Dementia: policy and practice challenges, economic responses

Martin Knapp

Personal Social Services Research Unit
London School of Economics and Political Science
Structure of my talk

A. The individual with dementia
B. New realities?
C. New responses?
D. New scenarios?
E. New directions?
An individual with dementia
An older person with dementia ...
... supported by family and friends ...
... with support from paid care staff ...
... in their care setting / facility ...
... managed by a local provider ...
... and located within a national body, ...
... whose services are commissioned ...
... within various regulatory, advocacy and policy contexts
But two enormous, exogenous pressures influence what happens.
New realities

Big impacts on overall disability / ill-health:

Growth in disability-adjusted life years (DALYs) due to dementia, between 1990 and 2010, in the UK = 76%; higher than almost every other cause.

And big consequences for expenditure:

- for healthcare and long-term care systems;
- for individuals with dementia and their families.
Public spending on long-term care as % of GDP: 2010 and projected to 2060

Spending on dementia care will be proportionately much higher by 2060

European Union, Ageing Report 2012
Global economic recession
Recession hurts

Unemployment
Poverty
Lower salaries
Reduced income
More personal debt
Mortgage failures
Recession hurts

Unemployment
Poverty
Lower salaries
Reduced income
More personal debt
Mortgage failures

Lower wellbeing
More mental health needs
Lower resilience
Slower recovery
Higher suicide rate
Alcohol misuse (?)
Hardened attitudes
Greater inequalities

Worse physical health
More social isolation
Recession, unemployment and stigma

Recession widened the gap in unemployment rates between individuals with and without MH problems ... especially for males and people with low education levels.

Evans-Lacko et al. *PLOS ONE* 2013
Stigmatising attitudes

Public attitudes played a part in this increase:

Eurobarometer 2006 asked the general public questions about ‘people with psychological or emotional health problems’. Do you agree that:

1. … “they constitute a danger to others”
2. … “they are unpredictable”
3. … “they have themselves to blame”
4. … “they never recover”.

We converted these to a single overall measure of stigmatizing beliefs concerning mental illness.
The disadvantage facing people with mental health problems is greater in countries with higher levels of stigmatizing attitudes towards mental illness.

Those stigmatizing attitudes probably carry over to people with dementia and their family carers.

Evans-Lacko et al. *PLOS ONE* 2013
Recession hurts

But does austerity kill?

Many national governments have responded to recession with ‘austerity policies’ – big cuts in government spending; big increases in taxes.

New responses
What works … in ways that key decision-makers consider affordable?

- Prevention
- Screening
- Carer support
- Community capacity
- Staff skills training
- Treatments
- Telehealth / telecare
- Self-directed support
- Re-ablement home care

This ought to be a winner – but not enough economics evidence yet.

Early detection ought to be another winner – but again no strong economics evidence.

Both areas urgently need research attention.

Knapp et al. *IJGP* 2012 – reviews some of the above.
What works ... in ways that key decision-makers consider affordable?

- Prevention
- Screening
- **Carer support**
- Community capacity
- Staff skills training
- Treatments
- Telehealth / telecare
- Self-directed support
- Re-ablement home care

Family & other unpaid carers are the **frontline providers**

Cooper et al. *Int Psychoger* 2007; Mahoney et al. *AJGP* 2005
The cost of dementia in England 2015 - per person per year (£, at 2012 prices)

High costs; major impacts on quality of life

Knapp et al. *Scenarios of Dementia Care* 2014
What works ... in ways that key decision-makers consider affordable?

- Prevention
- Screening
- **Carer support**
- Community capacity
- Staff skills training
- Treatments
- Telehealth / telecare
- Self-directed support
- Re-ablement home care

Family & other unpaid carers are the **frontline providers**

Caring – rewarding and fulfilling, but emotionally & physically draining.

**Depression & anxiety**

highly prevalent.

**Poor carer wellbeing**

linked to: care breakdown; care home admission; elder abuse

Cooper et al. *Int Psychoger* 2007; Mahoney et al. *AJGP* 2005
START: encouraging new evidence of a carer support intervention

- Individual therapy programme (8 sessions with psychology graduate + manual)
- Techniques to understand/manage behaviours of person they support, change unhelpful thoughts, promote acceptance, improve communication, plan for future, relax, engagement.

Costs and outcomes (8-month & 24-month follow-up)

- More effective than standard care and no more costly (from NHS and societal perspectives) - at 8m and 24m
- Cost-effective by reference to carer and patient outcomes
- Reduces care home admission rate for patients

SADD: intriguing evidence on carer collateral benefits?

• SADD - a randomised trial of two different antidepressants for treating people with dementia who have co-morbid depression.

• Antidepressants (mirtazapine and sertaline) not different from each other or placebo in symptom alleviation ...

• ... But mirtazapine was more cost-effective because of carer effects - lower carer costs

• Ethics of treatment?
What works ... in ways that key decision-makers consider affordable?

- Prevention
- Screening
- Carer support
- **Community capacity**
- Staff skills training
- Treatments
- Telehealth / telecare
- Self-directed support
- Re-ablement home care

Can communities shoulder more of the responsibility? Maybe.

Befriending, time-banks etc. can be cost-effective to engage community involvement.

Knapp et al. *Comm Development J* 2013
What works ... in ways that key decision-makers consider affordable?

