An Australian Government Initiative

Transitions in care of people with dementia

A Systematic Review

February 2009

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A systematic review of the literature

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CONTENTS

■ Abbreviations

ACAP	Aged Care Assessment Program
ACAT	Aged Care Assessment Team
AD	Alzheimer's Disease
ADL	Activity of Daily Living
BPSD	Behavioural and psychological symptoms of dementia
BRSD	Behaviour Rating Scale for Dementia
CACP	Community Aged Care Packages (program)
CALD	Culturally And Linguistically Diverse (people)
CCC	Community Care Census
CDR	Clinical Dementia Rating
DBMAS	Dementia Behaviour Management Advisory Services
DNH	Do Not Hospitalise
DSM	Diagnostic and Statistical Manual
EACH	Extended Aged Care at Home
EACH-D	Extended Aged Care at Home for people with Dementia
EMI	Elderly Mentally Infirm
GDS	Global Deterioration Scale
GHQ	General Health Questionnaire
GP	General Practitioner
HACC	Home and Community Care (program)
MID	Multi-Infarct Dementia
MMSE	Mini-Mental State Exam
NDSP	National Dementia Support Program
NHMRC	National Health and Medical Research Council
NHA	Nursing Home Admission
NHP	Nursing Home Placement
QoL	Quality of Life
RCT	Randomised Controlled Trial
VaD	Vascular Dementia

■ Summary

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.

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.

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■ Introduction

The objective of this systematic review is to assess the evidence on pathways of people with dementia into and through the health and aged care system and implications of these for the quality of life of people with dementia and their families and carers. The review, undertaken for the Assessment and Better Care Outcomes Centre of the Dementia Collaborative Research Centres, aims to provide a basis for identifying the policy and practice implications for improving the care of people with dementia.

This review contributes to a number of the five key priority areas identified in the *National Framework for Action on Dementia.* In particular, the review informs key priority area 1 of the Framework, 'Care and Support', which states that outcomes should allow for the 'seamless transition for people with dementia between different types of care' (Australian Health Ministers' Conference 2006).

Under the 'Care and Support' priority area, the Australian Health Ministers' Conference notes that investigation of dementia-specific versus mainstream care and support for people with dementia is required. The ministers state that access to dementia-sensitive mainstream services is essential. This review includes within its scope, the question about the extent to which people with dementia and their carers utilise dementia-specific services and dementia-sensitive mainstream services and their interaction with both.

Funds under the *Dementia – A national health priority* initiative are being allocated for the provision of 'the right care in the right place', with an emphasis placed on helping people with dementia to be cared for in their own home. The initiative is funding 2,000 Extended Aged Care at Home (EACH) packages targeted to people with dementia. The current literature supports the view that the maintenance of home care is desirable for people with dementia, as nursing home placement can lead to increased confusion and risk of mortality (Mittelman 2006).

The scope of this review was broad, covering four distinct research areas in respect of care transitions and pathways.

1) What predicts the occurrence of transitions to or between types of care?

2) What are the care transitions and pathways for people with dementia and what is the nature of these transitions?

3) What can modify transitions to types of care?

4) What are the care transitions for special population groups of people with dementia?

Studies in these areas use a wide range of methodologies: the systematic review was innovative in its application of levels of evidence and quality assessments appropriate to each type of study. Bond and Corner (2001) noted that the complex nature of dementia and its care presents methodological challenges for its investigation. The systematic review examined these methodological challenges as they arose from the appraisal of the evidence.

Section 1 of this report provides the background and context for the review. An operational definition of the term 'care transition' is first discussed. This is followed by a brief outline of the health and aged care system in Australia, including a description of services currently available for people with dementia in Australia. Finally an overview of the nature of dementia, looking particularly at symptom manifestation and sub-types and their implications for care transitions and care pathways is discussed.

Section 2 outlines the review approach, encompassing the literature search methods employed, the selection process, how the quality of the research evidence was assessed and the search results.

The review of the evidence is provided in Section 3 and covers

- twelve studies that examine predictors of care transitions for people with dementia
- eleven studies that describe care transitions for people with dementia
- six studies about interventions that aim to modify care transitions for people with dementia
- three studies that look at care transition issues for people with dementia from special population groups and their families. A literature review is provided here to elucidate important issues that are not examined for these groups in quality assessable studies.

Section 4 details gaps in the research evidence as determined by the systematic review and a reading of the wider literature. Gaps in research scope and focus, and methodological rigour and outcome measures are discussed.

Section 5 makes recommendations for policy and practice and for future research as informed by the review of the literature.

■ 1 Background

Care transitions and care pathways

In the literature, a 'transition point' has been described as some form of destabilisation in the life of a person resulting in change in the level of care and/or support they require (Hollander 2001). For this review, a 'care transition' for a person with dementia is taken to mean any move between or within formal support interventions, whether a move is due to a change in the type or level of care required or due to other factors. The pattern of service use over time resulting from these care transitions forms a 'care pathway'. Due to the wide range of aged care services available (see Figure 1 for Australian context), there are a large number of potential care transitions and care pathways.

Australian service context

Patterns of service use are influenced by the nature of the health and care service system available, particularly the kinds of services available, eligibility rules governing access to them, the supply of places and consumer knowledge and awareness of available care options. Below is a description of Australia's health and aged care system, which is a large, complex system with a wide range of services available for older people and people with dementia. This discussion focuses on health and aged care services which are partly or entirely government-funded. People with the financial means may also purchase private services to supplement or replace government-funded services. However, information about the nature and use of these services is not currently available.

Australia's health and aged care system

Australia's health care system is characterised by universal access to health care, a mixture of public and private hospitals, and General Practitioners (GPs) as the entry point to the health system for the majority of people. Universal health care is provided by the federally funded Medicare scheme which subsidises payments for services provided by doctors and other health service providers. The federal government also subsidises the cost of prescription medications through the Pharmaceutical Benefits Scheme. Private health insurance can be purchased from private health insurance funds, with its uptake encouraged by the federal government through a number of incentives. Just under half of the Australian population holds private health insurance for hospital treatment.

The aged care system in Australia includes both residential aged care and community care services. Residential aged care services provide accommodation and support for older people who can no longer live at home. Low and high level care is available along with short-term respite care services. At 30 June 2007, there were 156,549 permanent residents in Australian aged care homes.

The mainstream community care services for older people are

- The Home and Community Care Program (HACC), which is the main provider of home-based care services in Australia. It provides a range of services, such as home nursing, delivered meals, transport assistance and respite care, for young people with disability, frail older people and their carers. During 2005–06, 777,471 clients received HACC services.

- Community Aged Care Packages (CACPs), which are an alternative to low-level residential aged care. A CACP provides a package of assistance managed by a care coordinator, who manages the complex care needs of the recipients and arranges provision of types of assistance such as personal care, domestic assistance and social support. On 30 June 2007, there were almost 35,000 recipients of a CACP and nearly 50,000 individuals received a package over the 2006–07 financial year (AIHW 2008).

- Extended Aged Care at Home (EACH) packages, which deliver care at home to people who are otherwise eligible for high-level residential care. EACH packages provide a similar range of care services as CACPs, with the addition of nursing and allied health care services. On 30 June 2007 there were about 3,000 recipients of an EACH package and about 4,600 individuals received a package over the 2006–07 financial year (AIHW 2008).

- The National Respite for Carers Program (NRCP) funds direct and indirect respite care options, offering respite care in a range of accommodation settings, including day centres and in-home respite services.

Services for people with dementia

In addition to mainstream health and aged care services, there are a number of dementia-specific services available for people with dementia and their carers. These include

- EACH-Dementia (EACH-D), which is a relatively new program (the first packages became available in March 2006) specifically aimed at frail older people with dementia-related high-care needs. A care recipient on an EACH-D package can access the same types of assistance that are available to an EACH package care recipient. However, delivery of that assistance may use a more flexible approach and strategies that are appropriate for people with dementia. In addition, EACH-D packages also provide access to dementia-specific specialist services and support.

- Dementia Behaviour Management Advisory Services (DBMAS), which are funded under the *Dementia – a National Health Priority* initiative, and which were established to assist caregivers of people with dementia to manage the difficult behaviours associated with the condition that impact on their care. Assistance provided under DBMAS includes advice, assessment, case management and specialised support for carers and community and residential care workers. DBMAS can be accessed through aged care homes, ACAT, CACP, EACH and EACH-D programs, day therapy centres and other dementia specific services (LAMA Consortium 2007).

- The National Dementia Support Program (NDSP), a program funded by the federal government and delivered by the dementia advocacy and support group, Alzheimer's Australia. The program aims to increase the capacity of people with dementia to remain in their homes and to improve their quality of life. The NDSP comprises of a national dementia helpline and referral service, dementia and memory community centres, early intervention programs, counselling, and education and training.

Movements through the health and aged care system

Major points of access to the publicly-funded health and care system include primary health care providers, especially GPs, and Aged Care Assessment Teams (ACATs). Residential aged care and most packages of community care (Community Aged Care Packages (CACP), Extended Aged Care at Home (EACH) and EACH-Dementia) are accessed through an ACAT, jointly funded by the Australian, state and territory governments and consisting of a multi-disciplinary team of health professionals.

The diagram below outlines the broad structure and possible pathways through major components of the publicly-funded health and aged care system in Australia.

Source: updated from AIHW 2003

Figure 1. Possible movements through the Australian health and aged care system
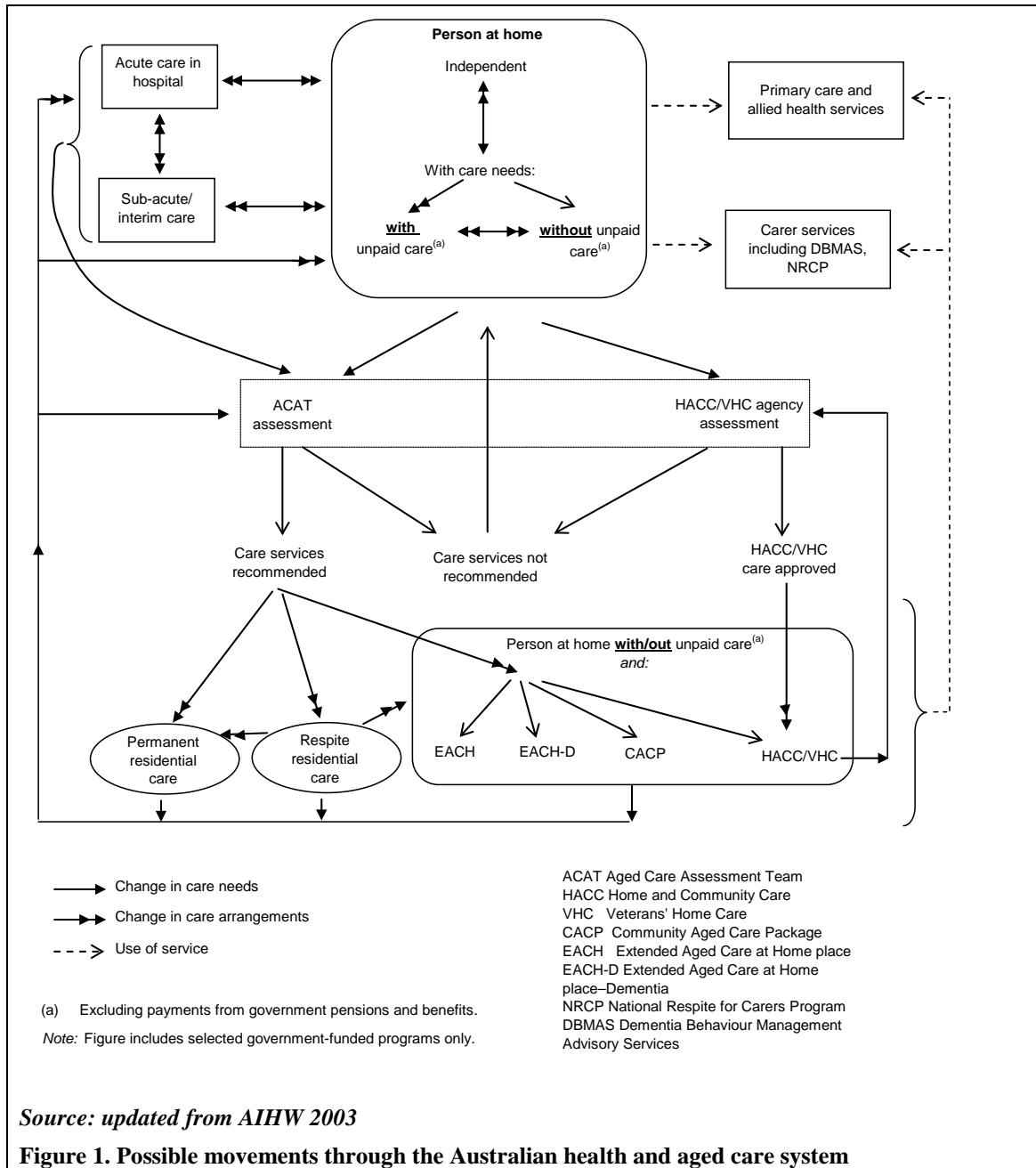
Dementia and care pathways

General research into care transitions and care pathways for the older population is heavily weighted towards the transition experience of nursing home placement. Dementia and cognitive impairment were identified as explanatory research variables in a number of predictors of nursing home placement studies. A review of these studies revealed that dementia and cognitive impairment were consistently found to be strongly associated with, or predictive of, institutionalisation (Banaszak-Holl et al. 2004; McCallum et al. 2005). Further, Miller and Weissert's (2000) review of predictor studies into hospitalisation for elderly people found that dementia or Alzheimer's disease increased the risk of placement in half of the reviewed studies.

However, the successful design of a seamless system of services and support for people with dementia and their carers requires a more detailed and specific understanding of the broader service use patterns and pathways of people with dementia. This is the focus of this literature review.

Dementia and its implications for service use and care pathways

In 2006, an estimated 189,600 Australians had dementia, and the number of people with dementia is projected to increase to 464,700 by 2031 (AIHW 2007b). Dementia describes a syndrome associated with a range of diseases, which are characterised by impairments to brain functions. Dementia is not a single specific disease, and there are over 100 types of illnesses and conditions that can result in dementia.

In 2003, dementia accounted for 94,000 lost years of 'healthy' life due to premature mortality and disability—this is 4% of 'lost years' due to all diseases (Begg et al 2007). Among those aged 85 or older, dementia is the leading cause of burden of disease. The majority of the burden of disease caused by dementia is due to disability rather than death thus contributing to a high need for care and support. In addition, the type of dementia, the nature of symptoms manifested – particularly behavioural and psychological symptoms – and the pace of degeneration are likely to influence not only the type of care and support which is required, but also the care pathways and transitions of people with dementia and their carers.

The most common types of dementia in Australia are:

- Dementia in Alzheimer's disease, estimated to be responsible for around 50–70% of dementia cases, involving abnormal plaques and tangles in the brain resulting in memory difficulties, among other things

- Vascular Dementia (formerly known as multi-infarct dementia), resulting from significant brain damage caused by cerebrovascular disease – onset may be sudden, following a stroke, or gradual, following a number of mini-strokes or because of small vessel disease

- Dementia with Lewy bodies, in which abnormal brain cells (Lewy bodies) form in all parts of the brain, and in which the progress of the disease is more rapid than for dementia in Alzheimer's disease

- Frontotemporal dementia (or Pick's disease), in which damage starts in the front part of the brain, with emotional, motivational and/or behavioural symptoms and/or language deficits commonly occurring in the early stages

- Mixed dementia, in which features of more than one type of dementia are present. For example, many people with dementia have features of both Alzheimer's disease and vascular dementia (AIHW 2007b).

Generally, people with dementia may have impairments with language, memory, perception, personality and cognitive skills (AIHW 2007b). These symptoms can result in a range of problems in daily functioning, for example, problems with familiar tasks, such as shopping, a reduced capacity for decision making, problem solving and making judgements, confusion and disorientation in relation to people and places and communication problems though loss of speech and ability to understand language. As dementia progresses more basic and core activities of daily living, such as self-care (for example eating, bathing and dressing) are affected.

Behavioural and psychological symptoms of dementia (BPSD) is an umbrella term for a heterogeneous group of non-cognitive symptoms including psychosis, aggression, agitation, depression, disinhibition, delusions, wandering, repetitive questioning and incontinence (Brodaty et al. 2003). BPSD are associated with lowered functional abilities and poorer prognosis, an increased burden on caregivers and nursing-home staff, higher costs of care and earlier institutionalisation (AIHW 2007b).

The presence of symptoms such as delirium and hallucinations, in particular, may result in markedly different formal service needs and use compared to people who do not experience these symptoms.

As dementia is not a static condition, a continual series of transitions at both personal and service levels can occur. These transitions can have a profound impact on the quality of life of the person with dementia and their families and carers. The progressive nature of dementia and the nature of certain symptom manifestations can be a trigger for care transitions, and certain transitions and pathways can be of benefit or detriment to the progression of the condition (Cohen et al 1993).

Service use by people with dementia in Australia

People with dementia and their carers are relatively heavy users of major types of health services in Australia. They accounted for 1.4 million patient days and 82,800 hospital separations in 2003 (AIHW 2007b). An estimated 450,000 GP-patient encounters, 82,500 GP-ordered pathology services, 42,000 referrals by GPs to other health care providers and 10,000 GP-ordered imaging services in 2003 were for the diagnosis and management of dementia (AIHW 2007b).

People with dementia also heavily rely on ACAT assessments, and subsequently on residential aged care and community care services. In 2005–06, dementia was the fourth most common health condition recorded by ACATs, with 48,892 completed assessments involving people with dementia (ACAP NDR 2006). Dementia was by far the most frequently listed main or primary health condition, with 33,899 assessments having dementia listed as the main condition.

The number of people with dementia accessing residential care is not currently known with any precision, but the most recent published estimates suggest that 49% of all permanent residents and 83% of high care residents probably have dementia (AIHW 2007b). The Aged Care Funding Instrument (ACFI), introduced in March 2008, will result in better information about the number of people with dementia in residential aged care.

The number of people with dementia accessing community care packages is not generally available for CACP, EACH and EACH-D programs. The 2002 Community Care Census conducted by the AIHW and the Department of Health and Ageing found that 18% of CACP recipients were identified as having dementia (AIHW 2007b), and 32% of EACH recipients had diagnosed dementia (AIHW 2004b). At this stage the EACH program was very small and this figure may not reflect the status of the current

EACH program. Routine data about the dementia status of EACH and CACP package recipients are not collected; however the 2008 Community Care Census will provide an update on the number of people with dementia receiving both packages.

