P., Maher, S., Saligari, J., Flicker, L. and Goldswain P., 2004. Can patients with dementia be assessed at a distance? The use of Telehealth and standardised assessments. *Internal Medicine Journal* **34** (5), 239-42.

McGrath, P. and Holewa, H. F., 2005. The 'right story' to the 'right person': communication issues in end-of-life care for Indigenous people. *Australian Health Review* **29** (3), 306-16.

Mykyta, L.J. and Lovell, G., 1989. Community care for dementia sufferers. *Australasian Journal on Ageing*, **8** (3), 17-9.

Neville, C.C., and Byrne, G.J., 2002. Behaviour of older people admitted for residential respite care. *Aust J Adv Nurs*, **20** (1), 8-12.

O'Reilly, M.T. and Strong, T., 1997. Caring for someone with dementia in a rural town, Part 1: family and friends. *Australasian Journal on Ageing*, **16** (4), 190-3.

O'Reilly, M.T. and Strong, T., 1997. Caring for someone with dementia in a rural town, Part 2: services. *Australasian Journal on Ageing*, **16** (4), 194-7.

Pollitt, P.A., 1997. The Problem of Dementia in Australian Aboriginal and Torres Strait Islander Communities: an Overview *International Journal of Geriatric Psychiatry* **12**, 155-163.

Rose-Miller, M., 1999. Beyond the black stump – who cares? In *Promoting Inclusion: Redressing Exclusion: the Social Work Challenge*, 1999 Brisbane. Brisbane: Australian Association of Social Workers (AASW), International Federation of Social Workers (Asia

Pacific Region IFSW), Asia and Pacific Association for Social Work Education (APASWE), and Australian Association for Social Work and Welfare Education (AASWWE), 210-215.

Saligari, J., Flicker, L., Loh, P.K., Maher, S., Ramesh, P. and Goldswain, P., 2002. The clinical achievements of a geriatric telehealth project in its first year. *Journal Telemed Telecare* **8** S3, 5.

Schofield H.L., Murphy, B., Herrman, H. E., Bloch, S. and Singh, B., 1997. Family caregiving: measurement of emotional well-being and various aspects of the caregiving role. *Psychological Medicine* **27**, 647-657.

Smith, K., 2005. Assessing dementia in Indigenous communities. *Agendas Spring*, 14-15.

Steffen, A. and Mangum, K., 2003. Distance-based skills training for depressed dementia family carers. *Clinical Psychologist* **17** (1), 1-10.

Squires, B. and Barr, F., 2005. The development of advance care directives in New South Wales. *Australasian Journal on Ageing* **24**(sl), S30-S35.

Van Ast, P., 2005. *Support Program for Rural Carers Utilising Videoconferencing – An Evaluation*. Geraldton:WACHS, Government of Western Australia and Combined Universities Centre for Rural Health.

Wareham, B. and Goddard, R., 2002. Respite on the move. *In National Respite Conference 2002*. Australia: Blue CareAccess Economics 2003 *The dementia epidemic: economic impact and positive solutions for Australia*. Canberra, ACT: Alzheimer's Australia, 2003.