Making strides in dementia treatment, care, support and awareness

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Structure of my talk

A. New challenges?
B. New responses?
C. New scenarios?
D. New directions?
New challenges?
### Huge changes since 1974

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<thead>
<tr>
<th></th>
<th>1974</th>
<th>2014</th>
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<tr>
<td>Number of people with dementia UK</td>
<td>c. 350,000</td>
<td>c. 816,000</td>
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<tr>
<td></td>
<td>in 1974</td>
<td>in 2014</td>
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<tr>
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<th>1970</th>
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<tr>
<td>Percentage of care home residents UK</td>
<td>11% ‘severely confused’</td>
<td>17% ‘severe dementia’</td>
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<td>in 1970</td>
<td>in 2014</td>
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<tr>
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<th>1975</th>
<th>75,646</th>
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<tr>
<td>Papers in Medline with keyword ‘Alzheimer’</td>
<td>42 in 1975</td>
<td>yesterday</td>
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Years lived with disability by cause and age, UK in 2010

Mental & behavioural disorders

Neurological disorders

Dementia makes a big contribution to total disability burden

76% growth in DALYs between 1990 and 2010

Murray et al, Lancet 2013
Huge challenges for my granddaughter - and for each of us

- 2 out of 5 girls born today will reach age 100 (ONS projections), and 72% of women aged 95+ have dementia (Dementia UK 2014) ...
- ... So (if prevalence rates stay the same), there is c.30% chance my new granddaughter will be living with dementia in 2114

- Dementia is not rare: almost all of us have a relative with dementia
- There is no cure. Nor any simple care solution.
- Responsibilities straddle health, social care, housing, social welfare
- ... but unpaid carers are the bedrock of dementia care
- Outcomes are hard to define and measure, particularly self-report
- And dementia costs a huge amount.
And total prevalence will continue to grow.

The growth in numbers of people with dementia is an epidemic, an emergency in slow motion, and a demographic time-bomb. This will have significant consequences for expenditure.

Although the CFAS II study and some others suggest that the prevalence rate might be slowing, this will have big consequences for expenditure:

- for healthcare and long-term care systems;
- for individuals with dementia and their families.
MODEM: a projections study (2014-18)

- 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

**Team:** Martin Knapp, Mauricio Avendano, Sally-Marie Bamford, Sube Banerjee, Ann Bowling, Adelina Comas, Margaret Dangoor, Josie Dixon, Emily Grundy, Bo Hu, Carol Jagger, Maria Karagiannidou, Derek King, Daniel Lombard, David McDaid, Jitka Pikhartova, Amritpal Rehill, Raphael Wittenberg,
New responses?
New responses: what works?

- Prevention
- Screening
- Carer support
- Staff skills training
- Treatments
- Home-based care
- Case management
- Attitudes

What is the evidence on ‘new responses’ in these areas?

Evidence here drawn from recent/imminent studies:

- Knapp, Black, Dixon et al. *Improvements in Dementia Care and Support since 2009*, forthcoming (PSSRU/PIRU/SSCR).
- Many recent trials & other studies (see later references)
Prevention

Population-attributable risk (PAR) of Alzheimer’s disease:

- Diabetes
- Midlife hypertension
- Midlife obesity
- Physical inactivity
- Depression
- Smoking
- Low educational attainment

Combined worldwide PAR, adjusting for interdependence, was 28%.

“Around a third of AD cases worldwide might be attributable to potentially modifiable risk factors”

Norton et al Lancet Neurology 2014
Individuals with dementia and their carers tried a tailored walking regimen (20-30 mins, at least 5 times per week). RCT, n= 131 dyads. Mixed findings:

- No improvement in behavioural or psychological symptoms of dementia
- But reduction in carer burden (Zarit)
- Probably cost-effective from health-social care and societal perspectives

Lowery et al *IJGP* 2014; Rehill et al, paper in preparation
Screening

Big debate about whether population screening for dementia is sensible.

- Raise unrealistic expectations among individuals about what can be done?
- Divert attention and resources away from those who are already diagnosed?
- **But** don’t individuals have the right to know and to plan?
- And isn’t there now promising evidence on interventions?

A one-off dementia screen at age 75 followed by post-diagnostic support (*model*):

- 2152 of 3514 people diagnosed would never have received a diagnosis
- Screening can be cost-effective, especially as better care and treatments become available

Dixon et al *IJGP* 2014
‘Research shows that carers of people with dementia experience greater strain and distress than carers of other older people. We want to see better support for carers’ (Prime Minister’s Challenge on Dementia, 2012)

- Unpaid carers - the unsung heroes of dementia care

- High out-of-pocket and imputed costs → → →
Estimates by PSSRU for *Dementia UK 2014* report to be launched by the Alzheimer’s Society 2014
‘Research shows that carers of people with dementia experience greater strain and distress than carers of other older people. We want to see better support for carers’ (Prime Minister’s Challenge on Dementia, 2012)

- Unpaid carers - the unsung heroes of dementia care
- High out-of-pocket and imputed costs ...
- ... and these costs will grow as prevalence increases, and as health and social care budgets get stretched.
- Many carers experience a lot of stress
- So, what works?
START: a manual-based coping strategy

Individual programme (8 sessions over 8-14 weeks, delivered by psychology graduates + manual); carers given techniques to:

- understand behaviours of person they care for
- manage behaviour
- change unhelpful thoughts
- promote acceptance
- improve communication
- plan for the future
- relax
- engage in meaningful, enjoyable activities.

