

Changing practice in dementia care in the community: developing and testing evidence-based interventions, from timely diagnosis to end of life (EVIDEM)

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Declared competing interests of authors: none

Published April 2015

DOI: 10.3310/pgfar03030

Scientific summary

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Programme Grants for Applied Research 2015; Vol. 3: No. 3

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Scientific summary

Background

Dementia has an enormous impact on the lives of individuals and families, and on health and social care services, and this impact is increasing as the population ages. The needs of people with dementia and their carers for information and support are inadequately addressed at all key points in the illness trajectory. The consequences are poor quality of life, inappropriate and costly responses to the problems that emerge (such as avoidable admissions to hospital), prolonged inpatient stays and further disablement.

During the life of this programme there has been increasing public awareness of dementia, and growing policy support for developing services for people with dementia and their carers. The most visible evidence of this was the launch of the Dementia Strategy for England in 2009, and this policy momentum has continued with the Prime Minister's Challenge on Dementia in 2012.

Aims and objectives

The aim of this programme was to study interventions along the disease trajectory of dementia syndrome, involving a cohort of people with dementia and their families at different stages of the disease.

Its *objectives* were to develop and test interventions that improve patient/user, carer and service outcomes at different points on the disease trajectory, namely:

1. the recognition of the syndrome and the first responses to it, in primary care
2. the management of behavioural and psychological symptoms of dementia (BPSD) using exercise as a therapy
3. the management of incontinence in people with dementia living in the community (but not in care homes)
4. the care and support given to people with dementia at the end of life.

The programme also evaluated the impact of the Mental Capacity Act (MCA) 2005, and developed educational interventions to support its application, specifically in relation to safeguarding.

Research plans

We aimed to assemble a cohort of people with dementia and their families, recruiting through primary and secondary health care, social care services and voluntary organisations, and to nest five projects within it. These projects were:

1. an educational intervention for primary care management, psychosocial interventions and shared care of medication for people with dementia, developed and tested in an experimental study
2. a randomised trial of exercise as therapy for BPSD
3. studies of the experience of, and management strategies for, incontinence in community-dwelling people with dementia, followed by the development and testing of evidence-based resources to reduce the impact of incontinence on them and their carers

4. a study of the pathway to death of older people with dementia, and the development and testing of interventions that would enable the UK NHS, social care staff, and family members to work together to provide end-of-life care
5. an evaluation of the impact of the MCA 2005 and the creation of practice guidance to enhance professionals' concordance with the MCA and with safeguarding practices.

The research team

The EVIDEM (Evidence Based Interventions for Dementia) team was multidisciplinary, with members from the fields of medicine, nursing, social work, social science, psychology, statistics and health economics. It drew on experiences of different methodologies, and had a track record of fruitful collaboration and project completion and an international reputation. This programme built on successful earlier work on dementia diagnosis and management in primary care, among other studies. We had close working relationships with the Dementias and Neurodegenerative Diseases Research Network (DeNDRoN) and the Primary Care Research Network-Greater London (PCRN-GL). We drew on expertise from the National Institute for Health and Clinical Excellence/Social Care Institute for Excellence dementia clinical guidelines development group and the National Care Home Research and Development Forum.

The research environment

Central and North West London NHS Foundation Trust hosted the EVIDEM programme. The cultural and social diversity of London and surrounding areas provided opportunities for testing interventions in different population groups and contexts. The trust has an energetic user forum, which played a role in the design and management of some projects, and the research team contributed to an annual 'school' (continued professional development event) for trust staff on developments in dementia care, using different methods to reach staff – day conferences, study half-days and workplace-based seminars and workshops.

