Community Occupational Therapy in Dementia intervention for people with mild to moderate dementia and their family carers in the UK: the VALID research programme including RCT

Jennifer Wenborn,1,2* Gail Mountain,3,4 Esme Moniz-Cook,5 Fiona Poland,6 Michael King,7 Rumana Omar,7,8 Aidan O’Keeffe,7,8 Stephen Morris,9 Elena Pizzo,9 Susan Michie,10 Myrra Vernooij-Dassen,11 Maud Graff,11 Jane Hill,2 David Challis,12 Ian Russell,13 Catherine Sackley,14 Sinéad Hynes,15 Nadia Crellin,2 Jacqueline Mundy,2,16 Jane Burgess,1,2 Tom Swinson,2 Laura Di Bona,4 Becky Field,4 Cathryn Hart,17 Jacki Stansfeld,1,2 Holly Walton,10 Sally Rooks,2 Ritchard Ledgerd2 and Martin Orrell18

1Division of Psychiatry, University College of London, London, UK
2Research and Development Department, North East London NHS Foundation Trust, London, UK
3Centre for Applied Dementia Studies, Faculty of Health Studies, University of Bradford, Bradford, UK
4School of Health and Related Research (ScHARR), University of Sheffield, Sheffield, UK
5Faculty of Health Sciences, University of Hull, Hull, UK
6School of Health Sciences, University of East Anglia, Norwich, UK
7Priment Clinical Trials Unit, University College London, London, UK
8Department of Statistical Science, University College London, London, UK
9Department of Applied Health Research, University College London, London, UK
10University College London Centre for Behaviour Change, Department of Clinical, Educational and Health Psychology, University College London, London, UK
11Radboud University Medical Centre (Radboudumc), Nijmegen, the Netherlands
12Personal Social Services Research Unit, Faculty of Medical and Human Sciences, University of Manchester, Manchester, UK
13Medical School, Swansea University, Swansea, UK
14Department of Public Health Sciences, King’s College London, London, UK
15School of Health Sciences, National University of Ireland Galway, Galway, Ireland
16School of Health Sciences, City, University of London, London, UK
17Humber Teaching NHS Foundation Trust, Hull, UK
18Institute of Mental Health, University of Nottingham, Nottingham, UK

*Corresponding author  j.wenborn@ucl.ac.uk
Disclosure of interests of authors: Michael King was a member of the following committees: National Institute for Health and Care Research (NIHR) Health Technology Assessment (HTA) Programme Trials Board (2007–10) and NIHR Rapid Trials and Add-on Studies Board (May–November 2012). Susan Michie reports grants from the Department of Health and Social Care, Cancer Research UK (London, UK), The Wellcome Trust (London, UK), NIHR School for Public Health Research, Public Health England, Economic and Social Research Council (ESRC), NIHR, NIHR Programme Grants for Applied Research, Bupa, Horizon2020 – European Commission, the Medical Research Council, ESRC/NIHR Dementia 2012, Engineering and Physical Sciences Research Council (EPSRC), National Institute for Health and Care Excellence and ESRC, Canadian Institute of Health Research and the British Psychological Society, outside the submitted work. Stephen Morris reports membership of the following committees: the NIHR Health and Social Care Delivery Research (HSDR) Funding Board (2014–19), NIHR HSDR Commissioning Board (2014–16), NIHR HSDR Evidence Synthesis Sub-board (2016), NIHR HTA Clinical Evaluation and Trials Board (associate member) (2007–10), NIHR HTA Commissioning Board (2009–13) and NIHR Public Health Research Funding Board (2011–17). Gail Mountain was a member of the NIHR HTA Commissioning Board (2011–16). Rumana Omar is a member of the NIHR HTA General Board (2016 to present). Martin Orrell reports the NIHR Programme Grant for Applied Research grant number RP-PG-0612–20004 (AQUEDUCT) outside the submitted work. Catherine Sackley has been a member of the following committees: the NIHR HSDR Researcher-Led Board (2012–16), NIHR Rapid Trials and Add-on Studies Board (May–November 2012) and NIHR HSDR Commissioning Board (2009–12). Holly Walton's PhD research was funded by the ESRC Doctoral Training Centre (grant reference ES/J500185/1), as part of the Promoting Independence in Dementia programme (grant references 2014–2015 ES/L001802/1 and 2015–2019: ES/L001802/2).
Plain language summary

Maintaining everyday and meaningful activities can be difficult for a person with dementia. Their family carer/supporter can feel stressed from needing to give increasing support. Occupational therapists assist people to improve their health and well-being by helping them to do the activities that are important to them.

Dutch researchers developed an occupational therapy programme for people with mild to moderate dementia and their supporters. Delivered at home, it improved the person’s ability to carry out daily activities, plus their mood and quality of life. Supporters’ sense of competence, mood and quality of life also improved, and it was also value for money.

We built on this by translating and adapting the Dutch materials to develop a version better suited to the UK health and social care services context: Community Occupational Therapy in Dementia – UK version.

The Community Occupational Therapy in Dementia – UK version comprises 10 hours of occupational therapy provided at home over 10 weeks. We tested whether or not it was more beneficial in terms of helping people with dementia to continue with activities and improving mood and quality of life than the usual service provided (treatment as usual), which may or may not include occupational therapy. In total, 468 pairs comprising a person with dementia and their supporter agreed to take part. Pairs were allocated at random to receive either The Community Occupational Therapy in Dementia – UK version or treatment as usual. We asked questions about daily activities performance, quality of life, mood, and the health and social care services used. We did this at the beginning of the programme and again at 12, 26, 52 and 78 weeks.