At 30 June 2007 there were about 1,300 people receiving an EACH-D package, with a slightly higher number receiving packages over the 2006–07 financial year (AIHW 2008). Again, this program was in the early stages and the figure is expected to grow.

■ 2 Review Approach

Inclusion and exclusion criteria

There is a wide range of literature available about the care of people with dementia, encompassing/addressing specific issues around clinical, diagnostic, pharmaceutical and treatment options. This systematic review is focused on the care transitions and care pathways of people with dementia through the health and aged care systems, that is, movements between types of care.

To be considered for inclusion in the review, studies had to meet the following criteria:

Publication Requirements – Studies had to be published 1) in English 2) between the years of 1990 and 2007 and 3) in a scientific journal or book. As a consequence this search process resulted in the exclusion of grey literature – conference papers, government reports, editorials and opinion pieces.

Study Population – Subjects had to be people with dementia that was either formally diagnosed or strongly suspected. Subjects with Mild Cognitive Impairment or memory problems were excluded. As a consequence this process excluded general studies that were not explicitly focused on populations of people with dementia.

Focus – Studies had to address questions relevant to the nature of care pathways and transitions, factors predicting transitions, or interventions modifying transitions.

Methodological Quality – Studies had to be of sufficient methodological rigour as determined by the relevant framework for appraising quality (see study quality below).

Search methods

Searches were conducted using the following online databases

- PsycINFO
- Cumulative Index to Nursing and Allied Health Literature (CINAHL)
- Medline
- ProQuest Health and Medical Complete
- AgeLine
- EMBASE

In addition, Google Scholar was used to identify studies that did not appear in the scientific databases. Google Scholar is able to search across many sources and is unrestrained by the indexing systems used in scientific databases.

The Cochrane Collaboration was searched for systematic reviews of any interventions that aimed to reduce, delay or prevent care transitions for people with dementia.

The reference lists of retrieved studies and the Current Awareness in Ageing Research E-clippings were also searched for relevant studies.

The following primary terms were used in combinations with the secondary terms (for example, Dementia and Pathways) to search for relevant studies in the above sources.

Primary terms	Secondary Terms	
Dementia	Acute care	Aged care
Alzheimer's Disease	Aged care homes	Assessment
Dementia with Lewy Bodies	Assisted-living facilities	Care homes
(Lewy body dementia/disease)	Care outcomes	Care pathways
Vascular dementia	Care planning	Community Care
Fronto-temporal dementia	Diagnosis	Intervention
Mixed dementia	General practitioners	Health service
Advanced Dementia	Hospital/hospitalisation(z)	Long-term care
Early-onset Dementia	Nursing home	Pathways
	Residential care	Respite
	Service use/utilisation(z)	Transition

Selection process

From the initial search over 100 studies were selected based on their adherence to the publication requirements, inclusion criteria, their title and a first reading of the abstract. These studies were categorised into one of four distinct areas: predictors of transitions, descriptions of pathways/transitions, interventions to modify transitions and specific transition issues for special population groups. Categorisation was based on the primary purpose of the study or a particular focus of the study. In most cases, but not all, the studies are mutually exclusive to their categories.

Studies were reviewed more closely in respect of their adherence to the study population and relevance criteria and examined in terms of their quality–namely their methodological robustness and capacity to be generalised to the wider population (see study quality below). Studies which were less relevant and which were ranked as weaker on quality measures were excluded from the systematic review. This process resulted in a final total of 32 studies for systematic review.

Search terms that identified selected studies

The search terms that proved effective in identifying studies that met the inclusion criteria were the primary terms dementia; vascular dementia and advanced dementia used in combinations with the terms community care; care homes; respite; service use; behavioural and psychological symptoms of dementia; institutionalisation; risk factors; nursing home; hospital; hospitalisation; transitions in care and residential care.

Country of origin

Of the thirty-two studies, just under half (15 studies) came from the United States, with 5 studies originating from the United Kingdom and 4 studies originating from Canada. Only four studies were of Australian origin, while three came from European nations, and the single systematic review was undertaken by the Cochrane Collaboration.

Study quality

The broad scope of the systematic review and complexity of the subject matter resulted in the selection of studies for inclusion with varied designs. Many valuable studies were not suitable for assessment using conventional frameworks, which focus on experimental technique and data analysis. This was particularly apparent in appraising qualitative, cross-sectional or descriptive studies. Therefore the project team searched

for existing quality appraisal frameworks that would best allow for a comprehensive assessment of all of the selected studies.

To measure the quality of the selected studies, the NHMRC levels of evidence were initially applied to all studies. However, due to the variety of methods and approaches used in the included studies, and the circumstances surrounding dementia research, this framework proved too limiting for certain studies in this field (Downs 2008).

The NHMRC levels of evidence were designed to determine the best available scientific evidence relating to medical treatments and interventions. As such, the tool has a strong focus on experimental design. This approach was well suited to included studies that examined intervention, prediction and prognosis. However, it was not suited to studies using less traditional designs and techniques.

Only one selected study in the review was rated at Level I (a systematic review of RCTs), with 'predictors of care transition' and 'intervention' studies generally fulfilling Level II criteria and the 'descriptions of care transitions' and 'special population groups' studies fulfilling Level III-2. Within the 'descriptions of care transitions' and 'special population groups' categories, eight studies analysing cross-sectional administrative data or employing qualitative study designs were not suitable for rating using the NHMRC levels of evidence.

The project team felt it was valuable to couple NHMRC levels of evidence with other appropriate tools in order to strengthen quality assessment, and to locate tools to assess studies that did not use an experimental design. The following frameworks were selected, with the details provided in Appendix 1.

- **Altman's Framework (Altman 2001).** Altman's framework was developed to address a lack of standard criteria for assessing prognostic studies. It has a strong focus on assessing the quality of statistical techniques used in studies, and was selected to complement NHMRC ratings for included survival and regression analysis studies.

- **Dorothy Forbes' External, Internal, and Statistical Conclusion Validity Rating Tool (Forbes 1998).** Dorothy Forbes' validity tool and rating scale was developed during her systematic review of strategies for managing the behavioural symptoms of dementia. As it was developed for the field of dementia research where experimental design is quite varied, it provides more detailed guidelines for the evaluation of varied experimental designs. This tool was selected to complement NHMRC assessment for studies using RCT, cohort and other experimental design techniques. The project team noted the tool's rigour. However, an element from the 'Checklist for appraising the quality of studies of interventions' developed by the Cochrane Collaboration was included to assess randomisation and blinding.

- **Joanna Briggs Institute Critical Appraisal of a Systematic Review (JBI 2000).** This tool was developed specifically to assess the quality of systematic reviews, and the project team considered it an appropriate tool to complement the NHMRC assessment of the one systematic review of studies selected for inclusion.

- **Angus Forbes' Appraisal Schedule (Forbes & Griffiths 2002).** The project team selected Angus Forbes' Appraisal Schedule to evaluate the quality of studies that could not be assessed using conventional assessment tools. The schedule provides a series of points on which to determine the strength of non-experimental studies, such as qualitative studies and cross-sectional

administrative data analysis. The Angus Forbes schedule proved invaluable in assessing the quality of studies included in the 'descriptive' and 'special groups' sections of this review.

The 'predictors of care transitions' studies all involved survival and/or regression analyses. The NHMRC Levels of evidence for 'prediction and prognosis' studies were applied and Altman's 'Framework for assessing internal validity of articles dealing with prognosis' was used to determine the quality of the studies. All of the selected 'predictors of care transition' studies fulfilled Level II of the NHMRC Levels of Evidence and were rated as strong according to Altman's Framework (Table 1).

Table 1: Level of evidence and quality of predictor studies

Number of studies that met criteria			
NHMRC Levels of Evidence	I	II	Total
		12	12/12
Altman's Framework	Strong	Moderate	
	12		12/12

The methodological quality of the 'description of care transition' studies was more varied than in the 'predictors of care transition' studies. Of the 'description of care transition' studies, the study designs included administrative data analysis, cross-sectional quantitative analysis and qualitative research designs. The NHMRC levels of evidence were applied to five studies – four studies fulfilled Level III-2 criteria and one fulfilled Level III-3. The Dorothy Forbes' rating tool was used to explain the strength of 5 of the studies – one was rated as strong, two as moderate to strong and two as moderate. A further 6 studies were rated by Angus Forbes' appraisal – four at the strong level and two at the moderate level (Table 2).

Table 2: Level of evidence and quality of descriptive studies

Number of studies that met criteria				
NHMRC Levels of Evidence	III-1	III-2	III-3	Total
		4	1	5/11
Dorothy Forbes rating tool	Strong	Moderate to Strong	Moderate	Total
	1	2	2	5/11
Angus Forbes Appraisal Schedule	Strong	Moderate		Total
	4	2		6/11

The 'intervention' studies all had an experimental design. The selected 'intervention' studies were all assessed according to the NHMRC levels of evidence, Dorothy Forbes' rating tool and the Joanna Briggs Institute (JBI) Critical Appraisal of a Systematic Review. All six of the studies could be assessed using the NHMRC levels of evidence – one study fulfilled level I, four fulfilled level II and two fulfilled level III-2 criteria. Five studies were measured by the Dorothy Forbes' rating tool – two as strong, one as

moderate and two as moderate to weak. One of the studies was measured as strong by the JBI appraisal (Table 3).

Table 3: Levels of evidence and quality of intervention studies

Number of studies that met criteria					
NHMRC Levels of Evidence	I	II	III-1	III-2	Total
	1	4		1	6/6
Dorothy Forbes rating tool	Strong	Moderate	Moderate to weak		Total
	2	1	2		5/6
JBI Appraisal	Strong				Total
	1				1/6

The three 'special population groups' studies had administrative data analysis, cross-sectional quantitative analysis and qualitative research designs. To measure the strength of the studies three different frameworks were applied. One study fulfilled NHMRC Level III-2 criteria. Another was measured as moderate by the Dorothy Forbes' rating tool. Two studies were measured by Angus Forbes' Appraisal Schedule – 1 as strong and 1 as moderate (Table 4).

Table 4: Levels of evidence and quality of special group studies

Number of studies that met criteria				
NHMRC Levels of Evidence	III-1	III-2	III-3	Total
		1		1/3
Dorothy Forbes rating tool	Strong	Moderate to Strong	Moderate	Total
			1	1/3
Angus Forbes Appraisal Schedule	Strong	Moderate		Total
	1	1		2/3

Assessment of methodological quality was based on the information provided in the study papers – thus the level of detail provided about study methods had an impact on the quality assessment. Some studies may have been graded as lower than deserved due to lack of sufficient methodological detail.

■ 3 Review of evidence

Predictors of care transitions

A considerable number of the retrieved studies aimed to determine the factors predicting care transitions for people with dementia. The overwhelming majority of studies focused on the transition to nursing home placement/institutionalisation. Twelve studies are included in this review, all with the outcome measure of institutionalisation. The studies are categorised by the nature of variables entered for analysis: however, these categories are not necessarily mutually exclusive. For further details about these studies, see the summary tables in Appendix 2.

General studies of predictors of institutionalisation

Cohen et al. (1993) conducted a prospective longitudinal study (*n*=196) to determine what predicts the institutionalisation of a person with dementia. Participants were community-dwelling people with a DSM-III diagnosis of dementia and their caregivers (59% of whom were spouses). Seventy percent of the people with dementia had Alzheimer's disease (AD), 15% had multi-infarct dementia (MID), and 15% had dementia of unknown aetiology. At baseline their mean Mini-Mental State Examination (MMSE) score was 15.79, indicating moderate severity of dementia. Follow-up occurred every 2 months by telephone and every 6 months by visit, over 18 months. While 150 of the 196 caregivers expressed a desire to maintain their care recipient at home at initial assessment, in 92 of the 148 cases successfully followed up, the care recipient was in institutional care after 18 months.

Using MANOVA analysis, variables found to predict institutionalisation at 18 months were: caregiver health and burden; use of services; enjoyment of caregiving; care receiver cognitive function and troublesome behaviours (particularly aggression and incontinence problems); and caregiver reaction to behaviours. The function correctly classified 75% of all caregivers – 86% for the group placing in institutions, and 55% for the group maintaining at home. Caregiver factors such as education and income were not found to be significant in this study and caregiver mental health issues, such as depression, were not explored.

Spruytte and colleagues (2001) examined how sociodemographic characteristics, patient characteristics, characteristics of the caregiving situation, caregiver characteristics, formal and informal care support and the quality of the caregiving relationship, predicted caregiver's preference for institutionalisation and actual institutionalisation. Special attention was given to quality of the caregiving relationship. Participants were 144 primary caregivers (39% of whom were partner, 51% child and 10% child-in-law) caring for an elderly relative with moderate to severe dementia. Data were collected through face-to-face interviews and follow up occurred 6 to 9 months later by postal or telephone interview. At follow-up 64% of the patients with dementia continued to receive care at home and only 17% of the patients had been institutionalised.

Multiple regression analysis indicated that caregivers expressed a higher preference for institutionalisation when they did not share the household with the patient, when they were not religious and when the patients showed more behavioural disturbances.

Further multiple regression analysis revealed four variables that were significant predictors of actual institutionalisation. Caregivers' preference for institutionalisation was the strongest predictor of actual institutionalisation. Secondly, institutionalisation

was more likely when the patient had a higher level of functioning. While this seems counterintuitive, Spruytte and colleagues explained that caregivers institutionalise patients when they are capable of handling new environments. If caregivers wait until functioning level is very low, the move is considered too risky. Thirdly, institutionalisation was less likely to occur when the relationship between caregivers and the patient was warm and had less conflict and critique. Finally, structural changes in the material care-giving situation, such as converting a downstairs room into a bedroom, was negatively associated with institutionalisation.

Surprisingly, no relationship was found between institutionalisation and sociodemographic characteristics, such as relationship to the patient and gender. Previous studies have found that spouses are less likely to place care receivers into institutions (Cohen et al. 1993) and children, especially daughters, are more likely to institutionalise (Cohen et al. 1993; de Vugt et al. 2005).

O'Donnell and colleagues (1992) used a prospective, longitudinal study to evaluate four types of factors – severity of functional impairment, behavioural disorders, individual patient characteristics and type of caregiver – for their value in predicting early institutionalisation. Participants in this study ($n=143$) were mostly patients with a diagnosis of AD, MID, or mixed AD and MID, recruited from an AD clinic. At baseline, over 70% of the sample had minimal to moderate severity of dementia. 51 patients (36%) were institutionalised before the study ended.

Kaplan-Meier life table results indicate that severity of functional impairment, and behavioural disorders such as incontinence, aggressive behaviour, paranoid ideas, disordered ideation (delusions, hallucinations), irritability, loss of emotional control, impairment of regard for the feelings of others, and inappropriate sexual behaviour, were associated with more rapid institutionalisation. Major diagnoses (AD, MID, AD+MID), age, education and gender of the patient, and type of caregiver did not influence institutionalisation (although there were only a small number of children caregivers in the sample). Behavioural disorders were often correlated, suggesting that they tend to occur in clusters.

All clinical features which were significant predictors of the institutionalisation using the Kaplan-Meier method were then entered into a Cox proportional hazards model. The best predictor of institutionalisation was found to be paranoia, followed by incontinence. When paranoia was removed from the model, incontinence and aggressive behaviour emerged as the best predictors of institutionalisation. Further analysis showed that patients who were both aggressive and incontinent were more likely to be institutionalised than patients suffering only one of the behavioural disturbances.

Hébert and colleagues (2001) examined factors associated with long-term institutionalisation of older people with dementia in a prospective longitudinal study ($n=326$) and found that institutionalisation is related more to the severity of disabilities experienced by the subjects with dementia (measured by need for assistance with activities of daily living) than to the severity of dementia (according to DSM-III criteria) or cognitive impairment (measured using the Modified Mini-Mental State Examination). Participants were informal caregivers of community-dwelling people with a DSM-III criteria diagnosed dementia. Follow-up occurred at 2.5 and 5 years after baseline interviews. Of the 326 subjects, 166 (51%) were institutionalised over the 5-year follow-up period – the median time from interview to institutionalisation was 41 months.

Bivariate analyses first investigated the prognostic value of each variable related to the subjects with dementia and those gathered from the caregivers. Seven variables were

then entered into a Cox proportional hazards model to identify factors associated with the time to institutionalise: sociodemographic information, need for assistance with activities of daily living (ADLs), behaviour problems, caregiver depression, caregiver health, caregiver burden, and caregiver desire to institutionalise.

The analysis revealed five factors that were significantly associated with institutionalisation: type of dementia; severity of disability; caregiver's age over 60; caregiver not a spouse or child; and severe caregiver burden. A linear multivariate regression analysis found that caregiver burden was associated with depressive mood and care receivers' behavioural disturbance, rather than cognitive or functional impairments or the severity of dementia.

In a logistic multivariate regression analysis, the variables independently associated with an increased risk of desire to institutionalise were moderate or severe dementia; subject cannot be left alone; caregiver living with the subject; two or more services used; and caregiver burden.

Focused studies of predictors of institutionalisation

The following studies examined a particular variable or set of variables that had been identified in the literature as having an influence on institutionalisation. These studies determined the individual predictive capacity of the variable(s) and elucidated their specific nature. Studies of the predictive capacity of the progression of dementia, behavioural symptoms of dementia, caregiver and family characteristics, and service use and interventions are reviewed here.

Dementia progression as a predictor of institutionalisation

Knopman and colleagues (1999) carried out a prospective cross-sectional study ($n=341$) to examine the relationship between nursing home placement and clinical measures of dementia. Participants were community-dwelling people with AD and an identified caregiver who were enrolled in a clinical drug trial. At baseline all participants had a Clinical Dementia Rating (CDR) score of 2 and a mean MMSE score of 12.6, indicating moderate severity of dementia.

Four measures of dementia severity and a measure of behavioural dysfunction were examined for their relationship with nursing home placement. Changes in dementia severity were measured using CDR scores, ADL performance, dependency levels and Blessed Dementia Rating Scale (BDRS) scores, while the Behaviour Rating Scale for Dementia (BRSD) measured behavioural dysfunction. Participants were followed up at three month intervals over two years, with 23 participants lost to follow-up before reaching an endpoint. 114 (33%) of the patients were institutionalised over the course of the study.

