

LSE

PSSRU

How can we Respond to the Global Challenge of Dementia

Raphael Wittenberg

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

ACKNOWLEDGEMENTS AND DISCLAIMER

This presentation covers research conducted by colleagues at the Personal Social Services Research Unit at LSE and other research units

Some of it was supported by NHS England, the National Institute for Health Research (NIHR), the Economic and Social Research Council (ESRC), the Alzheimer's Society and Alzheimer's Research UK

All views expressed are those of the presenter, and are not necessarily those of the NHSE, NIHR, ESRC, Alzheimer's Society and ARUK

CONTENT OF PRESENTATION

- Prevalence of dementia
- Cost of dementia
- Policy priorities
- Prevention
- Care
- Support for carers
- Potential new treatments

DEMENTIA

- Dementia describes a set of symptoms
- The commonest form is Alzheimer's Disease
- In AD abnormal proteins cause chemical connections between brain cells to be lost
- The process starts long before symptoms
- Dementia is progressive and irreversible
- It may affect memory, concentration, language, orientation, and mood

DEMENTIA PREVALENCE AND COSTS

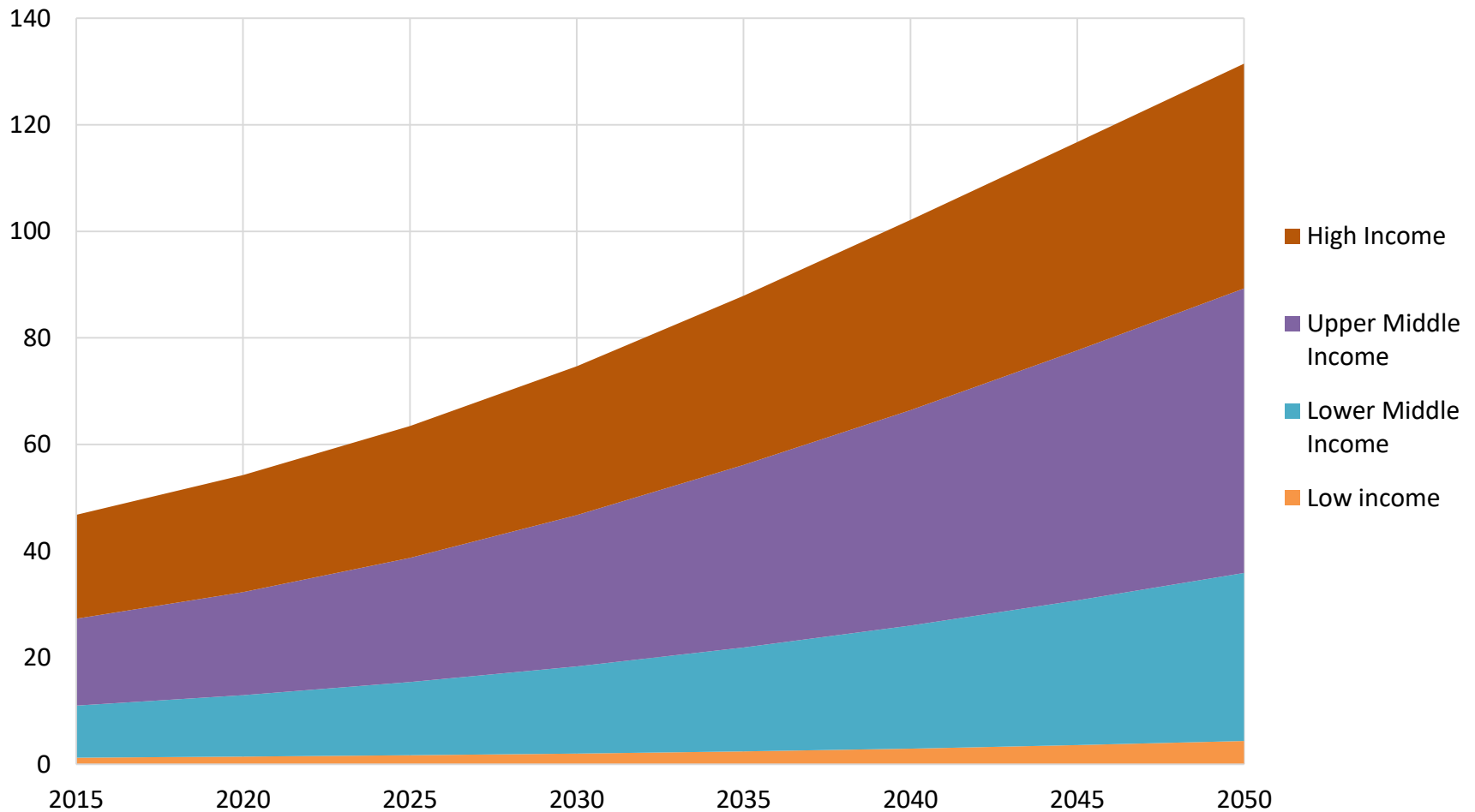
- Around 50 million people live with dementia worldwide, more than the population of Spain
- This number is projected to increase to more than 131 million by 2050, as populations age
- The total estimated worldwide cost of dementia is around one trillion US dollars, around 1.1% of global GDP
- The huge majority of people with dementia have not received a diagnosis, and so are unable to access care
- Even when it is diagnosed, the care provided is too often fragmented, uncoordinated, and unresponsive to the needs of people living with dementia, their carers and families

