Caring for People with Dementia: Linking Research, Policy and Practice

Professor Helen Bartlett
Australasian Centre on Ageing
The University of Queensland

Presentation to the East Dementia Training Study Centre, 25 October 2006
Overview

- Demographics and economics
- Policy context - national framework and priorities
- The evidence and translation into practice
- Linking research, policy and practice
- Partnership working
Figure 1  From pyramid to coffin
Changing age structure of the Australian population, 1925-2045

Source: Productivity Commission 2005
Demographic shifts in the Australian population

Source: ABS, Population Projections 2004-2101 (Cat 3222.0)
Prevalence rates in Australia: all dementias (cases per 1,000 population)

Jorm et al. 1987
Incidence Rates in Australia: all Dementias (cases per 1,000 person years)

Jorm & Jolley, 1998
## Economic Costs of Dementia

<table>
<thead>
<tr>
<th>Category</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>$6.6 billion</td>
</tr>
<tr>
<td>Direct health costs</td>
<td>$3.2 billion</td>
</tr>
<tr>
<td>Residential care</td>
<td>$2.9 billion</td>
</tr>
<tr>
<td>Home &amp; community care</td>
<td>$175 million</td>
</tr>
<tr>
<td>Real indirect costs</td>
<td>$1.75 billion</td>
</tr>
<tr>
<td>Mainly carer replacement</td>
<td></td>
</tr>
<tr>
<td>Transfer costs</td>
<td>$968 million</td>
</tr>
<tr>
<td>Including tax foregone,</td>
<td></td>
</tr>
<tr>
<td>carer payments, welfare</td>
<td></td>
</tr>
<tr>
<td>payments</td>
<td></td>
</tr>
</tbody>
</table>

Access Economics Report for Alzheimer’s Australia, March 2003
Challenges to the biomedical approach to dementia

- Care for the carer approaches
- Person-centred care
- Relationship centred care
- Whole system approach:
  - Biological system
  - Psychological system
  - Family system
  - Health and social care system
  - Cultural system
  - Socio-political system

Trevor Adams 2005
Dementia is a national health priority

- Helping Australians with Dementia and their Carers – Making Dementia a National health Priority $320.6m over 5 years from federal government
- Minister’s Dementia Health Priority Taskforce
- Dementia plans at state level to guide existing and future dementia support programs
State and Territory policy Frameworks

- NSW - Future Directions for Dementia Care and Support 2001-2006
- WA Dementia Action Plan 2003-2006
- Victoria – Dementia Framework for Victoria – 2005 and Beyond
- SA – draft dementia framework
- Queensland – one of seven priority areas in Directions for Aged Care 2004-2011
- Tasmania Dementia Care Plan 2000 and Beyond
Dementia – a National Health Priority

Initiatives:
- Mapping international research evidence on dementia
- Training and education centres
- Collaborative research centres
- Research project funding
- Supporting primary health sector in diagnosing and managing dementia
- Supporting prevention and encouraging early intervention for PWD and carers
National Framework for Action on Dementia

- **AIM:** to improve the quality of life of people living with dementia, their families and carers; to develop a shared vision for action on dementia

- **OUTCOMES:** community awareness, social participation; better care; involvement of carers/family; access to information and education; improved access to treatment, care and support; promotion of healthy lifestyles; better management of behavioural issues; quality standards for dementia care; cross-sectoral cooperation; improved transition between services; better skilled workforce
National Framework principles

- People with dementia are valued and respected
- Rights and interests will be protected
- Focus is on what the person can do
- People with dementia are central to care choices
- Person-centred care is most responsive care strategy
- All people with dementia should receive appropriate services
- Coordination and flexibility of care is vital
- Prevention and early intervention important for healthy ageing
- Well trained and supported health professional and advocates deliver best care
- Consultation with carers, health professionals and advocates essential
- Whole-of community approach ensures better care
Key priority areas for action

1. Research
2. Information and education: promotion of healthy lifestyles, information and education for PWD, families and carers; protection of rights and interests
3. Access and equity: CALD, ATSIC, rural/remote, younger people, homeless
4. Quality, integration and continuum of care: primary care, community care, respite care, acute care, residential care, palliative care, behavioural issues
5. Workforce and training
Research

