

A randomised controlled trial to evaluate the impact of a human rights based approach to dementia care in inpatient ward and care home settings

Peter Kinderman,¹ Sarah Butchard,^{2*} Ashley J Bruen,¹ Abbie Wall,¹ Nia Goulden,³ Zoe Hoare,³ Carys Jones⁴ and Rhiannon Edwards⁴

¹Institute of Psychology, Health and Society, University of Liverpool, Liverpool, UK

²Mersey Care NHS Foundation Trust, Liverpool, UK

³North Wales Organisation for Randomised Trials in Health (NWORTH),
School of Healthcare Sciences, Bangor University, Bangor, UK

⁴Centre for Health Economics and Medicines Evaluation, Institute of Medical and Social Care Research, Bangor University, Bangor, UK

*Corresponding author sarah.butchard@merseycare.nhs.uk

Declared competing interests of authors: none

Published March 2018

DOI: 10.3310/hsdr06130

Plain English summary

A human rights based approach to dementia care

Health Services and Delivery Research 2018; Vol. 6: No. 13

DOI: 10.3310/hsdr06130

NIHR Journals Library www.journalslibrary.nihr.ac.uk

Plain English summary

This study aimed to explore whether or not training staff to use a new assessment tool called 'Getting It Right' could improve the quality of care provided in dementia-specific NHS wards and care homes. The assessment tool was based on human rights principles and explicitly linked person-centred care to the human rights FREDa (Fairness, Respect, Equality, Dignity and Autonomy) principles. The assessment tool and training were designed by and piloted at Mersey Care NHS Foundation Trust. Staff members completed the assessment tool with residents on their unit and were offered booster consultation sessions to help them with any problems they encountered completing it.

Twenty sites were recruited to the study across the north-west of England (eight NHS wards and 12 care homes). These sites either received the intervention package described above (training, applying the 'Getting It Right' assessment tool and receiving booster sessions) or continued with care as usual. The measures were completed before the study began and after 4 months to see whether or not there were any differences in the well-being of people living with dementia and the quality of care provided. Staff members were also interviewed to look at whether or not the way that they made decisions had changed.

It was found that, although there were improvements in staff knowledge about human rights following the training, and staff expressed more positive attitudes towards human rights, there were no improvements in the care provided or in the well-being of people living with dementia. Staff also reported different decision-making strategies following the intervention.

Although staff generally reported that the approach was simple and easy to use, there was evidence that it had not been used routinely. Interviews showed that management support was an important factor in whether or not the approach was applied. Future research could focus on different ways of ensuring that people apply new initiatives.

Health Services and Delivery Research

ISSN 2050-4349 (Print)

ISSN 2050-4357 (Online)

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 HS&DR archive is freely available to view online at www.journalslibrary.nihr.ac.uk/hsdr. Print-on-demand copies can be purchased from the report pages of the NIHR Journals Library website: www.journalslibrary.nihr.ac.uk

Criteria for inclusion in the *Health Services and Delivery Research* journal

Reports are published in *Health Services and Delivery Research* (HS&DR) if (1) they have resulted from work for the HS&DR programme or programmes which preceded the HS&DR programme, and (2) they are of a sufficiently high scientific quality as assessed by the reviewers and editors.

HS&DR programme

The Health Services and Delivery Research (HS&DR) programme, part of the National Institute for Health Research (NIHR), was established to fund a broad range of research. It combines the strengths and contributions of two previous NIHR research programmes: the Health Services Research (HSR) programme and the Service Delivery and Organisation (SDO) programme, which were merged in January 2012.

The HS&DR programme aims to produce rigorous and relevant evidence on the quality, access and organisation of health services including costs and outcomes, as well as research on implementation. The programme will enhance the strategic focus on research that matters to the NHS and is keen to support ambitious evaluative research to improve health services.

For more information about the HS&DR programme please visit the website: <http://www.nets.nihr.ac.uk/programmes/hsdr>

This report

The research reported in this issue of the journal was funded by the HS&DR programme or one of its preceding programmes as project number 12/209/53. The contractual start date was in May 2014. The final report began editorial review in October 2016 and was accepted for publication in August 2017. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HS&DR 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, NETSCC, the HS&DR programme 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, NETSCC, the HS&DR programme or the Department of Health and Social Care.

© Queen's Printer and Controller of HMSO 2018. This work was produced by Kinderman *et al.* under the terms of a commissioning contract issued by the Secretary of State for Health and Social Care. This issue may be freely reproduced for the purposes of private research and study and extracts (or indeed, the full report) may be included in professional journals provided that suitable acknowledgement is made and the reproduction is not associated with any form of advertising. Applications for commercial reproduction should be addressed to: NIHR Journals Library, National Institute for Health Research, Evaluation, Trials and Studies Coordinating Centre, Alpha House, University of Southampton Science Park, Southampton SO16 7NS, UK.

Published by the NIHR Journals Library (www.journalslibrary.nihr.ac.uk), produced by Prepress Projects Ltd, Perth, Scotland (www.prepress-projects.co.uk).

Health Services and Delivery Research Editor-in-Chief

Professor Jo Rycroft-Malone Professor of Health Services and Implementation Research, Bangor University, UK

NIHR Journals Library Editor-in-Chief

Professor Tom Walley Director, NIHR Evaluation, Trials and Studies and Director of the EME Programme, UK

NIHR Journals Library Editors

Professor Ken Stein Chair of HTA and EME Editorial Board and Professor of Public Health, University of Exeter Medical School, UK

Professor Andrée Le May Chair of NIHR Journals Library Editorial Group (HS&DR, PGfAR, PHR journals)

Dr Martin Ashton-Key Consultant in Public Health Medicine/Consultant Advisor, NETSCC, 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 Senior Scientific Advisor, Wessex Institute, UK

Dr Peter Davidson Director of the NIHR Dissemination Centre, University of Southampton, UK

Ms Tara Lamont Scientific Advisor, NETSCC, UK

Dr Catriona McDaid Senior Research Fellow, York Trials Unit, 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 Professor of Wellbeing Research, University of Winchester, UK

Professor John Norrie Chair in Medical Statistics, University of Edinburgh, UK

Professor John Powell Consultant Clinical Adviser, National Institute for Health and Care Excellence (NICE), UK

Professor James Raftery Professor of Health Technology Assessment, Wessex Institute, Faculty of Medicine, University of Southampton, UK

Dr Rob Riemsma Reviews Manager, Kleijnen Systematic Reviews Ltd, UK

Professor Helen Roberts Professor of Child Health Research, UCL Great Ormond Street Institute of Child Health, 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

Professor Jim Thornton Professor of Obstetrics and Gynaecology, Faculty of Medicine and Health Sciences, University of Nottingham, UK

Professor Martin Underwood Director, Warwick Clinical Trials Unit, Warwick Medical School, University of Warwick, UK

Please visit the website for a list of members of the NIHR Journals Library Board:
www.journalslibrary.nihr.ac.uk/about/editors

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