The statistical analysis showed no evidence that Community Occupational Therapy in Dementia – UK version benefited the pairs on the outcomes selected or was value for money compared with the usual care already provided. We spoke in depth to some of the pairs and occupational therapists who participated in Community Occupational Therapy in Dementia – UK version, and they provided positive examples of meaningful activities that they had resumed or established as a result of the programme.

Future research should develop ways of measuring the outcomes that really matter to people with dementia and their supporters, and to collect the views of people with dementia themselves.
Programme Grants for Applied Research

ISSN 2050-4322 (Print)
ISSN 2050-4330 (Online)

Programme Grants for Applied Research (PGfAR) was launched in 2013 and is indexed by Europe PMC, NCBI Bookshelf, DOAJ, Ulrichschweb™ (ProQuest LLC, Ann Arbor, MI, USA) and Scopus® (Elsevier, Amsterdam, Netherlands).

This journal is a member of and subscribes to the principles of the Committee on Publication Ethics (COPE) (www.publicationethics.org/).

Editorial contact: journals.library@nihr.ac.uk

The full PGfAR archive is freely available to view online at www.journalslibrary.nihr.ac.uk/pgfar.

Criteria for inclusion in the Programme Grants for Applied Research journal
Reports are published in Programme Grants for Applied Research (PGfAR) if (1) they have resulted from work for the PGfAR programme, and (2) they are of a sufficiently high scientific quality as assessed by the reviewers and editors.

Programme Grants for Applied Research programme
The Programme Grants for Applied Research (PGfAR) programme, part of the National Institute for Health and Care Research (NIHR), was established in 2006 to fund collaborative, multidisciplinary programmes of applied research to solve health and social care challenges. Findings are expected to provide evidence that lead to clear and identifiable patient benefits, in the relatively near future.

PGfAR is researcher led and does not specify topics for research; however, the research must be in an area of priority or need for the NHS and the social care sector of the Department of Health and Social Care, with particular emphasis on health and social care areas that cause significant burden, where other research funders may not be focused, or where insufficient funding is available.

The programme is managed by the NIHR Central Commissioning Facility (CCF) with strategic input from the Programme Director. For more information about the PGfAR programme please visit the website: https://www.nihr.ac.uk/explore-nihr/funding-programmes/programme-grants-for-applied-research.htm

This report
The research reported in this issue of the journal was funded by PGfAR as project number RP-PG-0610-10108. The contractual start date was in January 2012. The final report began editorial review in February 2019 and was accepted for publication in April 2022. 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 and Care 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, PGfAR or the Department of Health and Social Care. 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, the PGfAR programme or the Department of Health and Social Care.

Copyright © 2023 Wenborn et al. This work was produced by Wenborn et al. under the terms of a commissioning contract issued by the Secretary of State for Health and Social Care. This is an Open Access publication distributed under the terms of the Creative Commons Attribution CC BY 4.0 licence, which permits unrestricted use, distribution, reproduction and adaption in any medium and for any purpose provided that it is properly attributed. See: https://creativecommons.org/licenses/by/4.0/. For attribution the title, original author(s), the publication source – NIHR Journals Library, and the DOI of the publication must be cited.

Published by NIHR Journals Library (www.journalslibrary.nihr.ac.uk), produced by Prepress, final files produced by Newgen Digitalworks Pvt Ltd, Chennai, India (www.newgen.co).
NIHR Journals Library Editor-in-Chief

Dr Cat Chatfield  Director of Health Services Research UK

NIHR Journals Library Editors

Professor Andrée Le May  Chair of NIHR Journals Library Editorial Group (HSDR, PGfAR, PHR journals) and Editor-in-Chief of HSDR, PGfAR, PHR journals

Dr Peter Davidson  Interim Chair of HTA and EME Editorial Board. Consultant Advisor, School of Healthcare Enterprise and Innovation, University of Southampton, UK

Professor Matthias Beck  Professor of Management, Cork University Business School, Department of Management and Marketing, University College Cork, Ireland

Dr Tessa Crilly  Director, Crystal Blue Consulting Ltd, UK

Dr Eugenia Cronin  Consultant in Public Health, Delta Public Health Consulting Ltd, UK

Ms Tara Lamont  Senior Adviser, School of Healthcare Enterprise and Innovation, University of Southampton, UK

Dr Catriona McDaid  Reader in Trials, Department of Health Sciences, University of York, UK

Professor William McGuire  Professor of Child Health, Hull York Medical School, University of York, UK

Professor Geoffrey Meads  Emeritus Professor of Wellbeing Research, University of Winchester, UK

Professor James Raftery  Professor of Health Technology Assessment, School of Healthcare Enterprise and Innovation, University of Southampton, UK

Dr Rob Riemsma  Consultant Advisor, School of Healthcare Enterprise and Innovation, University of Southampton, UK

Professor Helen Roberts  Professor of Child Health Research, Child and Adolescent Mental Health, Palliative Care and Paediatrics Unit, Population Policy and Practice Programme, UCL Great Ormond Street Institute of Child Health, London, UK

Professor Jonathan Ross  Professor of Sexual Health and HIV, University Hospital Birmingham, UK

Professor Helen Snooks  Professor of Health Services Research, Institute of Life Science, College of Medicine, Swansea University, UK

Please visit the website for a list of editors: www.journalslibrary.nihr.ac.uk/about/editors

Editorial contact:  journals.library@nihr.ac.uk