- Focus is on cause and cure
- Need more research on risk reduction, prevention, support, care and education for people with dementia and their carers
- Need broader better coordinated research funding base
- Better dissemination
- New funding streams, support for new researchers
Systematic reviews – care and support for people with dementia and their carers

- Disclosure of diagnosis - 2004
- Dementia care mapping
- Palliative care in dementia - 2005
- Strategies to assist eating - 2006
- Gait disturbance - 2004
- Oral hygiene - 2005
- Driving and dementia – 2000, 2005
- Housing provision and environmental design - 2000, 2005
Examples of evidence that can be acted upon

- Palliative care model is supported in dementia
- No evidence to support the use of enteral feeding tubes in preventing malnutrition, prolonging survival or reducing risk of pressure sores
- Well-planned and executed activities are necessary for any programs in preventing and minimising BPSD.
The experiences of older people with dementia

Individualised quality care central to policy goals in community and aged care in Australia, including older people with dementia

*Alzheimers Australia* (2003)

Negative impact of institutional life on autonomy of older people has been well documented, but less attention to the experiences of older people with dementia

*e.g. Bartlett 1993*
Decision making and empowerment of older people with dementia - Oxford study

Helen Bartlett and Wendy Martin
‘...a false impression, I thought I was just coming in for a cure, but when it came to it they all had their bit to say ... people I had never seen before. I suppose it was fairly done but I didn’t think it was. I know the doctor was on my side because he said he wanted to thank me for being so brave about it all. But I wasn’t brave, but I just didn’t want to say anything because I didn’t know what was going to happen ... didn’t expect to see a circle of people judging me’

Bartlett & Martin (2003) - Christine: Case review meeting in hospital
‘I approached the hospice people here and I thought I might be able to do something in their shop, you know sorting and that sort of thing, I went and saw them, and I am waiting to hear and I think I quite probably would be able to do a two hour spin or something like that and I could do it say three times a week. I like to be – to have a change of scene and there would be other people working there. So I hope it comes off.’

Bartlett and Martin (submitted for publication)
Oxford study: Maggie - Residential Aged Care Home
Impact of exclusion/lack of choice on older person with dementia

Imprisonment
Stuck inside all day
Forgotten about
Trap you in
Isolation
Not involved at all
Opinion never counts
Given a false impression
Not fairly done

People judging me
Feeling stupid
Being in trouble
Obey the rules
Low
Depressed
Nervous meeting people

Bartlett and Martin, Oxford study
Key findings

- Tensions exist between the ‘ideal’ and ‘reality’ in everyday practice.
- Older people with dementia are routinely excluded from decision-making by family, carers and professional staff.
- This exclusion has negative and disempowering consequences for the individuals concerned.
- The actions of community and care staff are influenced by duty of care and risk management.
- Better understanding is needed of the barriers to involving people with dementia in decisions that concern their lives.

Bartlett and Martin, Oxford study (submitted for publication)
Linking the policy/ research/ practice interface

- Different worlds – how to increase understanding across boundaries?
- Different agendas
- Where to find the evidence?
- What can be implemented in practice?
- Working in partnership with researchers
- Influencing the policy agenda
- Responding to consultations
- Time and timing
Partners come to the table with very different expectations of what the partnership is for. Rarely are these different expectations laid on the table and negotiated. They may revolve around the aims of the partnership: the level at which it will have influence...the powers of different partners (Hastings et al, 1996)

Purpose of partnerships

- Capacity building and value adding
- Integrated approach to project
- Raising matching funding
- Influence policy or practice
- Improved access to samples/data
- Professional development
- Market positioning
Potential partners

Researcher, industry, government or community initiated

- Government – federal, state, local level (e.g. housing, health, transport, communities)
- Community organisations/NGOs
- Industry - aged care providers, retirement villages, property developers, finance etc
- Other Universities/research centres
Challenges and issues

- Time and timing e.g. budget cycles
- Multiple partners vs sole partner
- Point of contact
- Developing trust/networks
- Competing agendas/priorities
- Different paradigms/cultures
- Power issues
- Ethical and philosophical issues
- Dissemination – IP issues
Lessons for partnership working

- Clarify purpose
- Think about the desired partnership model
- Identify advantages and threats
- Establish collaborative capacity
- Assess other options for achieving goal
- Establish communication strategy
- Be prepared to build relationships
- Clarify roles and responsibilities
THANK YOU!

For further information:
www.uq.edu.au/aca
h.bartlett@uq.edu.au