Country/region of primary focus: Australia

Title: Innovative models of enhanced dementia care in rural communities

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Dementia is a major health issues among older people. Key to dementia care is early diagnosis and access to support strategies, advice on challenging behaviour, translation and communication advice. Access to support services and opportunities for social participation is also important for carers who can experience deteriorating quality of life, due to the burden of their caring responsibilities.

People with dementia and their carers often experience difficulties in finding the right services, on diagnosis with dementia, and as their condition changes or progresses. Similarly, service providers are also challenged to ensure appropriate service provision in an area of healthcare that is particularly fragmented due to inconsistent services and funding rules between regions and even within the same region. This problem is particularly exacerbated in rural areas because there is a shortage of local specialist services, lack of knowledge amongst service providers of appropriate services in their local area, lack of continuous care and challenges to communication between health professionals and older people. People that live in rural areas tend to experience greater disadvantage, not just of accessibility to services, but also of material disadvantages and lower education levels, issues associated with poorer physical and mental health, but also with levels of confidence and persistence in navigating health services. Rural older people may have increasing mobility issues that limit their ability to travel long distances to access services. Uncertainty about what services to use may also deter people from travelling to use services that could help them. They may be faced with choices about which distant town to travel to and be unable to access good quality information about what is provided or whether the service might be appropriate.

Some evidence suggests rural people feel stigmatised in discussing a diagnosis of dementia with neighbours as they feel their ongoing role in the community may be threatened, potentially cutting them off from social activities, normal community life and even living at home in the community, long-term. All of these factors can affect capacity to seek services at a time when people are very vulnerable and with health and potentially mental health problems, especially for carers who have been shown to benefit from support to avoid anxiety and depression. Rural service providers too may be challenged by lack of knowledge and connection with/about different services. Health professionals are often invoked to be the gatekeepers to assisting those with dementia and their carers to find appropriate services, but they may lack knowledge and time to spend with individual patients.

This paper will illustrate innovative models to draw together that 'community' of experience to support of the individual person with dementia and to increase involvement and empowerment in care decision making among people with dementia and their carers. We will describe methods for working with a range of citizen participants and stakeholders to co-design aspects of rural service delivery that can be applied locally. We will also explore the use of assistive and supportive telecommunications and information technology that will build knowledge of, and between, service providers as well as giving people objective (i.e. which service is available) and more qualitative (reviews and reflections about services) knowledge rather than a replacement for, discussion with health and other support practitioners.