The patients who entered nursing homes did not differ at baseline from those who did not enter nursing homes in regards to gender, age, having a spouse as primary caregiver, duration of illness, CDR, Blessed Dementia Rating Scale or change in dependence level. However, the groups differed in baseline MMSE and BRSD scores.

All four measures of dementia progression were strongly associated with nursing home placement. Cox proportional hazards analysis (adjusting for differences in baseline MMSE) revealed that the risk of nursing home placement was higher at any given time during the study for those subjects who reached CDR3 (severe dementia) or who lost 2/3 ADL compared to subjects who did not reach those endpoints, indicating that nursing home placement closely reflects dementia progression. Patients reaching CDR3

or losing 2/3 ADLs were 8.2 and 7.5 times more likely to be institutionalised that those who remained at CDR2 or did not lose 2/3 ADLs.

Change in total BRSD score or BRSD subscales was not associated with a greater likelihood of nursing home placement – in fact, a greater worsening of the total BRSD score occurred in patients who did not undergo nursing home placement. However, the presence of behavioural adverse events, in particular agitation and to a lesser extent insomnia (but not psychosis or depression), was correlated with nursing home placement.

<u>Behavioural Symptoms of Dementia as predictors of institutionalisation</u>

Gilley and colleagues (2004) evaluated the relationship between behavioural symptoms and institutionalisation in a 4-year prospective longitudinal study (*n=410*). Subjects were people with clinically diagnosed AD living in a community setting recruited from a dementia speciality clinic. At baseline, the mean MMSE score of the subjects was 18.7, indicating moderate dementia. A total of 155 participants entered a nursing home during the observation period, with a median time to institutionalisation of 3.3 years.

Four behavioural symptoms of dementia (depressive symptoms, hallucinations, delusions and physical aggression) that had been associated with institutionalisation in prior studies were examined for their relationship to nursing home placement.

After annual follow-ups over four years, a Cox proportional hazards regression model found that four features emerged as significant predictors of institutionalisation: cognitive impairment level; physical aggression; hallucinations; and depressive symptoms (even after adjustment for demographic and social network variables such as male gender, higher educational attainment, living alone, and number of children living in the area which were associated with an increased risk of institutionalisation). In particular, physical aggression and hallucinations were associated with a two-fold increase in the risk of institutionalisation, and a 10-point increase in depressive symptoms on the Hamilton Rating Scale was associated with a 40% increase in the risk of institutionalisation.

De Vugt and colleagues (2005) did not find behavioural symptoms themselves to predict nursing home placement. In a longitudinal, prospective study (*n=119*), community-dwelling people with AD (76%), vascular dementia (VaD; 17%) and other types of dementia (7%), and their primary informal caregivers, were followed-up at six month intervals over 2 years. During the period 41% of patients were institutionalised, 19% lost to attrition at one year and 37% at two years.

De Vugt et al. rather found that caregiver distress related to patient behaviour was a significant predictor of nursing home placement. This is consistent with several other studies. Additionally, the results showed that it was BPSD-related distress rather than general distress that was particularly important in the decision to institutionalise the patient. However, the decision to institutionalise was not found to be related to specific aspects of patient behaviour. Pearson correlations showed that BPSD-related distress was significantly correlated with feelings of competence and depressive symptoms in caregivers.

Post-hoc analysis showed that children, especially daughters, were more likely to institutionalise the patient sooner (although gender alone was not found to predict the decision to institutionalise), and were more likely to feel distressed and less competent. This finding has been further explored in previous studies which were not reviewed here. For example, Hope and colleagues (1998) found spouses had a higher commitment to care, as younger carers probably have other competing life responsibilities.

Additionally, de Vugt and colleagues (2004) found that male carers tend to use a 'supporting care strategy' and only intervene with the patient when necessary, but female carers tend to use a 'nurturing care strategy' and feel responsible for all household and personal care activities, which can lead to feelings of overload or exhaustion.

<u>Caregiver and family characteristics as predictors of institutionalisation</u>

Gaugler and colleagues (2000) analysed the impact of family help on the timing of placement among people with dementia in a prospective longitudinal study (*n*=304). Participants were primary caregivers with an elderly relative diagnosed with dementia.

The researchers hypothesised that family help with some specific tasks may provide substantial relief for caregivers, thereby delaying placement, whereas assistance for other tasks may have little or no effect – therefore, the study examined different types of family help as well as the amount of family assistance provided to caregivers.

A number of measures were placed in a Cox proportional hazards model to test their predictive capacity: sociodemographic characteristics; primary stressors (behaviour problems and ADLs); subjective appraisal of primary stressors (role captivity, role overload, worry and strain); well-being (depression, anger, subjective physical health); paid help (hours of paid service use); and family help (assistance with care tasks).

After 2 years' follow-up, the model found that behaviour problems of the person with dementia were associated with an increased likelihood of early placement and caregivers who reported greater role captivity were more likely to institutionalise their elderly relatives sooner. Increased duration of care at baseline was found to predict a slight delay in institutionalisation, as was greater subjective caregiver health at baseline. Two types of family help were found to be related to a delay in placement – overnight help and assistance with activities of daily living care.

Caregiver health-related quality-of-life as a predictor of nursing home placement of people with dementia was evaluated in a prospective longitudinal study (*n*=181) conducted by Argimon and colleagues (2005). Participants were informal carers of people with a clinical diagnosis of AD, VaD and MID. At baseline, the mean MMSE score of the people with dementia was 13.2, indicating moderate-to-severe dementia.

A number of variables were evaluated in multiple regression analysis: sociodemographic data of the patient and caregiver; caregiver quality of life (QoL); help from family and friends; caregiver level of satisfaction with support; and the patients' health status which included presence of incontinence, psychotic behaviour, aggressive behaviour, wandering and waking of the caregiver at night.

The analysis revealed that a reduced health-related QoL in carers is related to nursing home placement of patients with dementia. In particular, the risk of being admitted to a nursing home was 6 times greater in patients cared for by relatives who rated their health as being 'much worse' compared with the previous year.

Initial scores showed the highest size effect in the level of physical function, general health and physical role as defined by the Short Form Health Survey (SF-36). After controlling for potential confounding variables, carers of patients who had been placed in a nursing home had lower values in five dimensions of the SF-36 (physical functioning, physical role, bodily pain, general health and vitality), with the highest adjusted difference observed in the level of the physical role (Argimon et al. 2005).

Caregiver health was also found to be a predictor of nursing home placement for dementia patients in a longitudinal study (*n*=926) undertaken by Whitlatch and colleagues (1999). Caregivers of community-dwelling people with a diagnosis of

Alzheimer's disease were followed-up every 6 months over 2 years. Caregiver and care receiver variables – sociodemographic information, care recipient functional status and problem behaviours, caregiver subjective burden, caregiver depression, caregiver subjective physical health, time spent in providing care, caregiver social support and caregiver service utilisation – were analysed.

Measures with a p-value <0.15 in bivariate correlation analyses were included in a logistic regression analysis predicting the dichotomous outcome 'placement versus continued in-home care'. Four factors were found to predict nursing home placement: care recipient problem behaviours; caregiver depression at baseline; caregiver use of in-home respite; and 24-hour out-of-home respite assistance. Care recipients' problem behaviours were found to be most predictive of placement. Years since onset of dementia, social support or help from family, friends and/or service providers, and adult day respite care were significant on the bivariate level but not in the multivariate logistic regression.

Results of t-tests indicate that levels of caregiver depression and burden (but not caregiver subjective physical health) were significantly higher for placement than in-home caregivers at baseline. Caregivers who later placed their relative in nursing homes also reported spending more hours providing care and used more types of respite assistance (particularly, in-home respite assistance) at baseline. No difference between groups was found in the number of supportive behaviours of friends, family and service providers (Whitlatch et al. 1999).

Service use & interventions as predictors of institutionalisation

Brodaty and colleagues (1993) undertook a prospective longitudinal study (*n*=91) to determine which variables best predict prognosis-time to nursing homes in patients with dementia. The study was conducted on patients and their caregivers participating in a controlled intervention of training for caregivers, thus the predictive model also evaluated the role of caregiver training on nursing home placement. Participants were patients with mild DSM-III defined dementia (68 of whom had AD, 20 VaD and 3 other types of dementia) and their carers (91% spouses). Follow-up occurred frequently in the first 12 months of the study and annually over the next 5 years.

Five years after index assessment, 76% of the sample under investigation had been admitted to a nursing home, 8% had died without entering a nursing home and 17% were still residing in the community. Five risk variables were entered into a Cox proportional hazards model: caregiver training group; dementia severity; caregiver stress; neuroticism and socialisation; changes in patient's dementia and caregiver stress during the first 12 months; and patient characteristics. This analysis revealed that dementia severity and rate of deterioration and caregiver psychological morbidity significantly influenced the rate of nursing home admission.

Risk variables that were associated with an increased likelihood of nursing home admission (by a direct method of entry and after allowing for caregiver training) included greater severity of dementia at index assessment (MMSE, total CDR score, Problem Behaviour Checklist) and a higher caregiver score on the General Health Questionnaire (GHQ) at index assessment. Additionally, greater deterioration in the patient's dementia (MMSE, category CDR score, Problem Behaviour Checklist) was associated with an increased likelihood of nursing home admission. Training of caregivers was significantly associated with a delay in nursing home admission (and reduction in caregiver distress with immediate training).

McCann and colleagues (2005) found adult day care use had a negative relationship with time to nursing home placement. In a prospective longitudinal study of

community-dwelling people with a diagnosis of Alzheimer's disease (*n=516*) the researchers compared two cohorts of people – those that had used adult day care for a minimum of 3 months for at least 2 times a week at baseline and those that had not used adult day care at all. At the close of the study 35% had transitioned to nursing home, 21% had died while living in the community and 44% were still living in the community.

A Cox proportional hazards model was used to analyse the impact of a large number of variables on risk of nursing home placement: use of adult day care services; use of other community-based services; income; sociodemographic characteristics; physical function; hospitalisations; positive and negative behaviours; urinary or bowel incontinence; duration of caregiving; caregiver positive and negative affect; caregiver depressive symptoms; caregiver self-reported health; caregiver physical function; and social support.

The model found that the risk of nursing home placement increased significantly with the number of days of adult day care attendance. The risk persisted despite consideration of multiple indicators of disease duration and severity and of caregiver burden and workload. The risk of nursing home placement also increased with caregiver age and nearly all of the increased risk associated with adult day care use was limited to male participants. However, the authors acknowledged that their findings may be due to a sample selection bias or other factors which were not accounted for in the model, particularly caregivers' willingness to receive help.

Predictors of care transition discussion

While the studies reviewed are not directly comparable due to differences in scope, sample characteristics, conceptualisation of the variables, country of origin and the availability and affordability of national health care, the predictive capacity of certain variables was relatively consistent across the literature. In particular, dementia severity and cognitive decline, behavioural and psychological symptoms of dementia and caregiver health and burden were all strong predictors of institutionalisation.

The strength of the association of nursing home placement with disease severity is controversial, but most studies have found baseline severity predictive of nursing home placement. Patients who have a severe dementia rating on tests such as the CDR (Knopman et al. 1999) and MMSE (Brodaty et al. 1993; Cohen et al. 1993; Gilley et al. 2004) and who have lost skills required for daily living (Knopman et al. 1999) are more likely to be institutionalised. On the other hand, Hébert and colleagues (2001) found that institutionalisation is related more to the need for assistance with activities of daily living ('severity of disability') than to the severity of dementia or cognitive impairment. Type of dementia was also significantly associated with institutionalisation. However, moderate or severe dementia and the subject not being able to be left alone were associated with an increased risk of desire to institutionalise.

Studies into behavioural and psychological symptoms of dementia (BPSD) have yielded mixed results, although the majority have found an association between BPSD and institutionalisation. Symptoms most likely to predict institutionalisation were incontinence and aggression (Cohen et al. 1993; Gilley et al. 2004; O'Donnell et al. 1992), paranoia, (O'Donnell et al. 1922), and hallucinations and depression (Gilley et al. 2004). However, Knopman et al. (1999) found the opposite, with worsening of behaviour actually reducing the likelihood of institutionalisation, after controlling for severity of dementia and ADL loss. Further, caregivers' reaction to BPSD is a

significant predictor of institutionalisation (de Vugt et al. 2005). Contradictory findings may be due to:

- differences in measures of BPSD and which specific symptoms are included in the modelling (for example paranoia, hallucinations, psychosis and aggression are fairly consistent predictors, compared to apathy and agitation which may not be)
- the extent to which carer's emotional reaction to BPSD is explored—the decision to institutionalise may depend more on the emotional reaction of the carer than the patient behaviour itself
- differences in context of care (for example kinship, gender, perceptions of care demands and stress) and the availability of secondary caregivers to assist

Caregiver health and burden were also found to be strong predictors of institutionalisation. Caregivers who ranked their physical health as being poorer compared to previous years (Argimon et al. 2005; Cohen et al. 2003) and were suffering from mental health issues, such as depression (Herbet et al. 2001; Whitlatch et al. 1999) were more likely to institutionalise the care receiver. Gaugler and colleagues (2000) also found that caregivers who felt trapped and did not receive help from other family members felt a greater burden and were more likely to institutionalise.

Further research has found that children, especially daughters, were more likely to institutionalise the patient sooner and were more likely to feel distressed and less competent (de Vugt et al. 2005). Spouses may have a higher commitment to care (Cohen et al. 1993; Hope et al. 1998), and female carers tend to use a 'nurturing care strategy' that may more easily result in feelings of overload or exhaustion (de Vugt et al. 2004).

A gap in the literature is the lack of research focused on predictors of community care, a key and growing form of aged care provision in Australia (AIHW 2008). Further research into the characteristics of people using community care and their transitions to and from community care would be beneficial.

In terms of methodological issues that arose from the reviewed studies, two aspects common to this type of research may impact on the rigour and broader application of the research findings – baseline and follow-up measures, and study populations.

Studies varied in terms of whether independent variables (for example dementia severity) were measured only at baseline or whether changes in the variable over time were also measured. An example of the latter is Brodaty and colleagues' (1993) study which used patient and caregiver data that were collected when the dementia was mild and more likely to be in the early stages of the condition, but close follow-up of participants during the first year also allowed for the inclusion of variables reflecting the rates of functional decline. Gilley and colleagues (2004) noted that the sporadic nature of behavioural symptoms makes them difficult to capture at one-yearly intervals, which can lead to possible underestimates of the effects of these symptoms. The case for inception cohorts in dementia research is well articulated in the wider literature. For example, patients become untestable on mental status examinations over time (Knopman et al. 1999), but rigorous follow-up of participants should also be encouraged to ensure that all variables associated with disease progression are analysed.

The majority of the studies reviewed used service or client-based samples in their studies. The use of a client samples as opposed to population samples can lead to a bias in the results. Gilley and colleagues (2004) noted that client samples tend to have more severe levels of dementia; while O'Donnell and colleagues (1992) note that clinic samples may be more likely to include caregivers who are experiencing management

problems. Knopman and colleagues (1999) also identified biases in samples selected from clinical trials. He noted that participation in a clinical trial entails a level of motivation and optimism on the part of the caregiver that greatly reduces the effects of caregiver issues in institutionalisation. Furthermore, Knopman and colleagues noted that possible benefits (nonspecific support) to caregivers from study participation could inflate the treatment effect for both study and control groups.

Finally, people with dementia also experience the full range of other health conditions. In fact, among the older population, dementia is more likely than other conditions to be associated with multiple health conditions (AIHW 2007b). While the studies reviewed did not highlight the role of co morbidities in terms of predicting institutionalisation, it is likely that the presence of multiple health conditions is associated with the severity of disability and the likelihood of nursing home admission.

Descriptions of care pathways and transitions

Eleven papers which describe the care pathways taken by people with dementia under different circumstances are included in this review. They include qualitative studies, cohort studies and examinations of administrative data. In some cases, the outcomes cannot be applied in a broader context due to the limited scope of the study. However common themes are evident. The following discussion is structured in relation to different parts of the care pathway. For further details about these studies, see the summary tables in Appendix 2

Diagnosis

Knopman and colleagues (2000) conducted a study involving carers of people with Alzheimer's disease in the United States ($n=1,480$), which examined their experiences of dementia diagnosis. Participants were selected from a nation wide consumer panel and completed a mailed questionnaire. The study concluded that the differences between Alzheimer's disease and normal changes to memory processes due to age are poorly understood by both carers and medical professionals, leading to delays in diagnosis. Diagnosis was frequently found to occur due to symptoms other than memory loss. However, memory problems were the symptom most commonly leading to a physician consultation (28%), followed by personality and behavioural changes (23%).

The mean time lag from observation of first symptoms to problem recognition for those diagnosed in the previous 12 months, the previous 13 to 48 months, and the previous 49 months or more was, respectively, 1.20 years, 1.56 years, and 2.25 years. Following recognition that a problem existed, a mean lag of around a year was reported prior to consultation with a medical professional.

The most common reasons for delaying consultation with a physician were that carers: were unsure of the severity of symptoms (47%); thought they were due to normal ageing (37%); found the problem difficult to raise with the patient (27%) or could not face the possibility of an Alzheimer's diagnosis (9%); or that the patient became angry (27%) or refused to see a physician (24%).

The kin relationship between caregiver and care recipient was not significantly related to these lags. Correct diagnosis of Alzheimer's disease was reported by caregivers in only 38% of cases at initial physician consultation.

Movements between care types

In an Australian study, Howe and Kung (2003) examined administrative by-product data from Aged Care Assessment Team (ACAT) evaluations in Victoria in the second half of 1999. They described the care recommendations made for people with dementia compared to those without. A total of 26,417 ACAT clients were included, 5,487 of whom had a primary diagnosis of dementia. Dementia was the most common primary diagnosis recorded by ACAT clients, representing 21% of those included in the study, followed by musculo-skeletal diseases (13%) and CVA/stroke and heart disease (each 11%).

At the time of assessment, clients with dementia were less likely to be living alone in the community, but were equally as likely to live in the community with others as those without dementia. They were more than twice as likely to be already living in a hostel as those without dementia. The proportion of ACAT clients presenting for a second or later assessment was also higher for those with dementia than for other clients, reflecting the progressive nature of the condition and the need to re-evaluate health status and care requirements on a regular basis. While 61% of clients without a dementia diagnosis were recommended for community care, only 41% of clients with a primary diagnosis of dementia were recommended to live in a community setting. Similar data were reported in the Australian Institute of Health and Welfare report *Dementia in Australia* (AIHW 2007b) which is not reviewed here.

