

**Dementia Collaborative Research Centre
Assessment and Better Care Outcomes**

Summary

**Project Title: Transitions in care of people with dementia
A systematic review of the literature**

Researchers: Catherine Runge, Joanna Gilham, Ann Peut¹
From the Australian Institute of Health and Welfare (AIHW)

This systematic review assesses the evidence on the pathways people with dementia take into and through the health and aged care system, and the implications of these transitions for the quality of life of people with dementia and their families and carers. The review focuses on four distinct areas: predictors of care transition, description of care pathways, intervention to modify care pathways, and pathways taken by special population groups such as Aboriginal and Torres Strait Islander peoples.

Search strategies and results

The project team searched a range of scientific databases, Google Scholar and the Cochrane Collaboration using keywords such as dementia/Alzheimer's disease and care pathways. Over 100 articles were retrieved and reviewed for their relevance and then assessed against a variety of relevant quality assessment frameworks, including the National Health and Medical Research Council's (NHMRC) levels of evidence. From these, 32 were selected for the systematic review.

Findings

- **Predictors of care transition**

There are three consistent predictors of entry to nursing home care: dementia severity and cognitive decline, behavioural and psychological symptoms of dementia (BPSD) and caregivers' health and burden. Institutionalisation is more likely to occur for dementia patients with severe cognitive decline and loss of daily living skills (Brodaty et al. 1993; Cohen et al. 1993; Knopman et al. 1999), as well as behaviour problems such as aggression and incontinence (Cohen et al. 1993; Gilley et al. 2004; O'Donnell et al. 1992). Further, caregivers who have poorer physical and mental health as a result of caregiving (Argimon et al. 2005; Cohen et al. 2003; Whitlatch et al. 1999) or who have a poorer relationship with the person with dementia (Cohen et al. 1993; de Vugt et al. 2005; Gaugler et al. 2000; Hope et al. 1998; Spruytte et al. 2001) are more likely to institutionalise.

¹ For more information please contact Ann Peut via email: ann.peut@aihw.gov.au

However, there is a lack of research into the predictors of community care use and transitions to and from these services. In Australia, community care is a rapidly growing and central component of the aged care system, reflecting the preference of many people who need support to remain living at home in the community rather than moving to institutional care (AIHW 2008).

- **Description of care pathways**

Research into the common care pathways and transitions between care types is limited. Formal diagnosis can have an important influence on subsequent care transitions, particularly as it can allow a person with dementia and their family/carers to plan for the future. However, the diagnosis process is not straightforward and dementia is often not diagnosed until the onset of severe symptoms (Knopman et al. 2000). Further research is required to develop a greater understanding of the process and the timing of dementia diagnosis and the role it plays in care pathways.

The majority of the reviewed research into care pathways has focused on the admission to long-term residential care. These studies have found that people with dementia are more likely than those without dementia to move into full-time residential care (Howe & Kung 2003). Studies have also suggested that people with dementia who use short-term care, such as dementia day services, respite services and hospitals, are more likely to be institutionalised (Adler et al. 1995; Butler et al. 2002; Cohen & Pushkar 1999; Moriarty & Webb 2000), suggesting that dementia patients may use short-term care as a stepping stone to long-term residential care.

However, there are gaps in the research and there is no solid understanding of the common care pathways used in Australia. In particular, evidence describing the use of hospitals, community care and early intervention programs, such as memory clinics, by Australians with dementia is needed. Further research is also warranted into the post-transition outcomes for people with dementia and their carers, and the way in which perceptions of possible outcomes from particular transitions affects subsequent care decisions. This information would allow identification of potentially beneficial timing, form and program placement for effective intervention.

- **Intervention to modify care pathways**

Early intervention that targets both the person with dementia and their caregivers is successful at reducing the likelihood of nursing home placement, delaying and even preventing placement. In particular, training caregivers to deal with stress and providing them with social support (Brodaty et al. 1997; Mittelman et al. 2006; Moniz-Cook et al. 1998), in addition to providing programs (such as memory and relaxation) and access to a range of health professionals for the person with dementia is beneficial (Bellantonio et al. 2008; Brodaty et al. 1997; Moniz-Cook et al. 1998). However, once the dementia progresses to a severe stage, the benefit of intervention diminishes. Therefore, it is important that diagnosis and intervention occur early in the course of the condition.

- **Care pathways of special population groups**

The care pathways and transitions experienced by people from special population groups have been poorly researched and are a key gap in the current understanding.

Research into people with younger-onset dementia has focused on the difficulties people in this group have in obtaining a diagnosis. However, no research has explored care pathways used by this group, how they might differ from older people and consequently what services are most beneficial for this group.

The other four identified groups; Indigenous Australians with dementia, people with dementia from culturally and linguistically diverse backgrounds, people with dementia living in rural and remote areas and people with intellectual disabilities and dementia, have been the subject of limited research and no studies were available about their care pathways to include in this review. These are significant population groups in Australia and research is needed into their experience of diagnostic, intervention and transition through care.

Recommendations

Seven key recommendations emerge from the systematic review:

1. Consistent with recommendations from the Care of People with Dementia in General Practice node of the Primary Dementia Collaborative Research Centre (Pond et al. 2007), encourage practices that promote and improve early, well-informed assessment and diagnosis of dementia. In addition, foster the development of strong linkages between those health professionals who provide assessment and diagnosis services and other early intervention and care services.
2. Encourage the development, use and evaluation of early intervention services for care receivers and caregivers to support the maintenance of care in the community where that is possible and desirable
 - interventions should focus on providing a supporting environment, where caregivers and people with dementia have access to a range of social support, such as counsellors and other health professionals.
3. Interventions should aim to influence the major predictors of institutionalisation (dementia severity, behavioural and psychological symptoms and caregivers' health and burden) so that people with dementia and their families and carers have increased opportunities to continue living in the community for as long as it is possible and reasonable
 - examine and implement (as appropriate) recommendations from the National Evaluation of the Dementia Health Priority Initiative in relation to programs such as Extended Aged Care Home Dementia packages, Dementia Behaviour Management Advisory Services and the National Dementia Support Program.
4. Support further research which provides a fuller, more methodologically robust understanding of the care pathways and transitions for people with dementia, particularly in relation to the hospitalisation experience, the use of community care and early intervention programs and the use of and relationship between dementia-specific services and dementia-sensitive mainstream services
 - longitudinal cohort studies, retrospective cohort studies, and data linkage are all suitable methodologies for improving understanding of the entire disease course and its relationship with patterns of care and service use transitions from initial diagnosis until death

5. Undertake further research into care transitions and pathways for special groups of people with dementia
 - support studies which look at the particular care transition experiences and needs of Aboriginal and Torres Strait Islander people with dementia, people from culturally and linguistically diverse groups, people with younger-onset dementia, people in rural and remote areas and people with intellectual disabilities and dementia
6. Conduct further research into the effects of care transitions on the quality of life and other outcomes for people with dementia and their carers.
7. Improving the quality and consistency of data about dementia in existing Australian data sources and greater use of current databases would support future research and health service planning. In particular, consideration should be given to expanding the Aged Care Assessment Program minimum data set by the inclusion of information about behaviour and continence recorded on ACAT client records.

© The University of New South Wales, as represented by the Dementia Collaborative Research Centre [2009].

The Dementia Collaborative Research Centres acknowledge the financial and other support provided to this Project by the Australian Government. The views expressed in this work are the views of its author/s and not necessarily those of the Commonwealth of Australia. The reader needs to be aware that the information in this work is not necessarily endorsed, and its contents may not have been approved or reviewed, by the Australian Government.