**Identifying support needs to improve rural dementia services for people with dementia
and their carers: A consultation study in Victoria, Australia.**

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Abstract

Objective: The support and service needs of people with dementia and their carers are not always addressed in rural regions, yet family carers play an important role in supporting the person living with dementia to remain living in their own home. This study sought to identify and prioritise service and support needs of people with dementia and carers.

Setting: A rural region in Victoria, Australia.

Design: A two phase mixed methods study involving qualitative focus groups and a survey.

Participants: People living with dementia, carers and health professionals.

Findings: Focus groups identified twelve areas of need. A follow-up survey reached consensus on the priority areas for service improvement. These included diagnosis and information access, dementia training, community understanding and carer support.

Conclusion: Living in a rural region imposes significant challenges on people with dementia and carers. We need to find ways to address gaps in service provision for carers and people with dementia in rural settings and examine their applicability in other rural regions more broadly.

What is already known on this subject:

What this paper adds:

- Carers require a more timely diagnosis of dementia so they can access support services.
- Health professionals need more training to help them better understand the experience of living with dementia and the importance of information sharing.
- Carers need more support and someone to talk to about their fears and struggles, their own health and well-being, and care strategies.
- In order to support carers and people living with dementia, the local community needs help to understand dementia and carers' experiences.

Keywords

Dementia, carers, support, rural health service delivery, focus groups, survey

Introduction and background

In Australia, nearly 1.5 million people are affected by dementia, including family members, friends and others who take on a role of caring (1). Two of every five persons living with dementia, live in regional cities, towns and rural and remote areas (2) (1). The higher proportion of people with dementia in rural and regional areas arises due to issues such as ageing in place, migration of young people out of the area, and retirees moving into rural regions (1).

Family carers play a crucial role in supporting the well-being of people with dementia and their ability to remain living at home (1). Caring for a person with dementia can place a substantial emotional, psychological and physical burden on family carers. Caring for someone with dementia can increase the carer's risk of social isolation (3) and can cause carers to give up their holidays and hobbies and spend less time with their family and friends (4). Carers are in general more likely to have smaller social networks than non-carers, and their social support often decreases over time (5).

In rural communities, the impact of dementia and the availability of support for people with dementia and their carers is a particularly significant issue. For example, gaining access to services can be difficult for older people living in rural areas due to their relative isolation (6) and their need to travel longer distances to use services (7). Accessing services may also be more difficult due to restrictions on driving as a person's condition deteriorates, the absence of public transport (7), and the lack of other cheap transport options. Other obstacles include fewer local specialist providers, insufficient education and training opportunities for health care workers, insufficient geriatric and diagnostic services, a lack of local knowledge among overseas-trained health professionals, inconvenient hours of operation, and the absence of local dementia-friendly acute services (8 , 9). Having a diagnosis of dementia is also known to attract social stigma (10) and in small rural communities where people are often well-known to each other, carers may avoid reaching

out for assistance for fear of being ostracised, or to avoid divulging their circumstances, and to maintain privacy.

This study sought to improve understanding of the experiences and service and support needs of rural carers of people living with dementia. We conducted research in a rural region in the State of Victoria, Australia between 2015 and 2016. Specifically, the study aimed to: (1) identify the support needs of people living with dementia and their carers; (2) obtain stakeholder agreement on the top three priority support and service needs; and, (3) identify existing interventions, models of care or evidence-based services and supports available to respond to these needs.

Methods

The study employed a two phase design. The first phase involved focus groups with key informants from the rural health service and with people living with dementia and their carers. It has been suggested that the 'felt' needs expressed by carers may be a good indicator of unmet service need and therefore may be a suitable 'red flag' for impending caregiver burnout (11). The second phase of the study used a survey to prioritise the dementia service needs and gaps that were identified from the focus groups in phase one. It was important to obtain consensus on the most important service gaps and needs so that any future interventions or planning to improve service and care delivery would be acceptable to the community. The university human research ethics committee and the participating health service approved the study (HREC No. 15/069).

Setting

The study took place in a geographically large rural region of approximately 7,000 square kilometres (2,700 square miles). The rural region is 300 km (186 miles) from Melbourne in the state of Victoria, Australia. The study was conducted in 2015 -2016. The population density in this region is 0.9 persons per square km (0.3 per square mile). Close to half the population lives outside the main towns, of which the majority have a population of less than 800 people. The region was chosen because of its recognised work in aged and dementia care and its multi-site health service.

Participants

Carers and people with dementia living in and around the main town and two catchment townships in the region that had community health services, were informed about the study and invited to participate by means of a flyer distributed through the health service, memory and primary care clinics, and an article in the local newspaper. People with dementia were included as there is a growing recognition that people with dementia can express their likes and dislikes and contribute valuable research data, and also because it is 'morally unacceptable' not to include their voices in research (12).