Butler and colleagues (2002) conducted a three year study of 60 day-patients and in-patients admitted to hospital for investigation or management of dementia in the United Kingdom. The study showed that people with dementia who were admitted from the community for specialist assessments as in-patients or day-patients tended to be admitted to long-term institutional care within a short period. However, the day-patients spent a higher proportion of time living in the community than in-patients did.

Similarly, Moriarty and Webb (2000) found that over an 18-month period, around 60% of people with dementia living in the community when referred to a social work team went into long-term care. Also conducted in the United Kingdom, this study examined the care pathways of 141 people with dementia assessed by social work teams. One of the issues that emerged during the research was the difficulty in determining when changes, such as admissions to hospital, were temporary and when they signalled a permanent change in the life of the person concerned. Sometimes the answer became clear only after some months.

While severity of dementia was the strongest predictor of entry into long-term care, other factors included whether or not the person had a carer and whether they received home care or day care. People with mild or moderate cognitive impairment were around half as likely to enter long-term care if they had a spouse or daughter as a carer than if they did not. Non-use of home and day care services was also predictive of entry into long-term care. Two thirds (67%) of those who did not use home care had moved to long-term care at follow-up, compared with 47% of people who used these services. Similarly, 76% of those not using day care services entered long-term care compared with 33% of attendees. The use of short-stay care did not affect the likelihood of admission to long-term care.

In Canada, Cohen and Pushkar (1999) obtained similar results in a study of 196 voluntary participants from a variety of sources, such as hospitals, dementia day centres, physicians and newspaper advertisements. Of the initial sample, 76 participants (39%) had moved to a long-term care institution by one year and 100 (51%) by 18 months. From the follow-up study, 31 of 103 patients spent some time in hospital before moving

to a long-term care institution or dying. Another common transition in care identified was from a respite care admission in a long-term care institution to permanent placement in the institution.

Use of respite care by people with dementia was also examined in the United States by Adler and colleagues (1995). The study included 58 carers of people with dementia, who received treatment in an outpatient memory loss clinic. Compared to those not using respite care, carers using respite care (39% of participants) had significantly higher burden and their care recipients had greater functional disability scores. It is possible that a high level of disability among people with dementia who use respite care explains the pathway from respite care to permanent placement in residential care.

End-of-life care and place of death

Many of the descriptive studies included in the review investigated end-of-life care and place of death. However, the focus and findings varied across the five included studies.

Mitchell and colleagues (2005) examined death certificates of all people who died in 2001 in the United States whose underlying cause of death was dementia, to determine place of death. The majority of 'dementia-related deaths' occurred in nursing homes (67%). By contrast, the most common place of death of older people with cancer was home (38%). Hospital was the most common site of death for all other conditions (52%).

However, Collins and Ogle (1994) found that the most frequent setting for death of a person with dementia was home (42%), followed by a nursing home (32%) or a hospital (26%). They interviewed 326 family caregivers of a person with dementia who experienced the death of their relative while participating in a longitudinal study. Although this study was also conducted in the United States, the proportion of deaths at home in the Collins and Ogle study is likely to be inflated by the inclusion of only people with dementia who had a family caregiver. In contrast, the study by Mitchell and colleagues included all deaths of people with dementia.

In a United States study of 154 family caregivers of a person with dementia who died during the previous year, Volicer and colleagues (2003) concluded care recipients spent an average of five weeks at home, seven weeks in an institution, and one week in a hospital during the last 90 days of life. Overall, 16% of care recipients spent the entire 90 days at home, 34% spent some time at home and some time in an institution, and 50% spent the entire 90 days in an institution. There were no differences evident in relation to age, gender and ethnicity of the care recipient, relationship between caregiver and care recipient, or caregiver education and income. Another finding of the study was that the presence of advanced care directives, where the family prepares and plans future medical treatment and end-of-life care, increased the likelihood of death in a nursing home.

Mitchell and colleagues (2007) also examined the effect on place of death of decisions to forgo hospitalisation for nursing home residents with advanced dementia. In a nation-wide study using administrative data from Medicare and Medicaid funded nursing homes in the United States, Mitchell and colleagues concluded that 'Do Not Hospitalise' (DNH) orders were rare. However, they were more common among patients with dementia (7%) than nursing home residents as a whole (3-4 %). DNH orders were also associated with clinical characteristics, such as the features of the facility, and the intensity of terminal care provided in the region. Demographic characteristics, particularly age and race, were also strong determinants of the presence

of such an order. DNH orders were more common among older people with dementia, and in nursing homes with predominantly white residents.

In a smaller study conducted in a 675 bed hospital in Boston, Lamberg and colleagues (2005) reported a much higher rate of DNH orders for people with dementia at time of death (84%), increasing from 34% 180 days prior to death and 50% 30 days from death. DNH orders were more likely to be in place where the decision maker was not the care recipient's child, and where the care recipient experienced eating problems, was older or had been in residential care for over two years.

Description of care pathways and transitions discussion

Diagnosis of dementia is not straightforward, and many medical practitioners face legitimate anxieties in diagnosis and management of the condition. Due to the progressive nature of the condition, it is hard to recognise in the early stages and symptoms can be masked by other conditions. A person in the early stages of dementia may be able to continue to function well without formal assistance, particularly with informal support. Additionally, there can be fear surrounding diagnosis and lack of understanding of the condition, which can result in an unwillingness to seek medical advice by both patients and carers.

Dementia is often diagnosed following a crisis event or the onset of severe symptoms. However, early diagnosis allows people with dementia, their families and their carers to prepare. Progression of the condition has implications in areas such as personal safety, use of motor vehicles, management of personal finances and access to assistance. Diagnosis can help family, friends and people with dementia to accept and understand their functional impairments. It allows time to plan future living arrangements, appropriate care and assistance, legal and financial matters and appropriate medical treatment.

Further research is needed into the relative progression of the condition by the timing of diagnosis. It would be valuable to quantify the differences in medical progression of dementia as well as the experiences of families, carers and people with dementia according to whether diagnosis was obtained early in the progression of the condition or later. A further gap in our knowledge of dementia diagnosis is the lack of data available for diagnosis by specialists rather than general practitioners.

Little evidence is available describing common pathways and transitions between care types, with the majority of research focusing on admission to long-term residential care. These reviewed studies have found that when dementia patients are assessed they are more likely to be recommended for long-term care compared to older people without dementia (Howe & Kung 2003; Moriarty & Webb 2000). Further, research has demonstrated that dementia patients often first access short-term care, such as dementia day centres, respite programs and hospitals, before moving to institutions (Adler et al. 1995; Butler et al. 2002; Cohen & Pushkar 1999). This could suggest that short-term care is a stepping stone to long-term care.

However, a greater understanding of transitions between other care types is needed, particularly evidence describing the use of hospitals, community care and early intervention programs such as memory clinics. This information would allow identification of potentially beneficial timing, form and program placement of interventions that may prove effective in improving quality of life and delaying long-term residential care.

Descriptions of end-of-life care are more prevalent. These studies highlight the severity of the late stages of the condition, and the need for high-level care. Most people with

dementia will eventually move to residential aged care, with many ending their lives in such facilities (Mitchel et al. 2005; Volicer et al. 2003). This has implications for the provision of such services in an ageing population, where the number of people with dementia is projected to increase markedly.

There is a notable gap in the reviewed literature in terms of studies which examine the implications of transitions in care for the quality of life and other outcomes of people with dementia and their families and carers. This type of post-care-transition research is important both in its own right and because carers' attitudes, motivations and decisions around care, particularly institutionalisation, are likely to be influenced by the perceived effects on both their own quality of life and that of the person for whom they care.

Interventions to modify care transitions

There are a number of interventions described in the literature that aim to reduce caregiver burden and BPSD, all of which may have an impact of reducing, delaying or preventing transitions to certain types of care. However, only a small number of intervention studies with an explicitly stated outcome measure of modifying a care transition were identified. Six such studies were included for review, and were categorised by the nature of the intervention provided – caregiver counselling and support; caregiver training; multidisciplinary intervention; family counselling; and memory clinic and respite. For further details about these studies, see the summary tables in Appendix 2

Caregiver counselling and support

Mittelman and colleagues (2006) conducted a randomised controlled trial (RCT; *n=406*) to determine the effectiveness of an intervention in delaying time to nursing home placement of patients with dementia in the United States. Participants were spouse caregivers of community-dwelling people with a confirmed diagnosis of Alzheimer's disease. Recruitment occurred through a university AD Centre, an Alzheimer's Association, other community organisations, private physicians and other study participants. At baseline, three-quarters (75%) of the people with AD had a Global Deterioration Scale (GDS) Score of 4 or 5, indicating mild to moderate cognitive decline.

Participants were randomised by lottery to either the intervention or control group, with participants and counsellors blinded to allocation until after baseline assessment. The intervention consisted of sessions of individual and family counselling, support group participation and continuous ad hoc telephone counselling. The control group received the usual care provided to patients and their caregivers enrolled at a local AD research centre. This care involved the provision of resource information and help upon request, but excluded an invitation to formal counselling and access to counsellors. Despite this, usual care recipients were free to join support groups of their own volition and call on counsellors. Within 12 months of enrolment in the study, 42% of the caregivers in the usual care group joined support groups, compared to 58% of those receiving the intervention.

After 6-monthly follow-ups over 9.5 years, with very low attrition, the study found efficacy for the intervention. Patients whose spouse caregivers received the enhanced counselling and support intervention experienced a 28.3% reduction in the rate of nursing home placement compared with the controls. The mechanism through which the intervention was most able to impact on nursing home placement was through changing caregiver reaction to patient behaviour. Controlling for other covariates by Cox

regression, decreasing caregiver reaction to memory and behaviour problems was found to account for 49% of the impact of the intervention on nursing home placement.

In contrast, Hébert and colleagues' (1995) much smaller (*n=45*) RCT of a support group program for caregivers in Canada found that the probability of institutionalisation at 24 months was not significantly different between their study and control groups. Participants in the study were caregivers of community-dwelling people with DSM-III-R criteria diagnosed dementia. After stratification, the caregivers were randomised to a study or control group. The study program involved weekly support group sessions with 4-8 caregivers present and led by a trained nurse. The sessions focussed on information related to dementia, role-playing and discussion on behavioural and emotional problems, and relaxation techniques. The control group was invited to attend the monthly meetings of the Alzheimer's Society.

Survival analysis conducted at follow-up 32-42 months after study entry and after a high level of attrition (20%), revealed that survival of the care-giving experience was slightly higher in the study group, but the difference was not statistically significant.

Caregiver training

The efficacy of an intensive caregiver training intervention was evaluated in an RCT (*n=96*) conducted by Brodaty and colleagues (1997) in Australia. Subjects were people with dementia and their cohabiting carers, 93% of whom were spouses. Sixty-five of the subjects had probable AD, twenty-one had multi-infarct (vascular) dementia, 3 had Pick's disease, and 4 had dementias of other types. At baseline, their mean MMSE score was 17, indicating a moderate level of dementia. Subjects were randomised to an immediate treatment, delayed treatment or control group sequentially by their date of application to a psychiatric unit.

The immediate treatment group received a ten-day intensive residential program for caregivers and a patient program. The content of the ten-day program focused on aspects of care-giving such as caregiver distress, coping skills and use of community services and was administered by a number of professionals including social workers, psychiatrists and occupational therapists. The patient program consisted of occupational therapy, outings and relaxation classes, group discussions, reminiscence therapy and a memory retraining program.

The delayed treatment group received the same caregiver training and patient program six months after their application to the psychiatric unit. The control group received the usual patient program and ten-days of respite for caregivers, with no training.

After 8 years of follow-up, with no attrition, analysis that combined the two caregiver treatment groups found that caregiver training had a significant effect in delaying nursing home admission and there was a trend towards training delaying patient death.

Multidisciplinary intervention

A randomised trial (*n=100*) undertaken by Bellantonio and colleagues (2008) examined the effect of a multidisciplinary team intervention on unanticipated transitions from dementia specific assisted living facility to either a permanent nursing facility, first emergency department visit or first hospitalisation. Participants were people with dementia who had moved to two dementia-specific assisted living facilities in Connecticut, United States. At baseline, the mean MMSE score of the participants was 15, indicating a moderate level of dementia. Group selection was determined by randomisation using sealed envelopes.

The intervention group received four systematic assessments by a geriatrician, geriatrics advanced practice nurse, physical therapist, dietician, and medical social worker during the first 9 months of residence in the facility. The rationale for team composition was based on an observation that transitions are due to acute medical, psychiatric and functioning event or change. The control group received usual clinical care of a medical evaluation conducted by their own primary care physician before or shortly after admission to the facility.

Survival analysis found that while the intervention reduced the risk of all transition types, none reached statistical significance. The risk of any unanticipated transitions were reduced by 13%, permanent transfer to a nursing home by 11%, emergency room visits by 12% and hospitalisation by 45%. The main mechanism reported to cause an unanticipated transition was falls, with or without a fracture, followed by medical conditions and behaviour problems.

Early intervention: family counselling and memory clinic

Moniz-Cook and colleagues (1998) employed a quasi-experimental study design (*n*=30) to evaluate a family counselling and memory management program in the United Kingdom. Participants were people with an International Classification of Diseases (ICD-10) diagnosed probable Alzheimer's disease, multi-infarct dementia (vascular) and frontal lobe dementia. Group selection was determined by randomisation using a sequential block procedure.

The intervention group was provided with a home-based individualised program administered by a clinical psychologist for the person with dementia and their caregiver. Components of the intervention included counselling and information, coping skills and individualised memory rehabilitation. After the program, people in the intervention group were referred to the services of local Elderly Mentally Infirm (EMI) support teams. Control subjects were referred directly to the EMI teams for advice and support.

After 18 months, significantly more control patients had been placed in permanent residential care at follow-up, with the experimental group performing better than controls on measures of patient memory and carer wellbeing.

Respite care

A Cochrane Collaboration Systematic Review assessed the effect of respite care on rates of institutionalisation. Lee and Cameron (2004) reviewed three randomised controlled trials (*n*=55; *n*=632; *n*=24) comparing respite care with a control intervention for people with dementia and their carers. The interventions were not comparable and thus pooling of data from the three studies was not possible. The first study evaluated in-home respite, the second evaluated in-home, day-care and institutional respite, and in the third study, the person with dementia was taken for a weekly walk.

The trials were assessed on their use of randomisation, blinding, patient selection, outcome measures and reporting of results. The reviewers state that no blinding was reported in any of the studies, but explain that blinding with this type of intervention is virtually impossible; however it is feasible for people measuring outcome measures to be blind to treatment allocation.

On the basis of the methodological quality of the three studies and their lack of comparable data, the review concluded that there was no reliable evidence of efficacy of respite care for people with dementia and their caregivers on the time to institutionalisation.

Intervention to modify care transitions discussion

The lack of comparable interventions reviewed makes it difficult to draw conclusions about the efficacy of strategies aimed at modifying care transitions for people with dementia. Three of the six studies found that a reduction or delay in nursing home placement was significantly associated with participation in an intervention (Brodaty et al. 1997; Mittelman et al. 2006; Moniz-Cook et al. 1998). A fourth study also found that intervention reduced the risk of transitions, however the results did not reach statistical significant (Bellantonio et al. 2008). Two of these studies were methodologically robust and longitudinal in nature.

A methodological quality issue that is common to research on interventions for people with dementia and their carers concerns the choice of control groups and control interventions. Lee and Cameron (2004) argued that the validity of a randomised control trial is in part dependant on the choice of control intervention, and a problem with intervention studies for people with dementia is the inability to have a control group that does not receive some form of 'treatment'. In all of the reviewed studies, the control groups received at least 'usual care' provided to people with dementia and their caregivers and were free to access services of their own volition. The nature of treatment for controls may confound the study of an intervention's efficacy.

Despite the lack of comparability, the outcomes of the three studies with positive results suggest that intensive early-interventions that are targeted at both the person with dementia and their caregiver can have a positive effect on reducing, delaying or preventing transitions. Further, due to these studies' longitudinal nature, they have demonstrated that the interventions have positive benefits in the long-term. However, Brodaty et al. (1993) contended that once dementia has progressed to later stages, the benefits of interventions diminish.

The efficacy of these interventions supports the function of two current Government-funded programs – Extended Aged Care at Home Dementia (EACH-D) and Dementia Behaviour Management Advisory Services (DBMAS; see chapter 1). EACH-D packages provide individually tailored care for people with dementia who have difficulties in their daily lives due to behavioural and psychological symptoms of dementia and periods of change in behaviour such as sundowning. Likewise, Dementia Behaviour Management Advisory Services assist caregivers of people with dementia to manage the difficult behaviours associated with the condition that impact on their care.

A gap in the literature is the lack of research about interventions that aim to modify transitions other than nursing home placement/institutionalisation. Four of the reviewed studies had the transition to nursing home placement/institutionalisation as an explicit outcome measure. As mentioned in the previous section, nursing home placement is an easily identified event that can be accurately dated (Knopman et al. 1999), and is often seen as an endpoint in the natural history of dementia. Interventions with outcome measures to reduce the risk of hospitalisation and outcome measures to increase uptake of community care and support early on the course of the condition may be of value to ascertain if and how these transitions can be modified.

Special population groups

Little research is available regarding population groups of special interest with dementia. In particular, little Australian research is available. People with younger-onset dementia have been researched to a greater degree than other special population groups,

and three such studies have been included in the review. For further details about these studies, see the summary tables in Appendix 2.

Research into culturally and linguistically diverse (CALD) people with dementia has mostly been conducted in the United States. Due to the differing CALD mix between the United States and Australia, such studies as are not transferrable to an Australian context. Consequently, a background discussion based on non-reviewed studies is included for this special group. Similarly, non-reviewed background information is provided about Aboriginal and Torres Strait Islander people with dementia, those in rural and remote areas, and those with intellectual disabilities as research in these areas is very sparse.

People with younger-onset dementia

Although dementia is primarily associated with older people, it also occurs in people aged less than 65 years. In these cases, it is usually referred to as presenile or younger-onset dementia.