Sources: Prince et al (2016) World Alzheimer's Report 2016, ADI

WHO (2017) Global action plan on the public health response to dementia 2017-2025

PROJECTED GROWTH IN PREVALENCE

Numbers of people living with dementia (millions)



GLOBAL MAP OF DEMENTIA



This map shows the estimated number of people living with dementia in each world region in 2015.

PREVALENCE AND INCIDENCE

- 850,000 people live with dementia in the UK
- Some 800,000 are aged 65 or over
- Prevalence rate doubles every five years of age from age 65
- Prevalence in old age 6.6%, down by over 20% over two decades
- Incidence around 200,000 new cases annually
- Diagnosis rate around 70% of cases

COSTS OF CARE IN THE UK

- The total annual UK cost £26.3 billion in 2013 (at 2012/3 prices)
- £4.3 billion health, £10.3 billion social care (public and private combined), £11.6 billion unpaid care and £0.1 billion other costs
- Average annual cost of £32,250 per person
- The lifetime risk of dementia from age 65 around 30% and the lifetime cost £200,000

TREATMENT AND CARE

- Alzheimer's disease is not currently treatable
- Four drugs licenced for Alzheimer's Disease (AD) in Europe, but they are symptomatic, slowing progression
- A considerable history of unsuccessful clinical trials of seemingly promising new drugs
- Governments have set (optimistic) target of availability of a disease modifying treatment by 2025
- Meanwhile there is need to promote prevention and post-diagnostic support to improve quality of life

POLICY PRIORITIES

- Prevention
- Public awareness
- Early diagnosis
- Post-diagnostic support
- Support for carers
- Quality long-term care
- End of life care
- Research

DEMENTIA PREVENTION

- A Lancet Commission on dementia prevention, intervention and care showed that there is good potential for prevention of dementia
- They reviewed a range of evidence and conducted modelling and found that more than a third of dementia cases might be theoretically preventable
- They stressed that delaying dementia for some years for even just a small proportion of people would enable many more people to reach the end of life without developing the condition

Source: Livingston et al (2017) Dementia prevention, intervention, and care, The Lancet, 20 July 2017

PREVENTION

Known risk factors:

- Genes (*at birth*)
- Education (*early life onward*)
- Hearing loss, hypertension, obesity (*mid-life*)
- Smoking, depression, physical inactivity, social isolation, diabetes (*late-life*)

Overall population-attributable risk = 35%
(Livingston et al 2017 The Lancet)

DIAGNOSIS

- Early diagnosis is important but too often not available
- It is a prerequisite for access to care
- It enables people with dementia and their families to prepare for the future
- It can be cost-effective, in particular through delaying admission to residential care