Representatives from the rural health service and other organisations that provide services for people with dementia were invited by email. A project assistant and the rural health service's cognitive rehabilitative therapist, who supported people living with dementia and who was known in the local communities, assisted with advertising and recruitment.

Data collection and analysis: Focus groups

Focus groups with people with dementia and carers explored their usage of existing services and their considerations of unmet service and support needs. Questions included: services used; types and levels of support available; service delivery and access; impacts of support on carers and people with dementia; service need and availability; service and system wide navigation; dementia diagnosis; and, staff education and training. Three focus groups involving people with dementia (n= 3) and carers (n= 13) were undertaken. One focus group with key informants from the health service, local government, and the local Alzheimer's Australia (Victoria) service (n= 5) was also conducted. Focus groups were between one and two hours in length and were recorded, transcribed and subjected to descriptive content analysis. Two researchers (MB & DF) read the transcripts several times and independently categorised and collapsed content according to the issues that were raised. The two lists of issues were compared and discussed and the researchers arrived at a consensus about the twelve main service needs or gaps reported by participants (Table 1).

1. Better and timely access to appropriate dementia services including less travel and reduced waiting time for appointments;2. Assistance to find information about what dementia services and other help is

<p>available to carers and how to access these;</p> <p>3. More training for health professionals to help them understand the experience of living with dementia, what it is like to be a carer and the importance of sharing information about current best practice;</p> <p>4. Improving early diagnosis of dementia so that services and appropriate information can be accessed;</p> <p>5. More community awareness and education about living with dementia, to reduce stigma in the community and increase awareness of the needs of carers;</p> <p>6. More memory support nurses to provide care;</p> <p>7. More day care and respite care options, for example extended times and evening care;</p> <p>8. More support for carers and someone to talk to and share experiences about fears, loneliness, struggles, health and well-being, and care strategies;</p> <p>9. Training for carers about how to care for someone with dementia;</p> <p>10. More training of health professionals so that they acknowledge carers' roles in decision-making and as partners in care;</p> <p>11. A greater role for volunteers to help the carers of people with dementia; and,</p> <p>12. Better care co-ordination to keep services involved and up-to-date with the needs of the people with dementia.</p>
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Table 1. Service and support needs and information gaps identified during focus groups

Data collection and analysis: Survey

To prioritise the dementia service needs and gaps perceived by consumers and health professionals, a survey based on the phase one data was developed. All focus group participants were sent a survey and a cover letter. Respondents were asked to review and rank the importance of the twelve service needs in Table 1, on a 5-point Likert scale ['Not at all important' (1) to 'Absolutely essential' (5)]. Respondents were also asked to list their top three and bottom three priorities and to provide any additional priorities and comments. The median and mode for the importance of each of the 12 survey items was calculated. Of the original 21 focus group participants, 12 did not respond even after two reminders, giving a response rate of 42%. Nine respondents completed the survey: six carers and three health professionals. Consensus was determined for an item when the median and mode response

on a 5-point Likert scale was 4 or higher. Using this measure, an acceptable level of agreement was achieved for all items. The item priority was calculated by how often each item was listed as a priority area by all participants. There was agreement on three priority issues (two issues were ranked equal third) (Table 2). Despite a lower than anticipated response rate, a high level of agreement on items was reached and the results are still useful for generating recommendations for planning and development of interventions and supports in rural regions similar to those of this study.

1. Improving early diagnosis of dementia so that services and appropriate information can be accessed;
2. More training for health professionals to help them understand the experience of living with dementia, what it is like to be a carer and the importance of sharing information about current best practice;
3. More community awareness and education about living with dementia to reduce stigma in the community and increase awareness of the support needs of carers AND more support for carers and someone to talk to and share experiences about fears, loneliness, struggles, health and well-being and care strategies.

Table 2. Priority service and support needs

Discussion

Our study found that the support and service needs of people with dementia and carers are not always addressed in rural regions, and there are significant unmet needs. These findings are consistent with reports in previous studies.

The importance of diagnosis and dementia training

Although the benefits of early diagnosis and support throughout the dementia trajectory is essential for delivering appropriate care (13), there is a reluctance among health professionals to make and disclose a formal diagnosis (14). Similarly, carers in our study reported frustration with not receiving a formal diagnosis until the disease was well advanced. A delayed diagnosis of dementia can be a significant barrier for access to health care and other services and as our participants also highlighted, this makes it more difficult to make plans and decisions about the future (15).

Paradoxically, although accepting a diagnosis of dementia and understanding dementia is the first step in learning to adjust to life with dementia, people in the early-stages of caring often fear being stigmatised, or as being seen to need help from others (16). Providing information and education about dementia may be a means of reducing stigma; however, our participants also reported that health professionals were not proactive in sharing information. These barriers to care highlight key areas for further action.