Obtaining a diagnosis can be problematic in younger-onset dementia, as medical practitioners may interpret symptoms differently for a younger patient. Ferran and colleagues (1996) found that the most common diagnoses of participants assessed by a younger-onset dementia service in Liverpool (United Kingdom) were Alzheimer's disease, vascular dementia and depressive pseudo-dementia. Significant difficulties were identified in differentiating between the symptoms of dementia and other conditions, such as depression, which often mimic dementia in younger people. In Ferran and colleagues' study, 18% of participants received a final diagnosis of depression rather than dementia.

Luscombe and colleagues (1997) also identified diagnosis as a significant issue for people with younger-onset dementia. Diagnostic difficulties were reported by the majority (71%) of Australian carers surveyed. The reported mean time to diagnosis was 3.4 years, with an average of 2.8 professionals consulted. While psychogeriatricians are more likely to recognise and correctly diagnose symptoms of dementia, they were rarely consulted due to the patient's age. The medical professionals most commonly consulted for diagnosis were general practitioners and neurologists.

Provision of appropriate care and support are also issues for people with younger-onset dementia. With a low prevalence among people under 65 years of age, dementia services are structured to support the needs of older clients. Delany and Rosenvinge (1995) found that such services did not make specific provision for people who are more physically active. Within this study, people with younger-onset dementia had a high degree of cognitive, self-care and behavioural disability, and carers showed considerable stress.

Ferran and colleagues' (1996) study also reported a high level of care need among people with early onset dementia, with 22% of people in the study placed in residential care within 12 months. For carers of people with younger-onset dementia, stress is a significant issue. Luscombe and colleagues (1998) found that carers experience psychological problems, financial worries, loss of employment and family conflict. Most carers used support services, but expressed some dissatisfaction with the appropriateness and availability of such services.

People from culturally and linguistically diverse backgrounds

The review did not identify any Australian studies examining culturally and linguistically diverse people with dementia. However, some Australian government

reports have identified and described the services used by this group. The 2003 Survey of Disability, Ageing and Carers found that 16% of people with dementia were born in non-English speaking countries and 16% were born overseas in English-speaking countries (AIHW 2007b). Other reports have found that in 2005–06, overseas-born people from CALD backgrounds used aged care packages in the community at higher rates than the Australian-born population, and used residential aged care at significantly lower rates (AIHW 2007a; AIHW 2007c).

Some international studies have been conducted, largely in the United States. However, as the CALD groups within the United States are very different from those in Australia, most findings are not transferrable to an Australian context.

In a 2001 literature review that included studies from the United States and Europe, Janevic and Connell found consistent difference across cultural groups. In comparison to African American, Hispanic and Chinese carers, white carers tended to report higher levels of stress and depression. White carers were also more likely to be spouses. Little evidence was found to support the common assumption that culturally diverse carers had greater access to informal support systems.

Hinton and colleagues (2004) examined ethnic differences in time to diagnosis within the United States. Although the small sample size precluded meaningful statistical analysis, differences in common diagnosis pathways were visible across CALD groups. A fragmented pathway involving multiple medical professionals was the most common pathway among Anglo European people (47%). Crisis event pathways were the most common among African American people (40%). For Chinese-Americans, a 'dead end' pathway was most common (43%), where no formal diagnosis was obtained. It was unclear whether this was due to under diagnosis, lack of disclosure or failure of communication.

Aboriginal and Torres Strait Islander people

Very little information is available regarding Aboriginal and Torres Strait Islander people with dementia, and no studies were identified for inclusion in the systematic review. While a small amount of background information is provided here, it is clear there is a considerable need for further research in the area of dementia among Indigenous Australians.

In 1997, Pollitt conducted a review of dementia in Aboriginal and Torres Strait Islander communities, reviewing published work in Indigenous mental health with relevance to cognitive impairment in old age. While such work was scarce, the review concluded that cultural differences in the way dementia is perceived were a significant issue. Cultural protocol is not to speak about others, making it difficult to establish an accurate case history. Cognitive impairment in old age is often perceived as normal 'tiredness' or 'childishness' associated with old age or in extreme cases as 'madness'.

Pollitt (1997) also identified difficulties with availability and access to formal services, and commented on the inappropriateness of standard assessment tools due to literacy limitations and cultural bias. These issues were reiterated in a 2002 Indigenous dementia project report produced by Alzheimer's Australia. In particular, the diversity of language, culture and education within Indigenous communities makes assessment and management of dementia a complex process. Within Indigenous communities, there is a lack of access to interpreters, a lack of access to medical specialists and a lack of specialist support (Alzheimer's Australia 2002).

Where services are available, they do not provide specifically for Indigenous clients, such as the provision of appropriate activities, food and language or catering to people

with younger-onset dementia. Aged care issues are often not a priority in Indigenous communities, due in part to cultural perceptions that cognitive decline is normal in old age and in part to the lower rate of survival to old age among Indigenous people. Essentially, the major difficulty in discussing dementia among Indigenous people is the lack of knowledge and certainty about the extent and implications of the condition.

There is little research into the prevalence of dementia among Aboriginal and Torres Strait Islander people. A recent report by Alzheimer's Australia (2007) found that the rate of dementia is five times higher for Indigenous Australians over the age of 45 and living in remote areas compared to the general Australian population. The number of Indigenous Australians with dementia is thought to be disproportionately high due to high rates of risk factors such as adverse environmental factors pre- and perinatally and in early childhood, cerebrovascular disease, diabetes, head injury and alcohol consumption. It is also likely to be difficult to diagnose, due to high morbidity among older Indigenous people. That is, high prevalence of other medical conditions may mask dementia and complicate the diagnostic process. The lower life expectancy for Indigenous Australians has resulted in less interest in age-related disease until recently.

One barrier to quantifying prevalence has been the lack of an appropriate cognitive assessment tool for use in Indigenous communities. A joint project between Alzheimer's Australia (NT), University of Western Australia and the National Ageing Research Institute is being undertaken to develop and validate such a tool. The result is the Kimberley Indigenous Cognitive Assessment (KICA) Tool. While still undergoing full validation, early results are comparable to other screening cognitive tools used in non-Indigenous cultures. An equivalent tool for urban Aboriginals is also under development (Broe T 2008 personal communication, Prince of Wales Medical Research Institute).

People living in rural and remote areas

Knowledge about transitions in care for people with dementia in rural and remote areas represents a significant research gap. No Australian studies were identified in the review, and only one international study was found. However, this small qualitative study was not sufficiently robust for inclusion.

The 2002 Canadian study conducted by Morgan and colleagues (2002) did, however, produce interesting findings that warrant further investigation. Participants relied on small local medical services for diagnosis and case management. These services were not specifically equipped for aged care. In addition to issues of service availability and access in rural areas, participants reported a high need, but a resistance to formal care use. Concerns commonly expressed by participants were the issues of privacy and stigma in smaller communities. Many of the available formal carers were themselves part of the local community (Morgan et al. 2002).

Intellectual Disability and Dementia

There is very little information on the transitions and pathways in care for people with intellectual disabilities and dementia. While no studies were identified for inclusion in the systematic review, some background information is provided here. Research into the prevalence of dementia for people with intellectual disability has found that there is an increased risk for those with Down syndrome. Holland and colleagues (2000) found that for people with Down syndrome, Alzheimer-like symptoms start to manifest from as early as 30 years of age, and by 40 and 50 years of age most people with Down syndrome have an AD diagnosis. However, some people with Down syndrome do not

develop dementia (NSW Health 2002). Research into those with intellectual disabilities without Down syndrome has found that the rate of dementia is similar to that of the general population (Zigman et al. 2004).

Special population groups discussion

The five main special population groups of interest – people with younger-onset dementia, Aboriginal and Torres Strait Islander people with dementia, people from CALD groups with dementia, people living in rural and remote areas with dementia and people with intellectual disabilities– have received little attention from researchers. The experiences of special groups are an important area of study, as they represent groups of significant size in Australia with needs that are likely to differ from the mainstream.

Younger-onset dementia has been researched to a greater extent than dementia among other special groups. It was found that younger-onset dementia can be particularly problematic to diagnose, due to the rarity of the condition among younger people. Among such cases the symptoms are often assumed to be due to other conditions. Younger people are less likely to be referred to a psychogeriatrician more familiar with the symptoms, and more likely to be referred to a neurologist. Further, once a diagnosis has occurred, it is hard to obtain appropriate care, as dementia support packages are tailored towards the elderly and do not account for young people who are physically active (Ferran et al. 1996; Luscombe et al. 1997).

Indigenous health is a government policy focus; however Indigenous ageing is an area that has received little attention to date. With little data or research available, we are currently uncertain of the extent or 'shape' of Indigenous aged care issues, including dementia care.

In 2006, an estimated 4.96 million Australian residents were born overseas (ABS 2007). As the population ages, we can anticipate large numbers of people with varied backgrounds using aged care services. In addition to considerations of the provision of language and culturally appropriate services, there are likely to be considerable differences in which services are accessed across CALD groups, and in how and when they are used.

International research, particularly within the United States, has looked at variations in use of aged care services across cultural groups and found significant differences. However, the CALD mix is considerably different, and most findings are not transferrable to an Australian context.

Differences in patterns of care usage in rural and remote areas are under researched both in Australia and internationally. Although different issues are likely to arise in less populated areas, particularly surrounding privacy and access issues, there has been virtually no research undertaken to describe or quantify these.

Similarly, little research has focused on people with intellectual disabilities and dementia. However, research suggests that people with Down syndrome have an increased risk of younger-onset dementia. Future research is needed to develop a greater understanding of the effects of dementia for people with intellectual disability, including people with Down syndrome, and develop appropriate care and transition pathways. Prior to and following a dementia diagnosis, people with intellectual disability are likely to use a different set of formal and informal services than many other people with dementia. It is therefore important that linkages between health, disability and aged care sectors are considered in research examining care pathways for this population group.

■ 4 Key gaps in the evidence

The evidence presented in this systematic review is heavily weighted toward the predictors of care transitions, particularly focused on predictors of transition to nursing homes. Broadly speaking, research on other areas of interest to this review was scarce. A number of specific gaps and weaknesses in the evidence on transitions in care for people with dementia were revealed from the systematic review. Five key gaps in the literature which the 'Transitions in Care' node consider to be of high policy priority are highlighted below

1. the diagnostic process and its connection to, and role in influencing, subsequent patterns of service use
2. the use of and transitions into and out of community-based care
3. the transition experience of hospitalisation
4. quality of life and other outcomes for people with dementia and their family and carers following care transitions
5. the care pathways of special population groups
6. the lack of Australian research.

Formal diagnosis can be an important influence on subsequent care transitions, particularly as it can allow a person with dementia and their families and carers to plan courses of action. The diagnosis of dementia is not straightforward due to differential diagnosis and the fact that many medical practitioners face legitimate anxieties in giving a diagnosis of dementia. The systematic review conducted by the 'Care of people with dementia in General Practice node' found that 'in general, GPs do not identify dementia early, do not complete a full assessment as described in the guidelines, and fail to provide the full range of recommended management options to their patients' (Williams et al. 2008).

In this review, the small amount of literature on the experience of diagnosis points to significant lags between problem recognition, consultation with a medical professional and a formal diagnosis. A greater understanding of the process and timing of the dementia diagnosis, including the roles played by a range of health and care professionals and services, would provide greater insight into the progression of the condition and the impact of formal diagnosis on subsequent care use. It would also inform improvements in the diagnostic journey for the patient and their family, for example improved linkages between assessment services and community care services and appropriate support for GPs.

This systematic review identified no studies which explored the transition to community care. In Australia, community care is a central and growing component of aged care provision, due to the preference of many people to live at home in the community rather than moving into institutionalised care (AIHW 2008). To meet this need, the Australian Government has established programs such as HACC, CACP, EACH and EACH-D, which provide support services and care for older people in their homes. The kinds of questions which future research could address would be

- what predicts use of community care services?
- what is the duration of community care use?
- what kinds of assistance provided through community care programs are the most effective in supporting care recipient and their families and carers?

- what changes in care needs of the person with dementia (or their carer) trigger changes in the level or amount of care received in the home?
- what kinds of environmental factors affect community care provision?
- do existing community care options address the needs of people with dementia?

The role of hospitalisation in the care pathways of people with dementia is not well addressed in the research literature. Key gaps in the literature include:

- the factors which influence the pathways into and out of hospital
- the nature and impact of the hospital experience on the health and functioning of patients with dementia
- the effectiveness of services which intervene at different points in the journey to and from hospital, including those interventions which aim to reduce the risk of subsequent entry to residential aged care.

People with dementia experience the full range of acute illnesses that require hospitalisation. However, there is evidence that 'hospitals can be dangerous and unfriendly places for frail older people or people with dementia' (Kurrle 2006). Hazards include polypharmacy, undernutrition, skin tears, pressure areas, fall-related injuries, nosocomial infections and deconditioning (Creditor 1993; Foremand & Gardner 2005; Torian et al. 1992). Compounding these risks, patients with dementia have a higher average length of stay in hospitals (19.6 days for any diagnosis of dementia in 2003–04 and 30.1 days for those with a principal diagnosis of dementia) (AIHW 2007b) compared with all patients aged 65 years or over (8.7 days) (AIHW 2007b). Finally, little is known about the post-hospital discharge destinations of patients with dementia, how these compare with other patients, and whether there is scope for improving the rate at which people are discharged into residential aged care facilities. The role of hospitalisation in the care pathways of people with dementia needs illumination to examine issues such as the extent to which hospitalisation might be avoided, the ways in which hospital length of stay could be reduced for patients with dementia, the hospital experience made less damaging, and improving the chances of the patient moving back into their own home after hospitalisation.

None of the reviewed evidence examined the experience of people with dementia and their families and carers post-care transition. Further research in this area is needed to improve understanding of the outcomes, including quality of life, for people with dementia and their carers following a major transition in care. This research is important both generally and because carer perceptions of the likely outcomes of new care arrangements, particularly institutional care, are likely to influence the care pathways taken.

The transition experiences of special population groups are poorly identified in the research literature. Information about Aboriginal and Torres Strait Islander people with dementia, people from CALD groups, people with younger-onset dementia, people in rural and remote areas and people with intellectual disabilities and dementia have received little research focus. These groups represent significant populations in Australia and are likely to have needs that differ from the general population. For example, it appears that CALD groups have a preference for community care over residential aged care (AIHW 2007a; AIHW 2007c). A further issue for people from CALD backgrounds is that in the late stages of dementia, a number of people who learnt English as a second language revert to their native tongue (DHS 2004). This phenomenon complicates the provision of appropriate services.

For Aboriginal and Torres Strait Islander communities, culturally appropriate cognitive assessment tools have only just been developed, thus prevalence rates of dementia are

largely unknown. A prevalence study conducted in the Kimberley region pointed to prevalence rates nearly five times higher than in the general Australian population (Alzheimer's Australia 2007). Once prevalence rates have been made clearer, investigations into the types of formal care services Indigenous people with dementia utilise should be conducted to determine levels of need and to identify better models of care.

Concerning people with younger-onset dementia, there is evidence that this group of people have a different experience with the diagnostic process, but little evidence exists about their pathways after diagnosis. The provision of age-appropriate care and support is an important issue for people with younger-onset dementia.

The transitions-in-care experiences of people with dementia living in rural and remote areas are not well known. The study of this group of people is warranted to determine how much health and aged care service accessibility in non-metropolitan areas influences care pathways. Finally, there is limited understanding of the experience of dementia for people with intellectual disabilities. An understanding of the different characteristics, treatment and care transitions experienced by this group is required.

The absence of substantial Australian research on care pathways and transitions of people with dementia is of significant importance. There is little evidence on how Australian services and programs (including the wide array of community care programs) are currently being used in the pathways of care of people with dementia and how these programs impact on care transitions. Recent years have also seen the implementation of dementia-specific services (EACH-Dementia packages and Dementia Behaviour Management Advisory Services) and post-hospital transition care programs (Transition Care Program) whose role and influence on care pathways and transitions of people with dementia is still unknown.

■ 5 Recommendations

For practice

While the evidence base provided in this review is limited, a few recommendations for practice can be suggested, namely

1. Practices that promote and improve early, well-informed assessment and diagnosis of dementia should be encouraged and links between assessment/ diagnosis services and early intervention and other care services should be fostered.

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. These services should involve both the person with dementia and caregiver (where there is one).

3. Interventions should aim to influence major predictors of institutionalisation— dementia progression, certain behavioural and psychological symptoms, carer capacity to cope with and respond to problem behaviours and carer health and wellbeing 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.

Given the importance of diagnosis for subsequent care (including transitions and pathways) the findings from this review lend support to recommendations from the systematic review from the 'Care of people with dementia in General Practice' node to support and involve GPs and practice nurses in initial identification and assessment of dementia in patients (Williams et al. 2008). To facilitate early diagnosis, it is imperative to foster increased awareness of the symptoms of dementia among the general public and to address GPs' attitudes towards communicating about a dementia diagnosis with patients. Because dementia is a relatively low prevalence disease among the general practice population, brief screening or assessment instruments are likely to produce as many false positive as true positive results. Efforts to support GPs in their assessment and diagnosis role therefore need to go beyond training in the administration of assessment tools and address their legitimate concerns about communicating a diagnosis based on such instruments.

In addition, well-developed linkages between health professionals who provide assessment, diagnostic services and early intervention and other care services would contribute to a more seamless system of service provision. The complexity of the health and aged care systems in Australia can make it very difficult and stressful for people with dementia and their families and carers to know about the kinds of services which are available and how to access them. In addition, GPs may be encouraged to communicate a dementia diagnosis if this can also be accompanied by information and guidance in relation to practical support and assistance.

The studies included in this review and the wider literature suggest that intensive early-interventions that are targeted at both the person with dementia and their caregiver can have a positive effect on maintaining care in the community.

Interventions that focus on reducing caregiver burden and improving their quality of life, including those that teach carers strategies to better manage patient behaviours that they find difficult, may be effective in improving the quality of life for both people with dementia and their caregivers. These interventions may also delay nursing home

placement and/or ensure improved decision making processes about care arrangements. A number of programs funded under the Dementia Health Priority Initiative are designed to provide support to caregivers and assist in the management of behavioural symptoms of dementia, particularly EACH Dementia packages, Dementia Behaviour Management Advisory Services and the National Dementia Support Program. Examining and implementing (as appropriate) recommendations from the National Evaluation of the Dementia Health Priority Initiative in relation to these programs may strengthen their capacity to respond to these

Interventions also need to take account of the unique and changing needs of specific groups of carers and of people with dementia—flexible responses to needs for physical and emotional support, education, information and training are required.

