

MODEM

modelling outcome and cost impacts
of interventions for dementia

Dementia Evidence Toolkit

What works in dementia treatment, care and support?
Evidence on effective interventions for people with dementia
and carers

Adelina Comas-Herrera, David McDaid, A-La Park, Bayo Adelaja, Daniel Lombard,
Klara Lorenz, Josie Dixon, Chiara di Poli, Martin Knapp

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

Aims and context

This project has been funded by ESRC and builds on a systematic mapping of literature carried out as part of the MODEM “Modelling Dementia Care to 2040” research project, funded by the ESRC and NIHR as part of their “Improving Dementia Care” initiative.

The **DEMENTIA EVIDENCE TOOLKIT** comprises two web-based resources:

- A searchable bibliographic database of empirical papers and systematic reviews on interventions for the treatment and care of people with dementia and carers.
- Non-technical summaries of the evidence on the effectiveness (and cost-effectiveness) of key care and treatment interventions.

We aim to provide clear information to both people affected by dementia and decision-makers at local and national level about the different treatments, care and support options. Our evidence summaries will focus on the effectiveness of interventions for people with dementia and carers, on the strength of the evidence, whether interventions are cost-effective and their economic costs. We will also highlight the areas of dementia care, treatment and support for which there is currently insufficient evidence.

The summaries will be accessed from a table that will offer a visual representation of ‘the state of the art’ of evidence in dementia care that summarises the key interventions, the availability of evidence and their outcomes.

We are consulting with commissioners, people with dementia, unpaid carers and care professionals, gathering their feedback on the contents, style and accessibility of the summaries, as well as to choose the key interventions.

Methods

Part one: the bibliographic database

As part of the MODEM project we carried out a systematic mapping of scientific literature on interventions for the care, treatment and support of people with dementia and carers, with the aim of identifying the state of the art on the efficacy and effectiveness (in terms of clinical outcomes and cost) of interventions to prevent or delay dementia onset, reduce symptom severity or improve quality of life of people with dementia and/or their carers. One output of that work is a coded searchable database, which allows for identification of trends in research and focused reviews on specific topics.

The review covered the medical and social science databases Medline, Psychinfo, CINAHL, Social Care Online and the International Bibliography of the Social Sciences for the period 1 January 2009 until 30 June 2015. There were no language restrictions but we focused on mapping studies produced in high income country settings. Studies in low income countries were documented. The papers were then coded on the basis of abstracts, keywords and titles alone to create the map. By August 2015, 2,871 studies had been included in the map, including 93 in languages other than English.

The studies were coded according to:

- Country of study and country of authors
- Type of dementia
- Type of study
- Outcomes reported (i.e. cognition, prevention or risk reduction, behavioural symptoms, quality of life of the person with dementia, service use, carer's health, carer burden, carer quality of life, etc.)
- Intervention setting (community, primary care, day care, care homes, hospital, etc.)
- Type of intervention
 - Risk factor modification (general population health promotion, at risk population)
 - Diagnostic/target identification (genetic testing, biological testing, etc)
 - Pharmacological interventions
 - Non-pharmacological interventions (such as cognitive stimulation therapies, reminiscence, case management, care brokerage, specialist nursing, social activities, occupational therapy, pet therapies, etc.)
 - End-of-life care
 - Interventions for carers (training programmes, respite services, peer support, etc.)
 - Treatment/prevention of co-morbidities or additional risks (such as falls, etc)
 - Workforce oriented interventions
 - Stigma reduction/dementia awareness campaigns
 - Technology (telephone, telecare, telehealth, robots, GPS, etc)
 - Other

A searchable version of this database will be made available in our Dementia Evidence Toolkit website, with various menus to help people obtain the literature they are interested in. Almost all papers contain an abstract and, where possible, we will include links to the full text.

Part two: Summaries of the evidence on effectiveness and cost-effectiveness

We are producing, for key interventions, a non-technical summary, aimed at health and social care commissioners, people with dementia, family carers, and professional care professionals. The summaries describe:

- (a) key features of the interventions, whether they are effective (and in some cases cost-effective),
- (b) what are the key outcomes (for example cognition, quality of life of the person with dementia, quality of life of unpaid carers, carer burden, cost reductions, etc),
- (c) an assessment of the quality of the studies on which the evidence is based
- (d) recommendations for future research (including methodological recommendations where appropriate)

The summaries are produced according to a protocol and standard quality assessment tools and extraction forms (available on request), to ensure consistency. We draw on evidence from good quality systematic reviews and empirical papers

As we have limited time to carry out the summaries with the current funding, we are prioritising the summaries to cover key interventions. The selection is based on the research evidence available (obtained through the MODEM bibliographic database), and from discussions with commissioners, people with dementia, carers and advocates. We will include some interventions that are 'popular' with commissioners and users of care and support, but for which there is no effectiveness evidence in the literature. In the case of such 'non-evidenced' interventions, we will highlight the need for effectiveness research, or whether there are interventions with similar goals for which there is better evidence.

Timeline

The project started in November 2015 and we will launch the website in June 2016.

Further information

For further information contact Adelina Comas-Herrera at a.comas@lse.ac.uk