Outputs, outcomes and impact

The EVIDEM programme has produced the following:

1. *An educational intervention for general practice*, tested in a randomised controlled trial (RCT), combining timely diagnosis and psychosocial support around the period of diagnosis. This includes simple decision aids in electronic format, and shared care guidelines for medication use, to enhance the quality of primary care practice. The records of > 1000 people with dementia were audited for this RCT, and 161 patient–carer dyads agreed to participate in in-depth studies. The findings of the RCT, together with literature reviews of subjective memory impairment and methods for improving primary care's performance with people with dementia and their carers, are outlined in *Chapter 1*.
2. The experience of and findings from a RCT of exercise promotion for the *management of distressing or challenging symptoms* (BPSD), which involved 131 patient–carer dyads. Because of slow recruitment, this project was granted a no-cost extension. This time extension did allow sufficient recruitment and follow-up to conclude the study, which found that the exercise intervention did reduce carer burden significantly; however, it made no difference to behavioural and psychological symptoms (as measured by the Neuropsychiatric Inventory) of the patient. The intervention tested in the trial, methods used in the study and evidence underpinning the experiment are all reported in *Chapter 2*.

3. *Evidence-based practice resources for the management of incontinence* in people with dementia living at home. In addition, data from a feasibility study of effectiveness and acceptability of different designs of absorbent pads have been gathered to inform a future clinical trial. These developments, together with an epidemiological study of incontinence in almost 114,000 people with dementia using The Health Improvement Network (THIN) database, are reported in *Chapter 3*. A paper from this project won the Royal College of General Practitioners and Novartis Research Paper of the Year Award 2011.
4. *Methods for enhancing collaborative working* between primary and social care to provide end-of-life care in dementia, suitable for use in care homes without on-site nursing. The development of these methods is summarised in *Chapter 4*.
5. *Practice guidance on the use of the MCA 2005*, including its use in adult safeguarding work. Adopting a longitudinal approach, this study has charted changes in familiarity with, and confidence in, using the MCA among a broad range of practitioners. It has been the first to study the MCA as a whole and to research patient and carer decision-making experiences in this context. The development of this guidance is reported in *Chapter 5*.
6. *Increased research capacity in the community* in the study of care for people with dementia. The EVIDEM programme has helped create a register of people with dementia interested in research, alongside its cohort of study participants, both of which are described in *Chapter 6*. The working relationships developed across disciplines and boundaries in the programme have allowed new research studies to be designed and funded. Two Doctor of Philosophy (PhD) studies have been nested in the programme, which also provided a supportive environment for postdoctoral studies and academic general practitioners. The expertise acquired by individuals in dementia research is reported in each chapter.
7. *A broad range of publications*. The EVIDEM programme has, to date, published more than 30 papers in professional and academic journals and a dozen articles in the professional press. More than 70 presentations of the programme and its findings have been made in professional, academic and public conferences, internet seminars and meetings. This report contains further discussion of EVIDEM's impact in the description of each project in *Chapter 7*.
8. *Public involvement*. We have made wide use of patient and public involvement in these research and development projects, and user and carer perspectives have contributed to project design, implementation and analysis. The programme benefited from the interest and contribution of an expert and enthusiastic advisory group, comprising service users, carers, patients and public representatives, as well as professionals and academics. Each project also had its own advisory group with similar compositions.

Finally, *the implications of the main findings and some cross-cutting themes* from the programme's projects are discussed in *Chapter 7*, along with a summary of what we have found and suggestions for future research and development.

Trial registration

This trial is registered as EVIDEM: ED-NCT00866099; EVIDEM: E-ISRCTN01423159.

Funding

Funding for this study was provided by the Programme Grants for Applied Research programme of the National Institute for Health Research.

Programme Grants for Applied Research

ISSN 2050-4322 (Print)

ISSN 2050-4330 (Online)

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Editorial contact: nihredit@southampton.ac.uk

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This report

The research reported in this issue of the journal was funded by PGfAR as project number RP-PG-0606-1005. The contractual start date was in August 2007. The final report began editorial review in February 2013 and was accepted for publication in July 2014. As the funder, the PGfAR programme agreed the research questions and study designs in advance with the investigators. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The PGfAR editors and production house have tried to ensure the accuracy of the authors' report and would like to thank the reviewers for their constructive comments on the final report document. However, they do not accept liability for damages or losses arising from material published in this report.

This report presents independent research funded by the National Institute for Health Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, CCF, NETSCC, PGfAR or the Department of Health. If there are verbatim quotations included in this publication the views and opinions expressed by the interviewees are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, NETSCC, the PGfAR programme or the Department of Health.

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