For further research

In terms of future research, four recommendations can be suggested

1. Develop fuller, more methodologically robust studies of the transitions in care for people with dementia.
2. Undertake further research into care transitions and pathways for special groups of people with dementia.
3. Conduct further research into the effects of care transitions on the quality of life and outcomes for people with dementia and their carers.
4. Undertake further data development.

At least three types of studies would provide a fuller, more methodologically robust understanding of the transitions in care of people with dementia. Firstly, longitudinal inception cohort studies (that follow people from dementia diagnosis) would be an exceptionally rich source of information in this area. Such studies would incorporate both clinical and social markers to determine how the natural history and clinical progression of dementia influences and impacts on pathways and should ideally incorporate data linkage with relevant administrative data sources (for example, Medicare data, hospital data, and various aged care data).

An example of a longitudinal incidence study currently underway is an investigation of ageing and Alzheimer's disease in an elderly population in Utah. The Cache County Study of Memory, Health and Aging commenced in 1994 and has followed an initial cohort of over 5,000 people to examine the development of cognitive impairment and dementia (Welsh-Bohmer 2006). It would be possible to extend a study such as this to record information about the formal diagnosis of dementia, while linkage with administrative data would allow identification of actual formal service use and intervention.

Secondly, retrospective cohort studies are a lower cost option that could provide similar information to prospective cohort studies. Such a study design could involve an informed relative or carer providing information about the pathways taken by the person with dementia from the time when dementia symptoms first appeared. As with a prospective cohort design, a retrospective study could also draw on linked administrative data to supplement information obtained through interview or survey methods.

Thirdly, greater use of existing data sources (such as hospital data, aged care assessment data and residential aged care data), particularly using linked data, could also be used to examine the pathways of large cohorts of people with dementia through various service pathways. A number of such projects are already underway in Australia (see below).

For example, the NHMRC has funded a project on the impact of hospital-based aged care and dementia services on outcomes for people with dementia admitted to hospital. This mixed-methods study proposes to link administrative by-product data from public hospitals, residential aged care services and Aged Care Assessment Teams, to investigate outcomes for older people with dementia admitted to hospital and how these outcomes differ from those for older people without dementia. Such studies are also capable of exploring transitions to and from psychiatric hospitals and, with further data development, could potentially be extended to incorporate pathways between other important service sectors such as community-based mental health care.

This review highlights the scarcity of research into the care transitions experiences of Aboriginal and Torres Strait Islander people with dementia, people from CALD groups, people with younger-onset dementia, people in rural and remote areas and people with intellectual disabilities and dementia. However, the available evidence does suggest that perceptions of the nature of dementia (for example, viewed as a natural part of ageing in some Indigenous communities), experience of diagnosis, care type preferences and care pathways are all likely to differ for these special population groups. Further research in this area is required.

Further research is also warranted into the post-care-transition quality of life and other outcomes for people with dementia and their carers and families. Such investigation is warranted both in its own right and because carer perceptions of the likely post-transition outcomes (both for themselves and the person they care for) are likely to predict their care preferences and the care pathways for people with dementia.

Any future research would benefit from further data development, especially the consistent identification of dementia diagnosis and its causal type on service records and datasets (see AIHW 2007b for a discussion of dementia data development in relation to key service data sets). In addition, consideration should be given to more comprehensive reporting of data already collected. For example, information about cognitive impairment and certain behaviour disorders is collected in a section of the client service record of the Aged Care Assessment Program (ACAP), but is not reported as part of the ACAP Minimum Dataset (MDS).

Some examples of current or upcoming research projects that will address some existing gaps in evidence about care transitions of people with dementia include the Pathways in Aged Care cohort study led by Duckett and Gibson (funded by NHMRC Health Services grant). This project is analysing patterns of aged care service use over time for people with dementia (and arthritis and cardiovascular disease) using linked data from the ACAP, RAC, HACC, CACP, and EACH programs.

Among the 2008 Dementia Research Grants assessed by NHMRC, the following projects will also make valuable contributions to addressing gaps in the evidence about care transitions and pathways:

- Outcomes of best practice diagnosis and management of dementia in general practice (Professor Dimity Pond)
- Clinical outcomes, staff and carer perceptions of acute hospitalisation of patients with dementia (Professor Len Gray)
- An efficacy study of a cognitive-communicative intervention to improve transition to residential care in dementia (Professor Helen Chenery)
- Dementia literacy in Greek, Italian and Chinese Australians (Dr Lee-Fay Low)
- The impact of hospital-based aged care and dementia services on outcomes for people with dementia admitted to hospital (Dr Diane Gibson).

APPENDIX 1

Levels of evidence

*National Health & Medical Research Council designations of levels of evidence –
Intervention, and prediction and prognosis studies (NHMRC 2000)*

Level	Intervention	Prediction and prognosis
I*	A systematic review of level II studies	A systematic review of level II studies
II	A randomised controlled trial	A Prospective cohort study***
III-1	A pseudorandomised controlled trial (i.e. alternate allocation or some other method)	All or none§§§
III-2	A comparative study with concurrent controls: • Non-randomised, experimental trial † • Cohort study • Case-control study • Interrupted time series with a control group	Analysis of prognostic factors amongst untreated control patients in a randomised controlled trial
III-3	A comparative study without concurrent controls: • Historical control study • Two or more single arm study ‡ • Interrupted time series without a parallel control group	A retrospective cohort study
IV	Case series with either post-test or pre-test/post-test outcomes	Case series, or cohort study of patients at different stages of disease

* A systematic review will only be assigned a level of evidence as high as the studies it contains, excepting where those studies are of level II evidence.
† This also includes controlled before-and-after (pre-test/post-test) studies, as well as indirect comparisons (ie. utilise A vs B and B vs C, to determine A vs C).
‡ Comparing single arm studies ie. case series from two studies.
*** At study inception the cohort is either non-diseased or all at the same stage of the disease
§§§ All or none of the people with the risk factor(s) experience the outcome. For example, no smallpox develops in the absence of the specific virus; and clear proof of the causal link has come from the disappearance of small pox after large-scale vaccination.

Frameworks for assessing quality

The Joanna Briggs Institute Critical Appraisal of a Systematic Review (JBI 2000)

Review Question	Is the review question clearly and explicitly stated?
Search Strategy	Were comprehensive search methods uses to locate studies?
	Was a thorough search done of appropriate databases, and were other potentially important sources explored?
Inclusion Criteria	How were the studies selected?
Critical Appraisal	Was the validity of studies assessed appropriately?
Data Synthesis	How were the studies combined?
	Were findings combined appropriately?
Similarity of Studies	Were the populations of the different studies similar?
	Was the same intervention evaluated by the individual studies?
	Were the same outcomes used to determine the effectiveness of the intervention being evaluated?
	Were reasons for differences between studies explored?
Reporting of Findings	Are review methods clearly documented?
	Is the review question clearly and explicitly stated?
	Was the search strategy reported?
	Was the inclusion criteria reported?
	Was the criteria for appraising studies reported?
	Were the methods used to combine studies reported?
Conclusions & Recommendations	Is a summary of findings provided?
	Are specific directives for new research proposed?
	Were the recommendations supported by the reported data?

Dorothy Forbes' External, Internal, and Statistical Conclusion Validity Rating Tool (Forbes 1998)

Category	Criteria	Rating

External Validity
 	
a) Design and allocation to intervention
	Random
	    Before/after or matched cohort
	    No control or unknown
		(1) Pass
		(2) Moderate
		(3) Fail

(b) Inclusion	(a) If consent to participate had been sought from subject, next of kin, or legal guardian: (1) >80% participation in both groups (2) 60-79% participation (3) <60% participation or level of participation not stated	 (1) Pass (2) Moderate (3) Fail
(c) Attrition	(1) <10% (2) 11-20% (3) >20%, did not indicate level of attrition, or not applicable	(1) Pass (2) Moderate (3) Fail
Internal Validity (d) Confounders controlled	(1) All relevant confounders controlled (e.g., age, sex, functional ability, level of cognitive impairment) (2) At least three confounders controlled, or subjects acted as their own control (3) Two or fewer confounders controlled	(1) Pass (2) Moderate (3) Fail
Statistical Conclusion Validity		
(e) Data collection	(1) At least one data-collection method (self-reported, assessment/screening, or medical records/vital statistics) had all of the following criteria rated as yes: well described, pretested, investigator blinded to participant's group allocation (2) At least one data-collection method had most criteria rated as yes (3) None of the data-collection methods adequately addressed	(1) Pass (2) Moderate (3) Fail
(f) Statistical analysis	(1) Multivariate (2) Bivariate (3) Descriptive or unknown	(1) Pass (2) Moderate (3) Fail

Checklist for appraising the quality of studies of interventions (NHMRC 2000)

1. Method of treatment assignment
a) Correct, blinded randomisation method described OR randomised, double-blind method stated AND group similarity documented
b) Blinding and randomisation stated but method not described OR suspect technique (e.g. allocation by drawing from an envelope)
c) Randomisation claimed but not described and investigator not blinded
d) Randomisation not mentioned
2. Control of selection bias after treatment assignment
a) Intention to treat analysis AND full follow-up
b) Intention to treat analysis AND <15% loss to follow-up
c) Analysis by treatment received only OR no mention of withdrawals
d) Analysis by treatment received AND no mention of withdrawals OR more than 15% withdrawals/loss-to-follow-up/post-randomisation exclusions
3. Blinding
a) Blinding of outcome assessor AND patient and care giver
b) Blinding of outcome assessor OR patient and care giver
c) Blinding not done
4. Outcome assessment (if blinding was not possible)
a) All patients had standardised assessment
b) No standardised assessment OR not mentioned
Source: modified from I Chalmers, Cochrane Handbook; available on the Cochrane Library CD-ROM

Altman's Framework for assessing internal validity of articles dealing with prognosis (Altman, 2001)

Study feature	Qualities sought
Sample of patients	Inclusion criteria defined, sample selection explained, adequate description of diagnostic criteria, clinical and demographic characteristics fully described, representative, assembled at common (usually early) point in course of disease, complete (all eligible patients included)
Follow up of patients	Sufficiently long
Outcome	Objective, unbiased (for example, assessment blinded to prognostic information), fully defined, appropriate, known for all or high proportion of patients
Prognostic Variable	Fully defined, including details of measurement methods if relevant, precisely measured, available for all or high proportion of patients
Analysis	Continuous predictor variable analysed appropriately, statistical adjustment for all important prognostic factors
Treatment subsequent to inclusion in cohort	Fully described, treatment standardised or randomised.

Angus Forbes' Appraisal Schedule (Forbes & Griffiths, 2002)

Appraisal questions	Score
1. Was there a clear statement of the aims of the research?	0 1 2 3 4
2. Was the sampling strategy clearly justified and linked to the target population?	0 1 2 3 4
3. Were the data collection methods adequately described?	0 1 2 3 4
4. Was the data analysis clearly linked to the themes/categories identified?	0 1 2 3 4
5. Were the themes and categories linked to the aims of the research and plausible?	0 1 2 3 4
6. How transferable were the study's findings?	0 1 2 3 4
7. What was the strength of the implications of the study for practice?	0 1 2 3 4
SUMMARY SCORE Weak Moderate Strong 0-11 12.20 21-28	

APPENDIX 2

Predictors of care transitions

General studies of predictors of institutionalisation

<table>
<tr><td></td><td>Level of evidence & Strength of study</td><td>NHMRC Level II;   Strong (Altman's)</td></tr>
<tr><td></td><td>Study</td><td>Cohen C, Gold, D., Shulman, K., Wortley, J., McDonald, G., Wargon, M. 1993. Factors determining the decision to institutionalise dementing individuals: A prospective study. The Gerontologist 33:714-20 (Canada)</td></tr>
<tr><td rowspan="3">Trial descriptors</td><td>Subjects</td><td>Caregiver/care-receiver dyads (59% spouse and 27% children caregivers)

Diagnosis of dementia according to DSM-III criteria for at least one year (70% AD; 15% multi-infarct; 15% unknown aetiology)

Care-receivers mean age: 77.46; MMSE mean: 15.79; No major physical problems; residing at home. Subjects had been referred for long-term supplementary home care and were on waiting lists for admission for permanent institutionalisation.

Caregivers mean age: 64.41, 76% were women</td></tr>
<tr><td>Predictor Variables</td><td>MANOVA: care receiver age, MMSE scores, presence or absence of troublesome behaviours, duration of caregiving and caregiver age, gender, income, total amount of assistance with ADLs provided, number of additional caregivers, total number of aspects of caregiving enjoyed, GHQ scores, burden scores, total frequency of problem behaviours, total negative reactions to problem behaviours, total number of services used, total extent of recreational activities, total extent of social support networks, and total satisfaction with social support received.

Chi-square analyses: caregiver gender, relationship to care receiver (spouse versus non-spouse), and presence versus absence of specific troublesome behaviours.</td></tr>
<tr><td></td><td></td></tr>
<tr><td rowspan="3">Quality items</td><td>Design, sample & participation</td><td>Prospective longitudinal study;   196 subjects;   100%</td></tr>
<tr><td>Statistical Analysis</td><td>MANOVA, chi-square analyses, discriminant function analyses, Univariate & multivariate analysis</td></tr>
<tr><td>Consent, follow-up & attrition</td><td>Not described

Telephone contact maintained every 2 months, follow-up visits every 6 months for up to 18 months.

After 18 months, 35 caregivers were not available for reassessment and 5 had died.</td></tr>
<tr><td></td><td>Outcomes</td><td>Six variables predicted actual institutionalisation at 18 months: caregiver health and burden, use of services, care receiver cognitive function and troublesome behaviours, and caregiver reaction to behaviours.

86% correct classification of prediction of institutionalisation at 18 months</td></tr>
<tr><td></td><td>Page 19</td><td></td></tr>
</table>

	Level of evidence & Strength of study	NHMRC Level II; Strong (Altman's)
	Study	Spruytte N, van Audenhove, C., & Lammertyn, F. 2001. Predictors of institutionalisation of cognitively-impaired elderly cared for by their relatives. International Journal of Geriatric Psychiatry 16:1119-28 *(Belgium)*
Trial descriptors	Subjects	Primary caregivers (parents, children and children-in-law) contacted by professional home-care services Patients had to show severe memory and orientation problems for at least 3 months resulting in severe psychological and social impairment. Diagnosis and severity of dementia for care receiver were verified with the cooperation of a GP for a subgroup of the sample (n=70) Moderate-to-severe dementia (GDS mean: 6)
	Predictor Variables	Sociodemographic characteristics (age, gender, marital status and education of patient and caregiver, patient income, patient living arrangements, relationship of patient and caregiver), patient characteristics (level of functioning, verbal and non-verbal behavioural disturbances), characteristics of the caregiving situation (duration of care, performance of caregiving tasks, cost of care environmental/material changes), caregiver characteristics (general and emotional burden, caregiving satisfaction, psychological and psychical wellbeing, religiosity), formal and informal support with care & the quality of the caregiving relationship (criticism, warmth and absence of conflict, premorbid relationship)
Quality items	Design, sample & participation	Prospective interview study; 144 informal caregivers; Not described
	Statistical Analysis	Bivariate analyses, multiple logistic regression analyses
	Consent, follow-up & attrition	Not described; Follow-up at 6 & 9 months after initial interview; 3%
	Outcomes	Institutionalisation rate was 16.5% and it was predicted by the caregiver's preference for institutionalisation, the functional level of the patient, the quality of the current relationship and the caregivers' willingness to performance changes to accommodation at home (such as convert a downstairs room into a bedroom).
	Page 19	

	Level of evidence & Strength of study	NHMRC Level II; Strong (Altman's)
	Study	O'Donnell B, Drachman, D., Barnes, H., Peterson, K., Swearer, J. & Lew, R. 1992. Incontinence and Troublesome Behaviors Predict Institutionalisation in Dementia. Journal of Geriatric Psychiatry and Neurology 5:45-52 *(USA)*
Trial descriptors	Subjects	Patients with a diagnosis of probable AD (82), MID (15), AD+MID (26), or AD+PD (7) or other (13)
		Subjects were outpatients at the University of Massachusetts Medical Center Alzheimer's Disease and Related Disorders Clinic.
		Clinical severity score: mild–moderate=64%; Mean age: 71$\pm$8; Majority suffering moderate-to-severe impairment of everyday activities; 60% female
	Predictor Variables	Severity of functional impairment, behavioural disorders (including incontinence), individual patient characteristics such as age, education and gender, and type of caregiver.
Quality items	Design, sample & participation	Prospective longitudinal study; 143 patients; 73%
	Statistical Analysis	Kaplan-Meier life-table method, Cox proportional hazards model
	Consent, follow-up & attrition	Not described
		Patients were re-evaluated at 6-month intervals over 19$\pm$ 12 months
		Patients who failed to return for follow-up visits were interviewed by phone at 6-month intervals.
	Outcomes	Kaplan-Meier life tables results indicate that severity of functional impairment and behavioural disorders, predicted institutionalisation. Using Cox model analysis, the best predictors of institutionalisation were paranoia, followed by incontinence and aggressive behaviour.
	Page 20	

	Level of evidence & Strength of study	NHMRC Level II; Strong (Altman's)
	Study	Hébert R, Dubois, M-F., Wolfson, C., Chambers, L., & Cohen, C. 2001. Factors Associated with long-term institutionalisation of older people with dementia: data from the Canadian Study of Health and Aging. Journal of Gerontology 56A:M693-M9 *(Canada)*
Trial descriptors	Subjects	Informal caregivers of individuals with dementia living in the community
		DSM-III diagnosed dementia – diagnosis of specific types of dementia made using the NINCD-ADRD for AD & ISCD10 for VaD
		Subjects recruited from population-based Canadian Study of Health and Aging
	Predictor Variables	Sociodemographic information, need of assistance with ADL, behaviour problems, caregiver depression, caregiver health, caregiver burden, caregiver desire to institutionalise
Quality items	Design, sample & participation	Prospective longitudinal cohort study; 326 informal caregivers; 81%
	Statistical Analysis	Bivariate analyses, Cox proportional hazard model, linear multivariate regression analysis, logistic multivariate regression analysis
	Consent, follow-up & attrition	Not described
		2.5 years and 5 years follow-up
		No attrition
	Outcomes	From multivariate analysis, the factors significantly associated with institutionalisation were: type of dementia, severity of disability, caregiver's age over 60, caregiver not a spouse or child, and severe caregiver burden. Caregiver's burden was associated with care-receiver's behavioural disturbance and the caregiver's depressive mood
	Page 20	

Focused studies of predictors of institutionalisation

Dementia progression as a predictor of institutionalisation

<table>
<tr><td rowspan="2"></td><td>Level of evidence & Strength of study</td><td>NHMRC Level II;   Strong (Altman's)</td></tr>
<tr><td>Study</td><td>Knopman D, Berg, J., Thomas, R., Grundman, M., Thal, L. & Sano, M. 1999. Nursing home placement is related to dementia progression. Neurology 52:714-8 *(USA)*</td></tr>
<tr><td rowspan="2">Trial descriptors</td><td>Subjects</td><td>At entry, all subjects had moderate AD rated as CDR stage 2 and independence in 2/3 ADLs, were community dwelling, and had an identified caregiver.

