The care of dying people in nursing homes and intensive care units: a qualitative mixed-methods study

Elizabeth Perkins,¹ Maureen Gambles,² Rachel Houten,³ Sheila Harper,² Alan Haycox,³ Terri O'Brien,² Sarah Richards,³ Hong Chen,² Kate Nolan² and John E Ellershaw²*

 ¹Health and Community Care Research Unit, Institute of Psychology, Health and Society, University of Liverpool, Liverpool, UK
²Marie Curie Palliative Care Institute Liverpool, Institute of Translational Medicine, University of Liverpool, Liverpool, UK
³Management School, University of Liverpool, Liverpool, UK

*Corresponding author

Declared competing interests of authors: John E Ellershaw reports grants from Marie Curie Cancer Care and the Department of Health End of Life Care Programme outside the submitted work. In addition, Professor Ellershaw has a patent Liverpool Care Pathway logo which is a registered trademark within the UK and European Community issued to Marie Curie Cancer Care and the Royal Liverpool and Broadgreen University Hospitals NHS Trust (joint holders). All Liverpool Care Pathway documentation is copyrighted as Marie Curie Palliative Care Institute Liverpool, a department of the University of Liverpool, Marie Curie Cancer Care and the Royal Liverpool and Broadgreen University Hospitals NHS Trust, using standard Berne Convention. Professor Ellershaw is employed by the Royal Liverpool and Broadgreen University Hospitals NHS Trust and has an honorary contract at the University of Liverpool.

Disclaimer: This report contains quotations from interviews conducted in the course of the research and contains language that may offend some readers.

Published June 2016 DOI: 10.3310/hsdr04200

Plain English summary

The care of dying people in nursing homes and intensive care units Health Services and Delivery Research 2016; Vol. 4: No. 20 DOI: 10.3310/hsdr04200

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

Plain English summary

What did we do?

We aimed to explore the impact of the Liverpool Care Pathway for the Dying Patient (LCP) in nursing homes and intensive care units (ICUs) in the north-west of England and in London. The distinction in the use of the LCP between sites recruited for their LCP use and those recruited for their non-LCP use was not always upheld in practice: this limited our capacity for direct comparisons. Twenty-three sites (12 ICUs and 11 nursing homes) took part.

We reviewed organisation and patient records, undertook interviews with staff and bereaved relatives and observed the care being delivered to patients who were dying. We undertook 25 observations of care (17 ICUs and eight nursing homes) in 12 of these sites. In the nursing homes, we observed only LCP-supported deaths. In the ICUs, we observed both LCP-supported and non-LCP-supported deaths, but the small number made it difficult to make useful comparisons between the two.

What did we find?

Although the study could not assess the impact of the LCP, it did provide important information about the care of dying people. In both settings, end-of-life care was seen as the responsibility of nurses. Nurses believed that the LCP could support good care, but the LCP was not well understood by relatives. Observations in nursing homes showed a focus on physical care and the monitoring of the patient. Although generally welcomed by relatives, some of this care was questioned. Observations in ICUs showed careful consideration of the benefit of continued intervention, which was usually withdrawn only after a long period of monitoring and review. Staff made great efforts to involve relatives in discussions. Ongoing education and training would be of benefit in both settings.

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: nihredit@southampton.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 08/1813/256. The contractual start date was in January 2010. The final report began editorial review in December 2013 and was accepted for publication in May 2015. 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. 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.

© Queen's Printer and Controller of HMSO 2016. This work was produced by Perkins *et al.* under the terms of a commissioning contract issued by the Secretary of State for Health. 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 Editorial Board and Professor of Public Health, University of Exeter Medical School, UK

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

Dr Martin Ashton-Key Consultant in Public Health Medicine/Consultant Advisor, NETSCC, UK

Professor Matthias Beck Chair in Public Sector Management and Subject Leader (Management Group), Queen's University Management School, Queen's University Belfast, UK

Professor Aileen Clarke Professor of Public Health and Health Services Research, Warwick Medical School, University of Warwick, UK

Dr Tessa Crilly Director, Crystal Blue Consulting Ltd, UK

Dr Eugenia Cronin Senior Scientific Advisor, Wessex Institute, UK

Dr Peter Davidson Director of NETSCC, HTA, UK

Ms Tara Lamont Scientific Advisor, NETSCC, UK

Professor Elaine McColl Director, Newcastle Clinical Trials Unit, Institute of Health and Society, Newcastle University, UK

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

Professor Geoffrey Meads Professor of Health Sciences Research, Health and Wellbeing Research and Development Group, University of Winchester, UK

Professor John Norrie Health Services Research Unit, University of Aberdeen, 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 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: nihredit@southampton.ac.uk