Source: Banerjee and Wittenberg (2009) IJGP 24(7)748-54

DEMENTIA CARE

- *Medications*
- *Psychosocial therapies*: e.g. cognitive stimulation, cognitive rehabilitation
- *Care arrangements*: e.g. home care, telecare, case management
- *Carer support*: e.g. training, awareness, relaxation, psychosocial therapies
- *End-of-life care*

UNPAID CARE

- Families are the largest source of dementia care resources (in-kind)
- Unpaid family care does not carry a price, but it certainly has a cost:
 - Cost of reduced employment (risk of impoverishment, loss of social protection...)
 - Costs in terms of carers health and quality of life
 - Long-term costs for child carers
- In many countries costs of formal care can be catastrophic, consuming lifetime savings

HEALTH CARE SYSTEM

- Most health expenditure for people with dementia is on hospital care
- **Diagnostic:** gateway for access to health and social care, but low coverage: 40-50% in most high income countries, 5-10% in most LMICs
- **Lack of specialist services:** very few in LMICs and HICs are already struggling to keep up with rapidly increasing numbers
- Even **interventions** with a strong evidence-base (e.g. anti-dementia drugs) are not being delivered to all who might benefit

LONG-TERM CARE SYSTEM

- In most high income countries, the majority of users of long-term care are people with dementia
- Benefits of formal long-term care: for both the person with dementia and their caregivers
- Most low and middle-income countries have very few formal long-term care services, particularly for people with dementia

WORLD ALZHEIMER'S REPORT 2016: MAIN FINDINGS

- Scaling up dementia care is affordable to 2030 with a proposed task-shifted healthcare pathway
- It has 40% lower cost than specialist care pathway (in the HICs in which it was modelled)
- Healthcare system features to improve coverage sustainably:
 - Universal health coverage
 - Central role (gate-keeping) for primary care
 - Low out-of-pocket payments
 - Dedicated dementia plans
 - Improved dementia training for all healthcare staff
 - Access to drugs at generic prices

RESPONDING TO THE CHALLENGE: WHAT WORKS?

- Risk reduction
- Screening & diagnosis
- **Carer support**
- Staff skills training
- Medications
- **Psychosocial treatments**
- Home-based care
- Case management
- Awareness and attitudes

For each area there is (some) international evidence on effectiveness; not much on cost-effectiveness.

+++++

Many trials underway

+++++

Review of evidence now underway (MODEM)

COGNITIVE STIMULATION THERAPY (CST)

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 medication (ACHEIs)

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

OUTCOMES & COST-EFFECTIVENESS AT 24 MONTHS

Effects on carers:

- Better mental health: carers with usual support were 7 times more likely to have clinically significant depression
- Significantly better quality of life

Effects on people with dementia:

- No differences in health status or quality of life
- Some delay to care home admission (not significant)

Service costs go up in both groups over time; but care home costs go up more for people in the usual care group.

Cost-effectiveness: START has better outcomes and does not cost any more ... It is clearly cost-effective.

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,

DISEASE-MODIFYING TREATMENTS

- A number of potential disease-modifying treatments are currently undergoing phase III trials
- They are likely to be administered, if effective, at asymptomatic or prodromal stages of AD
- This raises a series of challenges relating to diagnostic testing, demonstrating cost-effectiveness and funding the new drugs

THINKING DIFFERENTLY

Alzheimer's Research UK has made recommendation including:

- Comprehensive horizon scanning to understand the likely impact of new disease-modifying treatments on the health sector
- Scoping the scale of increased capacity and infrastructure required
- Development of innovative funding models to respond to the challenge
- Increasing public awareness of the value of earlier detection
- Preparation to shift diagnosis 15 to 20 years earlier
- Identification of domains that reflect true value of AD treatments for individuals and society

Source: ARUK (2018) *Thinking Differently* report

CONCLUSIONS

- The lifetime risk of dementia is high
- The costs of dementia are high and likely to rise rapidly
- Co-morbidities among people with dementia are frequent
- Greater public awareness, timely diagnosis, better care, support for carers and research have high policy priority
- The evidence on cost-effectiveness of therapies is limited but gradually increasing: commissioners want evidence
- Absent a cure, improved care, increased support for carers and promotion of risk reduction are very important