The Person, Interactions and Environment Programme to improve care of people with dementia in hospital: a multisite study

Mary Godfrey,^{1*} John Young,^{1,2} Rosemary Shannon,² Ann Skingley,^{3,4} Rosemary Woolley,² Frank Arrojo,⁵ Dawn Brooker,⁶ Kim Manley^{4,7} and Claire Surr⁸

Declared competing interests of authors: none

Published June 2018 DOI: 10.3310/hsdr06230

Scientific summary

PIE: a multisite study

Health Services and Delivery Research 2018; Vol. 6: No. 23

DOI: 10.3310/hsdr06230

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

¹Academic Unit of Elderly Care and Rehabilitation, Faculty of Medicine and Health, University of Leeds, Leeds, UK

²Bradford Institute for Health Research (BIHR), Bradford Teaching Hospitals NHS Foundation Trust, Bradford, UK

³Sidney de Haan Research Centre for Arts and Health, Faculty of Health and Wellbeing, Canterbury Christ Church University, Canterbury, UK

⁴East Kent Hospitals University NHS Foundation Trust, Canterbury, UK

⁵Patient and public involvement representative, Alzheimer's Society Research Network

⁶Association for Dementia Studies, Institute of Health and Society, University of Worcester, Worcester, UK

⁷England Centre for Practice Development, Faculty of Health and Wellbeing, Canterbury Christ Church University, Canterbury, UK

⁸School of Health and Community Studies, Leeds Beckett University, Leeds, UK

^{*}Corresponding author m.godfrey@leeds.ac.uk

Scientific summary

Background

Improving the care of people with dementia in hospital is a policy priority in the UK and internationally. Older people are the main users of acute hospital care and the prevalence of dementia is high among older patients. Evidence suggests that their specific needs are often unrecognised and inadequately addressed.

Person, Interactions and Environment (PIE) is a programme aimed at improving care practice for people with dementia on acute wards. Implementation is a cyclical process, starting with observation of current practice. Structured reflection on observations is the basis for identifying goals and action plans to improve practice. The review of progress against planned action, including an appraisal of the barriers to and facilitators of change, enables adjustment of action and review of goals. Each step is supported by tools, guidance and flow charts, encapsulated in a manual; implementation strategies include an interactive training workshop and method for leading change. The process is systematic, but the content [how observations are conducted (number, for how long, by whom and when), goals identified and action plans pursued] is flexible and tailored to local need. We used normalisation process theory as a sensitising framework to inform implementation.

Objectives

The overall objective of the research was to evaluate the process and outcomes of PIE as a method to improve the care of people with dementia on hospital wards. The study aimed to:

- provide a descriptive and explanatory account of how staff engaged with PIE in the real-life context of acute ward delivery
- test out the causal assumptions underpinning PIE (the theory of change)
- explore the impact of PIE on ward practice and the patient and caregiver experience, and seek
 preliminary evidence of effectiveness of PIE in improving selected clinical outcomes (delirium and falls).

We also sought to develop insight into what person-centred care might look like in a hospital setting. Although 'person-centred' care is regarded as a marker of care quality, there is no consensus on what it looks like in practice. There is also a paucity of research on what it might look like for people with dementia in hospital.

Design and methods

We adopted a longitudinal, comparative case study design to examine the process and outcomes of PIE over time and in the context of the organisational setting into which it was introduced. Case studies are holistic and may be used to examine formal and informal processes, as they occur in real time within organisations that are also dynamic. The comparative method permits an examination of how things happen, and provides insight into why interventions work in some settings and not in others.

Case studies were purposively selected: wards in which older people dominated among the patient profile, in NHS trusts that varied in size and type of catchment locality, in different English regions. 'Readiness' criteria were employed to ensure that the wards selected met the minimum criteria for engaging in the programme (investment of resources of ward and practice development staff in initiating and facilitating PIE and taking part in the research).