Pragmatic, multicentre RCT - START vs usual support.

n=260 family carers of people with dementia, North London area.

Analyses 8 & 24 months after end of intervention

Carers with usual support were 4 times more likely to have clinically significant depression than carers with the START intervention; HADS-total = 2.10 (95% CI 0.51 to 3.75).

Small incremental QALY gain for START group; mean 0.042 (95% CI 0.015 to 0.071).

At 24m - but awaiting review - these same effects were maintained. Plus QOL gains for people with dementia.
Carers getting START had slightly but not significantly higher costs (£252; 95% CI -28 to +565), adjusting for baseline.

Mean ICERs: £118 per unit change on HADS-total; and £6000 per QALY ... both measuring carer costs only.

At 24m - but awaiting review - START continued to be cost-effective, now looking at both carer and patient costs & outcomes.

Knapp et al BMJ 2013; Livingston et al submitted
Staff skills, training & turnover

The care workforce needs to be skilled in supporting people with dementia. But in England ...

- <1% of workers at establishments providing services to people with dementia have formal dementia qualifications
- c.33% have received dementia training (short courses not leading to qualifications)
- Compared to other parts of the social care workforce, the dementia workforce is more likely to be female, part-time, employed by agencies, and less qualified.
- Staff turnover for care workers working with older people with dementia is 31% annually.

HSCIC collections; Hussein & Manthorpe Ageing & Mental Health 2012
CST is a group intervention in care homes & day centres for people with mild-to-moderate dementia: themed activities to stimulate cognitive function. Effective and cost-effective if delivered bi-weekly over 7 weeks. Maintenance CST (weekly for 24 weeks) improves QOL; in combination with ACHEI meds it improves cognition. Also cost-effective over 24 weeks, especially with ACHEIs.

Woods et al Cochrane 2012; Orrell et al BJPsychiatry 2014; D’Amico et al, submitted
Other treatments

Comorbid dementia & depression:
- Sertraline & mirtazapine equally effective, but ...
- Mirtazapine more cost-effective because of effect on carer time

Comorbid dementia & anxiety:
- CBT is effective & cost-effective

People with dementia with fractured hip:
- Length of inpatient 43 vs 26 days

NICE-SCIE Guideline (2007, being updated 2014?) reviews evidence across the full range of treatment and care options.

Home-based care

Surprisingly little evidence on what works in home care.

Patterns of home support provided to people with dementia and their carers - study led by David Challis (reporting 2015)


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Surprisingly little evidence on what works in home care.

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Telecare is widely seen as a long-term solution. However, today’s evidence is not encouraging:

- WSD trial → telecare for (all) older people offers ‘small relative benefits’ over usual care, but is not cost-effective (cost per QALY = £297,000).

So, are robots the future?

Case management

Evidence on case management is also mixed. Cochrane Review (Siobhan Reilly et al) due to be published soon.

Reilly et al Cochrane Review, forthcoming
Attitudes and awareness

Policy aims in England:
- to build **dementia-friendly communities**
- to raise **public awareness**

Achievements:
- Rapid growth in numbers of individuals trained in **dementia awareness**; plus schools, shops, banks, transport orgs, ...
- Have **attitudes** changed? Yes but only modest improvement
- Similar evidence from other countries (e.g. Germany)
- World Alzheimer Report 2012 - still **widespread stigma** and social exclusion of people with dementia

New scenarios?
**Question:** What is the economic case for new dementia care scenarios?

A. **Current care scenario:** Care and support as currently provided in England [as illustrated earlier]

B. **No-diagnosis scenario:** Dementia is not diagnosed or treated.

C. **Diagnosis-only scenario:** Dementia is diagnosed but not treated.

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

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

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

These analyses have limitations; we have not examined:
- changes ‘within cells’
- distributional impacts
- better targeting
- stacking of impacts

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

Knapp et al. Scenarios of Dementia Care 2014

Highest cost ... but also highest QALY gain
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
New directions?
World Dementia Council: priorities (1)

- **Finance** - propose new incentives and financial structures that drive new investment by lowering risk and increasing reward.

- **Research collaboration** - develop incentives for new research partnerships between government, academia and industry, with an emphasis on entrepreneurial effort and a patient-focused research approach.

- **Regulation and trials** - seek to harmonise the regulatory pathway and find other ways to make it more flexible and efficient, in order to accelerate drug development.
World Dementia Council: priorities (2)

- **Sharing knowledge** - support global efforts to build inventories of research activity & databases. Address disincentives for collaboration in both industry and academia. Encourage data-sharing. Establish networks for synthesising and disseminating knowledge.

- **Health and care** - identify and disseminate innovative practice in dementia care. Make these and existing practices available to people with dementia, families & carers globally.

- **Awareness** - raise public awareness re. economic and social challenges and the urgent need for a radical global response. Change policies and practice to increase diagnosis rates and improve treatment and care.
So ... the future should be two-pronged

- Dementia has become a major, world-wide focus for long-term care and health care.
- ... with many associated challenges
- But new and encouraging evidence is emerging of effective and cost-effective care and treatment.
- However, doubts about long-term affordability of currently known interventions.
- And so the search for new, better care and treatment interventions must continue apace.
- The future needs to be two-pronged: cure and care.
Thank you

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