One successful approach with specific application to rural regions, where health and care specialists are often located long distances from the person needing a diagnosis or expert consultation, has been telemedicine. Telemedicine can achieve a dramatic reduction in patient waiting list times; Tso et al (17) reported that both patients and carers were satisfied with this type of service.

If people with dementia and their carers are to receive appropriate and needed support in a timely manner, it is essential that health professionals and service providers understand dementia and its impact. However, we found that service providers required additional training in working with people living with dementia and their families. Other research (9) has similarly established that there is a need for further and continuing dementia-specific education and training for rural health professionals. Orpin (5) noted that rural carers' satisfaction with medical practitioners' knowledge and support with respect to dementia varies widely.

An assessment of the educational and training needs of community based health professionals found that most professionals evaluated themselves as having only a beginner's level of knowledge and skill in dementia care (18). Using existing dementia training programs and translating them into different local contexts may be one approach to address dementia education needs in rural regions. A randomised controlled trial by Scott et al (19) found that modifying an existing training program was acceptable to local health practitioners and carers, and was less expensive and less time consuming than developing a similar support program from inception.

Support for carers

An important finding from our study was that rural carers need more support. Increased support can improve outcomes for carers and people living with dementia. For example, two randomised controlled trials showed that the establishment of early-stage memory loss social support groups can reduce levels of depression and improve quality of life and self-esteem (20). However, there is considerable challenge in finding ways to access and provide additional support, particularly in rural communities, where care and support are lacking.

Innovative methods of support provision in rural communities are therefore critical to support carers of people with dementia. A randomized controlled trial of rural carers in Germany tested a standard intervention (usual carer support) with an experimental intervention (specially qualified family support volunteer) and determined that the family support volunteer increased the health-related quality of life of family carers (21). In addition, carers who received counselling support were more likely to use additional support services, and family support stabilised the home care context.

Another means of increasing support particularly for rural carers could be to use video technology to facilitate carer support groups. O'Connell (22) established a videoconference support group for rural carers of people with fronto-temporal dementia and found that the group had high participation and low attrition. Participants perceived that the group was beneficial in overcoming the barrier of distance by reducing travelling time.

Another way to enhance local support structures could be to use online technology. A systematic review concluded, albeit cautiously, that internet based support interventions such as information websites, websites with additional telephone or email support, and websites with options for online social exchanges, could have positive effects upon carers (23) such as improved confidence and self-efficacy, and reduced stress, burden, and depression. In addition, the authors noted that the guidance of a coach may enhance positive outcomes of internet-based programs. Connecting carers to a network of other carers and support systems in a virtual community warrants further exploration.

Support for communities

The value of strong social support networks and having community members who look out for each other in rural regions is well established. Wiersma and Denton (24) found that informal social support and social networks were worthwhile for people living in small rural

towns in Canada. The townspeople they interviewed considered it neighbourly and appropriate to look out for older people with dementia who were part of the community. The social support provided by the community advantaged older people with dementia, augmented support provided by formal services, and enabled people with dementia to live for longer in their homes.

Nevertheless, not all rural communities have strong public awareness and not all are dementia friendly. Chen, Boyle, Conwell, Xiao and Chiu (25) described the significant problems faced by China in caring for rural older people with dementia, specifically the very large number of older people experiencing dementia, the erosion of the traditional model of families providing elder care, the lack of services in rural areas, and the substantial stigma that is attached to dementia. Our participants also raised the issue of stigma in rural communities as a barrier to seeking support and as a contributor to social isolation.

There is some evidence that targeted education can raise levels of awareness about dementia in the community and improve community members' understanding of the needs of people living with dementia. Kardile and Peisah (26) trialled a community education and awareness program that was designed to assist police during large festivals in India. The training helped police learn how to cue older people with memory problems to remember their home towns, their names, significant landmarks in their home towns, and the names of relatives. This training in turn assisted the police to reunite older people with their relatives and return them to their home towns (26).

Limitations of the study

As with all qualitative studies, the findings from this research are of most relevance to communities that have similar characteristics to those of the rural community that was the focus of our study. Clearly, different results and issues may be highlighted if the study were to be repeated in different types of communities. However, the gaps in dementia services and community issues that were identified and prioritised by the participants in our study are typical of those reported in other studies in rural and remote areas of different countries.

Conclusion

This study identified the priority service needs of caregivers, people with dementia and health professionals in a rural region. Specifically, it has highlighted several important gaps including: improving the early diagnosis of people with dementia, better carer support, further health professional education, and greater community understanding of dementia. The findings underscore the requirement to learn more about possible and innovative ways of addressing the needs of rural people living with dementia. The applicability of these needs in other rural regions also ought to be investigated.

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