Patients were enrolled in the multicentre Alzheimer's Disease Cooperative Study clinical trial

Patient mean age: 73.3;   Mean MMSE at entry: 12.6; 65% women</td></tr>
<tr><td>Predictor Variables</td><td>Four measures of dementia severity (reaching CDR3, losing 2/3 ADL, change in dependence level from baseline to last measurement, and change on the Blessed Dementia Rating Scale from baseline to last measurement), behavioural disturbances on the BRSD, adverse events of a behavioural nature, plus demographic and clinical variables as possible confounders</td></tr>
<tr><td rowspan="3">Quality items</td><td>Design, sample & participation</td><td>Prospective cross-sectional study;   341 patients;   Not described</td></tr>
<tr><td>Statistical Analysis</td><td>Chi-square analyses, Wilcoxon rank-sum tests, Cox regression</td></tr>
<tr><td>Consent, follow-up & attrition</td><td>Not described

Follow-up at 3 month intervals over 2 years (plus contact with caregivers every 6 weeks by telephone)

<10%</td></tr>
<tr><td></td><td>Outcomes</td><td>The risk of nursing home placement was higher at any given time during the study for those subjects who reached a clinical dementia rating of 3 or who lost 2/3 of their activity of daily living compared to subjects who did not reach those endpoints.</td></tr>
<tr><td></td><td>Page 21</td><td></td></tr>
</table>

Behavioural Symptoms of Dementia as predictors of institutionalisation

<table>
<tr>
<td rowspan="2"></td>
<td>Level of evidence & Strength of study</td>
<td>NHMRC Level II;   Strong (Altman's)</td>
</tr>
<tr>
<td>Study</td>
<td>Gilley D, Bienias, J., Wilson, R., Bennett, D., Beck, T. & Evans, D. 2004. Influence of behavioral symptoms on rates of institutionalisation for persons with Alzheimer's Disease. Psychological Medicine 34:1129-35 (USA)</td>
</tr>
<tr>
<td rowspan="2">Trial descriptors</td>
<td>Subjects</td>
<td>People with clinically diagnosed AD living in a community setting – those with severe cognitive impairment at baseline (MMSE < 10) were excluded. Subjects were recruited through the Rush Alzheimer's Disease Centre.

Mean age: 75.5;   MMSE score: 18.7 (SD=7.1); 59.1% female</td>
</tr>
<tr>
<td>Predictor Variables</td>
<td>Behavioural symptoms: depressive symptoms, hallucinations, delusions and physical aggression; demographic information, other clinical characteristics: MMSE score, physical function</td>
</tr>
<tr>
<td rowspan="4">Quality items</td>
<td>Design, sample & participation</td>
<td>Prospective longitudinal study;   410 subjects;   83%</td>
</tr>
<tr>
<td>Statistical Analysis</td>
<td>Proportional hazards regression models</td>
</tr>
<tr>
<td>Consent, follow-up & attrition</td>
<td>Signed consent was obtained from participants and a family member. The informant was the person with the most contact with the participant.

Annual follow-ups over 4 years

<10% (participation rates over the 4 years ranged from 90.9% to 95.1%)</td>
</tr>
<tr>
<td>Outcomes</td>
<td>In multivariate models, adjusted for demographic and social variables, four clinical features emerged as the predominant predictors of institutionalisation: cognitive impairment level, physical aggression, hallucinations and depressive symptoms.</td>
</tr>
<tr>
<td></td>
<td>Page 22</td>
<td></td>
</tr>
</table>

	Level of evidence & Strength of study	NHMRC Level II; Strong (Altman's)
	Study	de Vugt M, Stevens, F., Aalten, P., Lousberg, R., Jaspers, N. & Verhey, F. 2005. A prospective study of the effects of behavioral symptoms on the institutionalisation of patients with dementia. International Psychogeriatrics 17:577-89 *(Netherlands)*
Trial descriptors	Subjects	People with DSM-IV diagnosed dementia with informal primary caregivers who were in contact at least once a week. (AD=90; VaD=20; FTD=2; PD=3; PPD=1; AD/VaD=3) All patients were living at home at baseline. Patients were part of the Maastricht Study of Behavior in Dementia and were referred by the Memory Clinic of the Academic Hospital Maastricht of geriatric division of the Regional Institute for Community Mental Health Maastricht.
	Predictor Variables	Patient behavioural problems (hyperactivity, mood/apathy and psychosis factors), cognitive functioning, patient's dependence on others, severity of dementia, caregiver distress due to behavioural problems, caregiver subjective competence, caregiver depressive symptoms
Quality items	Design, sample & participation	Prospective longitudinal study; 119 (power calculation: significance level 0.05/ HR of 2 - power=0.965); Not described
	Statistical Analysis	Cox regression analyses, principal component analysis, t-tests, χ-tests
	Consent, follow-up & attrition	Informed consent was obtained from all subjects. Patients and their caregivers were seen at 6-month intervals for 2 years 1-year - 18% 2-year - 37% (Caregivers lost to follow-up were older, patients more cognitively impaired on the MMSE and dementia more severe on the GDS).
	Outcomes	Caregiver distress related to patient behaviour was a significant predictor of NHP, while behaviour in itself did not predict NHP. Pearson correlations showed that BPSD-related distress was significantly correlated with feelings of competence and depressive symptoms in the caregiver
	Page 22	

Caregiver and family characteristics as predictors of institutionalisation

<table>
<tr>
<td rowspan="4">Trial descriptors</td>
<td>Level of evidence & Strength of study</td>
<td>NHMRC Level II;   Strong (Altman's)</td>
</tr>
<tr>
<td>Study</td>
<td>Gaugler J, Edwards, A., Femia, E., Zarit, S., Stephens, M-A., Townsend, A., et al 2000. Predictors of Institutionalisation of Cognitively Impaired Elders: Family help and the timing of placement. The Journals of Gerontology 55B:247-55 *(USA)*</td>
</tr>
<tr>
<td>Subjects</td>
<td>Primary caregivers with an elderly relative diagnosed with dementia. Subjects were a control group in the Adult Day Care Collaborative Study – the treatment group receiving >8 hours of adult day care a week were excluded from the analysis.
Mean age of caregivers: 59.37;   Mean age of care receivers: 77.96</td>
</tr>
<tr>
<td>Predictor Variables</td>
<td>Sociodemographic characteristics, primary stressors (behaviour problems, ADLs), subjective appraisal of primary stressors (role captivity, role overload, worry & strain), well-being (depression, anger, subjective physical health), paid help (hours of paid service use), family help (assistance with care tasks)</td>
</tr>
<tr>
<td rowspan="4">Quality items</td>
<td>Design, sample & participation</td>
<td>Prospective longitudinal interview study; 304 primary caregivers;   Not described</td>
</tr>
<tr>
<td>Statistical Analysis</td>
<td>Cox proportional hazards model</td>
</tr>
<tr>
<td>Consent, follow-up & attrition</td>
<td>Not described
Interviews at baseline, 3 months and 1 year, with follow-up calls over an additional 2 years
28.6% remained in the study for the entire 3-years. 19.7% died at home during the 3-years and 13.5% were lost to follow-up</td>
</tr>
<tr>
<td>Outcomes</td>
<td>Caregivers were far less likely to institutionalise their relatives when family members provided overnight help (B=-.52, SE=.20, exp(B)=.69, p=0.1) and assisted with activities of daily living care (B=-.37, SE=.13, exp(B)=.69, p=.01)</td>
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<tr>
<td></td>
<td>Page 23</td>
</tr>
</table>

	Level of evidence & Strength of study	NHMRC Level II; Strong (Altman's)
	Study	Argimon J, Limon, E., Vila, J., & Cabezas, C. 2005. Health-related quality-of-life of care-givers as a predictor of nursing-home placement of patients with dementia. Alzheimer Disease and Associated Disorders 19:41-4 *(Spain)*
Trial descriptors	Subjects	Informal carers who were spouses (33%) or adult relatives of people with a clinical diagnosis of AD (52%), vascular dementia (25%) or mixed dementia (23%). Carers were those who took most responsibility for day-to-day decisions and provision of home-care for the patient ≥6 months of the year. Majority of patients had moderate-to-severe dementia (mean MMSE: 13.2) Subjects were recruited form primary health centres.
	Predictor Variables	Sociodemographic data of patient and caregiver, caregiver's QoL as assessed with the Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36), help from family and friends, caregiver's level of satisfaction with support, patient's health status – incontinence, psychotic behaviour, aggressive behaviour, wandering, waking of caregiver at night
Quality items	Design, sample & participation	Prospective longitudinal study; 181 carers; 86%
	Statistical Analysis	General linear regression & multiple logistic regression analysis
	Consent, follow-up & attrition	Obtained from informal carer At 6 and 12 months Not described
	Outcomes	The risk of being admitted to a nursing home was 6 times greater in patients cared for by relatives who rated their health as being 'much worse' compared with the previous year. Initial scores showed the highest size effect in the level of physical function, general health and physical role as defined by the SF-36. After controlling for potential confounding variables, carers of patients who had been placed in a nursing home had lower values in five dimensions of the SF-36, with the highest adjusted difference observed in the level of the physical role.
	Page 23	

	Level of evidence & Strength of study	NHMRC Level II; Strong (Altman's)
	Study	Whitlatch C, Feinberg, L., & Stevens, E. 1999. Predictors of institutionalisation for persons with Alzheimer's Disease and the impact on family caregivers. Journal of Mental Health and Aging 5:275-88 *(USA)*
Trial descriptors	Subjects	Co-resident caregivers of community-dwelling people with a diagnosis of Alzheimer's disease. Participants were part of an ongoing research program of family caregivers seeking information or services from Caregiver Resource Centres. Placement and continuing in-home caregivers mean age: 67.3 and 65.6, 68.7% and 73.6% female; care receivers mean age 76 years
	Predictor Variables	Caregiver and care recipient sociodemographics, care recipient functional status and problem behaviours, caregiver subjective burden, caregiver depression, caregiver subjective physical health, time spent in providing care, caregiver social support, caregiver service utilisation.
Quality items	Design, sample & participation	Longitudinal cohort study; 926 (1st cohort 284, 2nd cohort 642) Not described
	Statistical Analysis	Bivariate correlation analyses, multivariate logistic regression analysis, t-tests
	Consent, follow-up & attrition	Not described Every 6 months over 2 years Not described
	Outcomes	Four factors predicted nursing home placement: care recipient problem behaviours, caregiver depression at baseline, caregiver use in-home and 24-hour out-of-home respite assistance
	Page 23	

Service use and interventions as predictors of institutionalisation

	Level of evidence & Strength of study	NHMRC Level II; Strong (Altman's)
	Study	Brodaty H, McGilchrist, C., Harris, L. & Peters, K. 1993. Time Until Institutionalisation and Death in Patients with Dementia - Role of Caregiver Training and Risk Factors. Archives of Neurology 50:643-50 *(Australia)*
Trial descriptors	Subjects	Patients with mild DSM-III-defined dementia (68 AD, 20 VD, 3 other types) and their carers (91% spouses) Data from participants in a caregiver training program allocated to immediate or 6 month delayed caregiver training, or caregiver respite. Average patient age: 70.2, 49% women; Average caregiver age: 67.3, 53% women
	Predictor Variables	Caregiver training group, dementia severity (duration, MMSE, CDRS, Problem Behaviour Checklist), caregiver stress, neuroticism & socialisation, changes in patient's dementia & caregiver stress during the first 12 months, patient characteristics (age, gender, type of dementia)
Quality items	Design, sample & participation	Prospective longitudinal study; 91 patient-caregiver pairs (33 in immediate caregiver training group, 29 in delayed caregiver training group, 29 in caregiver respite group); 95%
	Statistical Analysis	Survival analysis – Cox proportional hazards model
	Consent, follow-up & attrition	Not described Frequent follow-up in first 12 months and annual follow-up over 5 years. No attrition
	Outcomes	Training of caregivers was significantly associated with delayed NHA.
	Page 24	

	Level of evidence & Strength of study	NHMRC Level II; Strong (Altman's)
	Study	McCann J, Hebert, L., Li, Y., Wolinsky, F., Gilley, D., Aggarwal, N., et al. 2005. The effect of Adult Day Care Services on Time to Nursing Home Placement in Older Adults with Alzheimer's Disease. The Gerontologist 45:754-63 *(USA)*
Trial descriptors	Subjects	Community-dwelling people aged 65+ with a diagnosis of Alzheimer's Disease. 1st cohort - Subjects had used adult day care a minimum of 3 months at baseline and at least 2 days a week during the previous month. 2nd cohort – Subjects had not used adult day care
	Predictor Variables	Use of adult day care services, use of other community-based services, income, sociodemographics of patient and caregiver, patient physical function and disability, hospitalisations, positive and negative behaviours, urinary or bowel incontinence, cognitive impairment, time spent caregiving, interference of caregiving with work, caregiver positive and negative affect and appraisals, caregiver depressive symptoms, caregiver self-reported health, caregiver physical function and disability, social support, spirituality
Quality items	Design, sample & participation	Prospective longitudinal study; 516 (1st cohort 218; 2nd cohort 298); 73.4%/71.8%
	Statistical Analysis	Cox proportional hazards model, Kaplan-Meier survival curves, multivariate logistic regression
	Consent, follow-up & attrition	Signed consent obtained from participant and a family member Interview with the caregiver every 3 months for 48 months Around 15% (77-100% participated at each follow-up)
	Outcomes	Risk of nursing home placement increased significantly with the number of days of adult day care attendance. Participant disability and hospitalizations and caregiver age and burden were independent predictors, but their inclusion in the model did not alter the risk associated with adult day care.
	Page 24	

Descriptions of care pathways and transitions

Diagnosis

Descriptors	Level of evidence & Strength of study	Strong (A. Forbes)
	Study	Knopman D, Donohue, J., & Gutterman, E. 2000. Patterns of Care in the Early Stages of Alzheimer's Disease: Impediments to Timely Diagnosis. Journal of the American Geriatrics Society 48:300-4. *USA*
	Subjects	Caregivers of people with Alzheimer's who were part of a nationwide consumer panel
Quality items	Design, sample & participation	Qualitative; 1,480; Not described
	Consent, follow-up & attrition	Voluntary; Not described; 13%
	Confounders & statistical analysis	Not described; Bivariate
	Outcomes	Mean lag from first symptoms to problem recognition for those diagnosed in the past 12 months, the past 13 to 48 months, and the past 49 months or more was, respectively, 1.20 year, 1.56 years, and 2.25 years. Caregiver relationship was not significantly related to lags. Correct diagnosis of AD was reported by caregivers in 38% of cases at initial consultation.
	Page 27	

Movements between care types

Descriptors	Level of evidence & Strength of study	Strong (A. Forbes)
	Study	Howe A, & Kung, F. 2003. Does assessment make a difference for people with dementia? The effectiveness of the Aged Care Assessment Teams in Australia. International Journal of Geriatric Psychiatry 18:205-10 *Australia*
	Subjects	Clients of Victorian ACAT Assessment teams July-December 1999
Quality items	Design, sample & participation	Administrative data analysis (cross-sectional); 20,939 (5,487 with dementia); Not described
	Consent, follow-up & attrition	Not described
	Confounders & statistical analysis	NA; Descriptive
	Outcomes	Dementia most common primary diagnosis (21%); Less likely to be living alone in the community; More likely to be referred to residential care
	Page 27	

	Level of evidence & Strength of study	NHMRC Level III-2; Moderate (D. Forbes)
	Study	Butler R, Orrell, M. & Bebbington, P. 2002. Pathways through care for patients with dementia: a 3-year follow-up study. Primary Care Psychiatry 8:103-6. *UK*
Descriptors	Subjects	First consecutive 60 day patients and in patients admitted for investigation or management of dementia Mean age: 80
Quality items	Design, sample & participation	Cohort study; 60; Not described
	Consent, follow-up & attrition	Not described; 3 years; No attrition
	Confounders & statistical analysis	Excluded those with recent hospital admission or other condition likely to affect cognition Bivariate
	Outcomes	People with dementia tended to be admitted to long-term institutional care within a short period. Day patients spent a higher proportion of time living in the community.
	Page 28	

	Level of evidence & Strength of study	NHMRC Level III-2; Strong (D. Forbes)
	Study	Moriarty, J and Webb, S. 2000. Part of their lives - Community care for older people with dementia. Bristol: The Policy Press. *UK*
Descriptors	Subjects	People with dementia assessed by social work teams
Quality items	Design, sample & participation	Cohort study; 141; Not described
	Consent, follow-up & attrition	Consent of care giver or recipient 18 months 92% re-interview response rate
	Confounders & statistical analysis	Type of carer
	Outcomes	60% of those living in community went to long-term care; Severity of dementia strongest predictor of entry
	Page 28	

	Level of evidence & Strength of study	NHMRC Level III-2; Strong (D. Forbes)
	Study	Cohen C, Pushkar, D. 1999. Transitions in Care - Lessons learned from a longitudinal study of dementia care. The American Journal of Geriatric Psychiatry 7:139-46. *Canada*
Descriptors	Subjects	Volunteers from various public and service based sources.
Quality items	Design, sample & participation	Cohort study; 196; Not described
	Consent, follow-up & attrition	Voluntary; 18 months; 74% follow up response rate
	Confounders & statistical analysis	Excluded those with absences from home or other condition likely to affect cognition. Bivariate
	Outcomes	39% of the initial sample moved to a long-term care institution by 1 year and 51% by 18 months. From the follow up study, 30% spent sometime in the hospital before moving to a long-term care institution or dying.
	Page 28	