We employed mixed methods: qualitative interviews and questionnaires with staff; ethnographic observation of ward routines and practice; patient/caregiver case studies (observation and conversations 'in the moment' with patients, interviews with relatives/carers and an examination of patient case records); and the collection of anonymised data relating to the structure and organisation of care delivery and patient and staff profiles. An embedded process evaluation examined how PIE was enacted by staff in real time through observation, informant interviews with PIE team members and qualitative interviews at the conclusion of the study with purposively selected staff. Outcomes relating to practice change, patient and caregiver experience, and delirium and falls were also collected. Data sets were combined to create individual case studies of PIE implementation and outcomes in context. A cross-case comparison facilitated an explanatory account of the pattern of variation, what shaped it and the consequences flowing from it. Qualitative data analysis employed grounded theory methods. Quantitative data were analysed using simple descriptive statistics. The emerging analysis at each stage involved discussion among the research team; the Programme Management Group, which included carers from the Alzheimer's Society Research Network; and a reference group of older people. The findings were also discussed among an established group of older people with dementia, and with people with dementia and their carers at a dementia café forum.

Cases were oversampled. Ten wards in five acute NHS trusts in three regions in England were recruited. Wards were a mix of care of older people, acute trauma, dementia and rehabilitation.

Results

Patient profile, structure and organisational context

People with a cognitive impairment, including delirium, constituted at least half of the patient profile. Many had moderate to severe impairment; they lacked capacity to communicate verbally, and required assistance with personal care and active support with eating and drinking. On every ward there were people who called out repeatedly, seemingly in deep distress. Most were in advanced older age, with multiple health problems, in addition to the event that had precipitated their acute admission. Their care networks were often fragile and vulnerable to disruption as a result of deteriorating health and acute health crises.

There existed considerable variation between sites in their organisation and care culture predating PIE. Three out of 10 wards did not attain the Royal College of Nursing staff-to-patient ratio for safe working on older people's wards (1:3.5), and most did not meet the recommended ratio of registered nurse to health-care assistant of 65:35 or above, notwithstanding the level of medical acuity, complexity of patient need and prevalence and severity of cognitive impairment. The picture was bleaker than this suggests: on several wards, staff complement was maintained only through the use of Bank and agency staff, with consequences for staff morale, sustainability of a coherent care culture and the availability of 'headroom' to engage in service improvement.

Most study wards had been the subject of environmental improvement to make them more 'dementia friendly'. Apart from two dementia wards, including those recently refurbished, there was a dearth of spaces for patients to engage with each other or with staff.

Dimensions of quality care

The study provides insight into the content and dimensions of practice that constitute a person-focused approach and address the specific needs of people with dementia in an acute hospital setting. Comparing and contrasting how care was actually accomplished by staff across wards, we discerned a continuum of practices supportive of, or barriers to, sustaining personhood and the organisational, spatial and care environment factors that shaped them. Although the literature contrasts person-centred with task-focused communication and care, we identified more differentiated styles of practice. Indeed, this binary conception of care delivery was unhelpful. The multiple and interacting needs of this patient group spanning medical, therapy and support meant that care delivery needed to encompass tasks suffused with understanding of the person. Specifically, providing appropriate support to facilitate the acute recovery of people

living with dementia and respond to the complexity of their needs required biographical knowledge to communicate with and interpret embodied communication, including distress; knowledge, whether learned or experiential, of how dementia affected the person; interpersonal skills to engage at a sensory, emotional and cognitive level with them; empathic connection with the person in 'their world' based on the understanding that their actions and interactions were meaningful, although the meaning might not be evident; and a problem-solving approach to practice, building on these multiple sources of knowledge, experience and expertise. Furthermore, recognition that there was an element of uncertainty and unpredictability about how the person would respond in a given situation meant that strategies to engage him or her were emergent, built up through trial and error and required creative, tailor-made solutions. This combination of knowledge and skills occurred in pockets apart from the dementia wards, and was reported by staff as what they lacked. It also necessitated time with patients. Constraints on time included the legitimacy attached to such work by middle managers, staffing difficulties and the pressure of demand.