- Prevention
- Screening
- Carer support
- Community capacity
- **Staff skills training**
- Treatments
- Telehealth / telecare
- Self-directed support
- Re-ablement home care

Dementia care – not a high-status occupation.

Low wages; high turnover.

Cognitive stimulation therapy works and it is cost-effective ...

... but not widely commissioned or provided (in UK).

What works ... in ways that key decision-makers consider affordable?

- Prevention
- Screening
- Carer support
- Community capacity
- Staff skills training
- **Treatments**
- Telehealth / telecare
- Self-directed support
- Re-ablement home care

**NICE Technology Appraisals**

- Lots of evidence now on medications and when they are likely to be cost-effective.
- Some evidence on CBT effectiveness for co-morbid depression and anxiety, but no economics evidence.
- But little evidence on treatment when there are co-morbid physical health problems.
What works ... in ways that key decision-makers consider affordable?

- Prevention
- Screening
- Carer support
- Community capacity
- Staff skills training
- Treatments
- **Telehealth / telecare**
- Self-directed support
- Re-ablement home care

ICT-based monitoring or treatment really *ought* to be one way forward ...

... especially to support family carers.

But the evidence from robust trials is equivocal.

Needs technological development and better targeting.

What works ... in ways that key decision-makers consider affordable?

- Prevention
- Screening
- Carer support
- Community capacity
- Staff skills training
- Treatments
- Telehealth / telecare
- **Self-directed support**
- Re-ablement home care

Greater choice and control for people with dementia and their carers.

Personal budgets work!

Carer-held budgets especially successful.

BUT is there risk of financial abuse?

Glendinning et al *IBSEN report* 2007; Manthorpe & Samsi *BJSW* 2013
New scenarios
Question: What is the economic case for new dementia care scenarios?

- **Current care scenario**: Care and support as currently provided in England (*Scenario A*).
- **No-diagnosis scenario**: Dementia is not diagnosed or treated (*B*).
- **Diagnosis-only scenario**: Dementia is diagnosed but not treated (*C*).
- **Improved care scenario**: Dementia is diagnosed, followed by evidence-based, ‘improved’ care and support (*D*).
- **Disease-modifying scenario**: Disease-modifying treatments are available to slow progression or delay (*E*).
Methods for our models

1. Prevalent dementia population by age & gender
2. Severity of cognitive impairment
3. Place of residence: community or care home
4. Type of care (formal, unpaid, both, neither)
5. Cost & quality of life data from trials (n = 1400)
6. Estimate & compare scenario costs and QALYs
The cost of dementia in England today - per person per year (£) (Scenario A)

High costs; major impacts on quality of life

Knapp et al. *Scenarios of Dementia Care* 2014
Is there an economic case for alternative dementia care scenarios?

- **Current care scenario**: Care and support as currently provided in England (*Scenario A*).

- The two ‘worse’ scenarios - no diagnosis (B), no post-diagnostic support (C) - both increase costs and worsen quality of life.

- **Improved care scenario**: Dementia is diagnosed, followed by evidence-based, ‘improved’ care and support.

- **Disease-modifying scenario**: Disease-modifying treatments are available to slow progression or delay.

So what about the ‘better’ scenarios?

Knapp et al. *Scenarios of Dementia Care* 2014
Improving dementia care: modest effects on costs (£ millions, 2012 prices, UK)

Quality of life improvements
- important but not huge

But we have not examined:
- distributional impacts
- better targeting

Knapp et al. Scenarios of Dementia Care 2014
Disease-modification: effects on costs (£ millions, 2012 prices, UK)

What about the treatment costs?

Knapp et al. *Scenarios of Dementia Care* 2014

Highest cost ... but also highest QALY gain
Disease-modification: factoring in the costs of the new treatments

Treatment costs will have a huge influence, depending on price and number treated

These treatment costs are purely hypothetical

Knapp et al. *Scenarios of Dementia Care* 2014
MODERM: a projections study (2014-18)

Research questions

• How many people with dementia between now and 2040?
• What will be the costs and outcomes of their treatment, care and support under present arrangements?
• How do these costs and outcomes vary with individual characteristics and circumstances?
• How could costs and cost-effectiveness change if better interventions were more widely available and accessed?

Methods - data-heavy modelling:

• Micro-simulation, macro-simulation, care pathways
New directions
Are we facing the ‘perfect storm’?

- Demography is rapidly pushing up prevalence ...
- ... and creating smaller families ...
- ... which are geographically more dispersed.
- Communities may be less supportive(?)
- Hence huge (and long-term?) economic pressures on individuals and governments
- Hardening attitudes towards mental illness
- ... While decision-makers retreat into their silos, in pursuit of immediate cashable savings.
Dementia is already costly ... and much of that impact falls to family and other unpaid carers.

Dementia will get much more costly ... everywhere, soon.

Known evidence-based ‘improvements’ will help ... to achieve quality of life gains, but costs won’t fall much.

Some of those economic gains rely heavily on carers ... can they cope with greater responsibilities?

Disease-modifying treatments are needed ... to delay onset / slow progression ... to cut costs and improve lives.

We need a two-pronged approach ... improve today’s care and find tomorrow’s cure (treatment breakthroughs).
Further details

Thank you.

m.knapp@lse.ac.uk