	Level of evidence & Strength of study	NHMRC Level III-2; Strong (D. Forbes)
	Study	Adler G, Kuskowski, M., Mortimer, J. 1995. Respite Use in Dementia Patients. Clinical Gerontologist 15:17-30. *United States*
Descriptors	Subjects	Caregivers of community-dwelling people with dementia receiving care at a memory loss clinic in Minneapolis
Quality items	Design, sample & participation	Cohort study; 58; 88%
	Consent, follow-up & attrition	Consent of caregiver; 12 months; No attrition
	Confounders & statistical analysis	Not described Bivariate
	Outcomes	39% used respite care Carer burden & functional disability scores significantly differed.
	Page 28	

End-of-life care and place of death

<table>
<tr><td rowspan="3"></td><td>Level of evidence & Strength of study</td><td>Strong (A. Forbes)</td></tr>
<tr><td>Study</td><td>Mitchell S, Teno, J., Miller, S. & Mor, V. 2005. A National Study of the Location of Death for Older Persons with Dementia. Journal of the American Geriatrics Society 53:299-305. *United States*</td></tr>
<tr><td rowspan="1">Subjects</td><td>All people aged 65+ who died with dementia as the underlying cause in the United States in 2001</td></tr>
<tr><td style="writing-mode:vertical-rl">Descriptors</td><td>Design, sample & participation</td><td>Administrative data (cross-sectional);   88,523</td></tr>
<tr><td rowspan="4" style="writing-mode:vertical-rl">Quality items</td><td>Consent, follow-up & attrition</td><td>Not described</td></tr>
<tr><td>Confounders & statistical analysis</td><td>Not described;   Multivariate</td></tr>
<tr><td>Outcomes</td><td>Majority of deaths in nursing homes (67%). Affected by state-level factors such as availability of hospital & nursing home beds</td></tr>
<tr><td>Page 29</td><td></td></tr>
</table>

<table>
<tr><td></td><td>Level of evidence & Strength of study</td><td>Moderate (A. Forbes)</td></tr>
<tr><td></td><td>Study</td><td>Collins C, & Ogle, K. 1994. Patterns of Predeath Service Use by Dementia Patients with a Family Caregiver. Journal of the American Geriatrics Society 42:719-22. *United States*</td></tr>
<tr><td style="writing-mode:vertical-rl">Descriptors</td><td>Subjects</td><td>Family caregivers of a person with dementia who died during a study</td></tr>
<tr><td></td><td>Design, sample & participation</td><td>Qualitative;   326;   Not described</td></tr>
<tr><td style="writing-mode:vertical-rl">Quality items</td><td>Consent, follow-up & attrition</td><td>Voluntary;   5 years;   Not described</td></tr>
<tr><td></td><td>Confounders & statistical analysis</td><td>Not described
Descriptive</td></tr>
<tr><td></td><td>Outcomes</td><td>Most died at home (42%), followed by nursing home (32%) and hospital (26%).</td></tr>
<tr><td></td><td>Page 29</td><td></td></tr>
</table>

	Level of evidence & Strength of study	Moderate (A. Forbes)
	Study	Volicer L, Hurley, A., & Blasi, Z. 2003. Characteristics of dementia end-of-life care across care settings. American Journal of Hospice & Palliative Care 20:191-200. *United States*
Descriptors	Subjects	Family caregivers of a person with dementia who died during the previous year
Quality items	Design, sample & participation	Qualitative; 154; Not described
	Consent, follow-up & attrition	Voluntary; Not described; 16%
	Confounders & statistical analysis	Not described Bivariate
	Outcomes	Average 5 weeks at home, 7 in institution and 1 in hospital in last 90 days Provision of home/community services not related to days spent at home Carer burden high with psychiatric symptoms Those with advance directives spent less time in hospital 49% died in nursing home, 22% at home, 21% hospital
	Page 29	

	Level of evidence & Strength of study	Strong (A. Forbes)
	Study	Mitchell S, Teno, J., Intrator, O., Feng, Z., & Mor, V. 2007. Decisions to forgo hospitalization in advanced dementia: a nationwide study. Journal of the American Geriatrics Society 55:432-8. *United States*
Descriptors	Subjects	Nursing home residents with advanced dementia, living in Medicare & Medicaid-certified homes
Quality items	Design, sample & participation	Administrative data (cross-sectional); 91,521; Not described
	Consent, follow-up & attrition	Not described
	Confounders & statistical analysis	Not described Multivariate
	Outcomes	7% had do not hospitalise orders, with high variability by state. Resident characteristics associated with orders were older age, living will, white, durable power of attorney for healthcare, functional dependence
	Page 29	

	Level of evidence & Strength of study	NHMRC Level III-3; Moderate to strong (D. Forbes)
	Study	Lamberg J, Person, C., Kiely, D., & Mitchell, S. 2005. Decisions to hospitalize nursing home residents dying with advanced dementia. Journal of the American Geriatrics Society 53:1396-401. *United States*
Descriptors	Subjects	Residents of a teaching nursing home with advanced dementia who died between Jan 2001 and Dec 2003
Quality items	Design, sample & participation	Cohort study (retrospective); 240; Not described
	Consent, follow-up & attrition	Not described 3 Years Not described
	Confounders & statistical analysis	Not described Bivariate
	Outcomes	83.8% had a do not hospitalise order at time of death Hospital transfers 25% in last 6 months of life
	Page 29	

Interventions to modify care transitions

Caregiver Counselling & Support

	Level of evidence & Strength of study	NHMRC Level II; Strong (D. Forbes)
	Study	Mittelman M, Haley, W., Clay, O. & Roth, D. 2006. Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease. Neurology 67:1592-9. (*USA*)
Trial descriptors	Intervention	Counselling and support intervention for spouse caregivers. Group A: Six sessions of individual and family counselling, support group participation, and continuous availability of ad hoc telephone counselling. Group B: Services routinely provided to patients and their families in the NYU-ADRC, such as resource information and help upon request.
	Subjects	Spouse caregivers of community-dwelling people with a diagnosis of AD; Mean age of caregiver: 71.33 Mean age of patient: 74.31 GDS: 33.5% at 4, 41.4% at 5, 25.1% at 6 or 7
Quality items	Design, sample & participation	RCT; 406 (Group A: *n*=203; Group B: *n*=203); 99%
	Randomisation and blinding	Lottery; Double
	Consent, follow-up & attrition	Informed consent obtained from all participants Follow-up every 4 months for the first year & then every 6 months over 9.5 years 2.5 % for follow-up interview, no attrition at endpoint
	Confounders & statistical analysis	Confounders controlled; Multivariate
	Outcomes	Patients whose spouses received the intervention experienced a 28.3% reduction in the rate of nursing home placement compared with usual care controls (hazard ratio=0.717, p=0.025)
	Page 31	

	Level of evidence & Strength of study	NHMRC Level II; Moderate-Weak (D. Forbes)
Trial descriptors	Study	Hébert R, Girouard D., Leclerc, G., Bravo, G. & Lefrançois, R. 1995. The impact of a support group program for care-givers on the institutionalisation of demented patients. Archives of Gerontology and Geriatrics 20:129-34. *(Canada)*
	Intervention	Support group program for caregivers. Group A: Structured program of 8 weekly sessions of 3hr each. Group B: Referral to the informal monthly meetings of the Alzheimer's Society
	Subjects	Caregivers of community-dwelling DSM-III-R criteria demented patients. Mean age of caregiver: 60.3
Quality items	Design, sample & participation	RCT; 45(Group A: *n*=24; Group B: *n*=21); Not described
	Randomisation and blinding	Randomised, but not described; Not described
	Consent, follow-up & attrition	Signed consent Follow-up at 32-42 months after entry into the study n/a
	Confounders & statistical analysis	Confounders controlled; Multivariate
	Outcomes	At 24 months, the probability of being institutionalised was 0.33 in the study group and 0.45 in the control group for a difference of 0.11 and a 95% CI from -0.21 to +0.43. The survival of the care-giving experience was slightly higher in the study group but this difference was not statistically significant (x^2-1.02; p=0.31)
	Page 31	

Caregiver Training

<table>
<tr><td rowspan="2"></td><td>Level of evidence & Strength of study</td><td>NHMRC Level II;   Strong (D. Forbes)</td></tr>
<tr><td>Study</td><td>Brodaty H, Gresham, M. & Luscombe, G. 1997. The Prince Henry Hospital Dementia Caregivers' Training Program. International Journal of Geriatric Psychiatry 12:183-92. *(Australia)*</td></tr>
<tr><td rowspan="2">Trial descriptors</td><td>Intervention</td><td>Caregiver training
Group A: Immediate caregiver training – 10-day intensive program + patient program
Group B: Wait-list for delayed caregiver training + patient program
Group C: Caregivers received 10 days respite and no training + patient program</td></tr>
<tr><td>Subjects</td><td>People with dementia & their cohabiting carers (93% spouses)
65 with probable AD; 21 with multi-infarct; 3 Pick's disease; 4 other
Mean MMSE: 17; Mean CDRS: 1.1
Mean age of patient: 70.1; Mean age of caregiver: 67.5</td></tr>
<tr><td rowspan="5">Quality items</td><td>Design, sample & participation</td><td>RCT; 96(Group A: *n*=33; Group B: *n*= 32; Group C: *n*= 31); Not described</td></tr>
<tr><td>Randomisation and blinding</td><td>According to whether postal date of application was odd, even or divisible by three;
No blinding, main psychological outcome was self- complete</td></tr>
<tr><td>Consent, follow-up & attrition</td><td>Not described
Teleconferences at decreasing intervals over 12 months after intervention, cohorts of assessments at 2, 6 & 12 months after & annual telephone follow-up for mean 7.7 years
No attrition</td></tr>
<tr><td>Confounders & statistical analysis</td><td>Confounders controlled;   Multivariate</td></tr>
<tr><td>Outcomes</td><td>Caregiver training had a significant effect in delaying nursing home admission (log rank test statistic=4.35, d*f*=1, *p*=0.05) and there was a trend towards training delaying patient death (log rank test statistic=3.03, d*f*=1, *p*=0.08)</td></tr>
<tr><td></td><td>Page 32</td><td></td></tr>
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Multidisciplinary intervention

<table>
<tr><td rowspan="2"></td><td>Level of evidence & Strength of study</td><td>NHMRC Level II;   Moderate (D. Forbes)</td></tr>
<tr><td>Study</td><td>Bellantonio S, Kenny, A., Fortinsky, R., Kleppinger, A., Robison, J., Gruman, C, et al. 2008. Efficacy of a geriatrics team intervention for residents in dementia-specific assisted living facilities: effect on unanticipated transitions. Journal of the American Geriatrics Society DOI: 10.1111/j.1532-5415.2007.01591.x. *(USA)*</td></tr>
<tr><td rowspan="2">Trial descriptors</td><td>Intervention</td><td>Assessments by a multidisciplinary geriatrics team.

Group A: Four systematic, multidisciplinary assessments conducted by a geriatrician or geriatrics advanced practice nurse, a physical therapist, a dietician, and a medical social worker during the first 9 months of their residence in assisted living.
Group B: Usual clinical care consisted of a medical evaluation conducted by the resident's primary care physician 30 days before move-in or within 7 days of admission, per facility policy.</td></tr>
<tr><td>Subjects</td><td>Persons with dementia moving into two dementia-specific assisted living facilities in Connecticut.
MMSE: 14.8 $\pm$ 6.4; Mean age of person with dementia: 82.2(SD6.9)</td></tr>
<tr><td rowspan="5">Quality items</td><td>Design, sample & participation</td><td>Randomized trial;   100(Group A: *n*=48; Group B: *n*=52);   86%</td></tr>
<tr><td>Randomisation and blinding</td><td>Sealed envelopes;   Not described</td></tr>
<tr><td>Consent, follow-up & attrition</td><td>Verbal assent and written informed consent
Residents were observed from the time of enrolment to the end of the study (9 months) or until they permanently moved out of the facility.
Not described</td></tr>
<tr><td>Confounders & statistical analysis</td><td>Confounders controlled;   Multivariate</td></tr>
<tr><td>Outcomes</td><td>The intervention reduced the risk of all transition types, although none reached statistical significance. Specifically, permanent nursing home facility transfer was lowered 11%, ED visits were lowered 12%, hospitalization was lowered 45%, and death was lowered 63%.</td></tr>
<tr><td></td><td>Page 32</td><td></td></tr>
</table>

Early intervention: family counselling and Memory Clinic

<table>
<tr><td rowspan="2"></td><td>Level of evidence & Strength of study</td><td>NHMRC Level III-2; Moderate-Weak (D. Forbes)</td></tr>
<tr><td>Study</td><td>Moniz-Cook E, Agar, S., Gibson, G., Win, T. & Wang, M. 1998. A preliminary study of the effects of early intervention with people with dementia and their families in a memory clinic. Aging & Mental Health 2:199-211. *(UK)*</td></tr>
<tr><td rowspan="2">Trial descriptors</td><td>Intervention</td><td>Family counselling and memory management program.

Group A: Brief home-based intervention of six to 12 hours, ranging from four to 14 weeks and then referred to the usual services of the Elderly Mentally Infirm support team.

Group B: Direct referral to the local EMI support team</td></tr>
<tr><td>Subjects</td><td>Patients ICD-10 diagnosed with probable Alzheimer's Disease, multi-infarct dementia or frontal lobe dementia</td></tr>
<tr><td rowspan="5">Quality items</td><td>Design, sample & participation</td><td>Quasi-experimental;   30(power calculation: 94%patients/75% carers) (Group A: n=15; Group B: n=15);   Not described</td></tr>
<tr><td>Randomisation and blinding</td><td>Sequential block procedure;   Not described</td></tr>
<tr><td>Consent, follow-up & attrition</td><td>Not described
Follow-up every sixth months over 18 months
1/3rd at 6 months, no attrition at 18 months</td></tr>
<tr><td>Confounders & statistical analysis</td><td>Confounders controlled;   Multivariate</td></tr>
<tr><td>Outcomes</td><td>In statistical terms, the experimental group did better on measures of patient memory and carer wellbeing, and more control patients had been placed in permanent residential care at follow-up.</td></tr>
<tr><td></td><td>Page 33</td><td></td></tr>
</table>

Respite care

Level of evidence	NHMRC Level I; Strong (JBI)
Study	Lee H, & Cameron, M. 2004. Respite care for people with dementia and their carers (Review). The Cochrane Collaboration.
Intervention	Respite care
Study design	Systematic Review
Outcomes	No evidence of efficacy of respite care for people with dementia on time to institutionalisation.
	Appraisal
Review Question	Review Question clearly and explicitly stated
Search Strategy	Comprehensive search methods and thorough search of appropriate databases.
Inclusion Criteria	A predefined inclusion criteria was adhered to, but the criteria is not detailed.
Critical Appraisal	Validity of the studies assessed appropriately – review looked at randomization, blinding, patient selection, selection of control group, reporting of results and statistical analysis of the included trials
Data Synthesis	"No pooling of study data was possible because the interventions and outcomes were too dissimilar."
Similarity of studies	
Reporting of findings	Review methods clearly documented, search strategy reported, inclusion criteria not detailed, criteria for appraising studies not detailed.
Conclusions & Recommendations	A summary of findings is provided, specific directives for new research are proposed, and recommendations are supported by the reported data
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Special population groups

People with younger-onset dementia

	Level of evidence & Strength of study	NHMRC Level III-2; Moderate (D. Forbes)
Descriptors	Study	Ferran J, Wilson, K., Doran, M., Ghadiali, E., Johnson, F., Cooper, P., et al 1996. The early onset dementias: a study of clinical characteristics and service use. International Journal of Geriatric Psychiatry 11:863-9. *UK*
	Subjects	First 200 patients referred to and assessed by an early onset dementia service
Quality items	Design, sample & participation	Cohort study; 200; Not described
	Consent, follow-up & attrition	Not described; 3 to 23 months; Not described
	Confounders & statistical analysis	-
	Outcomes	Most common diagnoses were Alzheimer's, vascular dementia, depressive pseudo-dementia. 22% of patients in residential care after a year, compared to 8% initially.
	Page 35	

	Level of evidence & Strength of study	Strong (A. Forbes)
Descriptors	Study	Luscombe G, Brodaty, H., & Freeth, S. 1998. Younger people with dementia: diagnostic issues, effects on carers and use of services. International Journal of Geriatric Psychiatry 13:323-30. *Australia*
	Subjects	Convenience sample from medical practitioners and support groups.
Quality items	Design, sample & participation	Cross-sectional; 102: Not described
	Consent, follow-up & attrition	Voluntary; NA; Not described
	Confounders & statistical analysis	Multivariate
	Outcomes	Younger people with dementia, and their carers, face difficulties in obtaining a diagnosis. Carers also experience psychological problems, financial worries, loss of employment and family conflict, and their children are affected. Most carers used services, but some dissatisfaction existed.
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	Level of evidence & Strength of study	Moderate (A. Forbes)
Descriptors	Study	Delany N, & Rosenvinge, H. 1995. Presenile dementia: sufferers, carers and services. International Journal of Geriatric Psychiatry 10:597-601. *UK*
	Subjects	People aged under 65 with dementia in Southampton Health District.
Quality items	Design, sample & participation	Qualitative interviews; 27
	Consent, follow-up & attrition	Consent obtained; NA; No attrition
	Confounders & statistical analysis	NA
	Outcomes	People with PSD had a high degree of cognitive, self-care and behavioral disability. Carers showed stress. Most received support, community nurses most common form. Issues with unmet need – no specific provision for more physically active
	Page 35	

References

Adler G, Kuskowski, M., Mortimer, J. 1995. Respite Use in Dementia Patients. Clinical Gerontologist 15:17-30.

ABS (Australian Bureau of Statistics) 2007. Migration Australia 2005–06. ABS cat. no. 3412.0. Canberra: ABS.

ACAP NDR 2006. Aged Care Assessment Program National Data Repository Minimum Data Set Report Annual Report 2004 – 2005. National Data Repository for the Aged Care Assessment Program.

AIHW (Australian Institute of Health and Welfare) 2003. Australia's Welfare. Canberra: AIHW.

AIHW 2004a. Community Aged Care Packages census 2002. Canberra: AIHW.

AIHW 2004b. Extended aged care at home census 2002: a report of the May 2002 Census prepared for the Australian Government Department of Health and Ageing. Canberra: AIHW.

AIHW 2007a. Aged care packages in the community 2005-06: a statistical overview. Canberra: AIHW.

AIHW 2007b. Dementia in Australia: national data analysis and development. Canberra: AIHW.

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