Although these dimensions of practice are not necessarily exhaustive, they were sufficiently sensitive to differentiate between wards in our sample, suggesting a continuum of supportive practices and the factors that contributed to them. On wards where practice was generally poor for people with dementia in the terms considered above, a vicious circle operated. Inadequate staffing, including the widespread use of temporary staff without the necessary skills and knowledge to work with patients with moderate to severe cognitive impairment, meant that getting through daily routine tasks was a challenge; this contributed to a care environment in which there was neither time nor space to reflect on practice, which in turn affected the levels of distress of patients on the ward, taxing the skill level of staff to respond appropriately; resulting in staff stress and low morale and seeing the patient as the problem. The pattern of work reflected in this vicious cycle could be temporary, resulting from a particular confluence of organisational factors; or it could evolve as routinised practice, with little energy or headroom to change. Even within such wards, there were staff who sought to provide an empathic and supportive response to patients with dementia, but were under considerable stress. Overall, such environments were not conducive to engagement in service improvement initiatives either.

Person, Interactions and Environment implementation

Person, Interactions and Environment was fully adopted in only 2 out of 10 study wards; and had proceeded to innovation and sustainability in those. Evidence from observation and staff interviews on both wards suggests that the programme had a significant impact on practice. There was evidence that practice change positively affected the experience of patients and caregivers, although the heterogeneity of need and severity of impairment meant that some of the more visible changes did not affect everyone equally. We are unable to draw any conclusions about the effect of PIE on clinical outcomes, as data on delirium and falls were not collected on these wards.

The successful engagement in PIE from installation to adoption and sustainability required a 'driver', outside the day-to-day demands of managing a ward, whose professional authority and vertical networks legitimated the work of improvement in the face of competing priorities; a 'facilitator' to provide support and encouragement, typically the ward manager, to legitimate staff time and investment in PIE and extend its reach to the wider staff team; and team members to pursue action on the ward and generate interest from colleagues, an additional factor in extending the reach of the intervention. The PIE 'driver' was critical in getting the change process started and keeping it going, particularly in the light of the day-to-day pressures on ward staff. These included staff sickness and movement; crises events with major impact, such as temporary ward closures resulting from norovirus outbreaks; and periods of high demand on beds during 'winter pressures', a misnomer insofar as 'winter' pressures extended over most of the year. This confluence of aspects of leadership at ward level was enabled by features of the organisational context at trust and executive level: clear and consistent focus on care quality, and 'fit' between practice change and strategic priorities on dementia.

In exploring why some wards proceeded to full adoption of PIE and others only partially adopted it or did not adopt it at all, we examined the relationship between what was intended to happen, what actually

happened and the interface with the organisational context over time. Factors contributing to failure to proceed with PIE installation were multiple and interactive. They included absence of one or more aspects of 'leadership' (drivers, facilitators, teams or networks), a lack of congruence between PIE and strategic initiatives on dementia, and a lack of resources to provide the headroom for staff to pursue service improvement.

Although these factors are local expressions of forces operating at meso and macro levels, the degree of organisational instability and turbulence encountered was surprising: 4 out of the 10 wards closed during the study, either suddenly or over a protracted period, affecting the staff investment in a collective shared future that is critical to a culture of service improvement.

Conclusions and limitations

When implemented, PIE has the potential to improve the care of older people on acute wards living with dementia. However, the findings are indicative for two reasons. First, as data on delirium and falls were not systematically collected on wards where PIE was implemented, there is no evidence on whether or not the programme is effective in improving clinical outcomes. Second, although PIE worked as intended on two wards to effect change in practice, it was not adopted in most study wards. Partial or non-adoption was affected by a change in ward 'readiness' to pursue service improvement between site recruitment and programme installation; the absence of 'drivers' and 'facilitators' to harness the energy and creativity of front-line staff to make change happen; and sufficient staffing to provide the 'headroom' to reflect on practice, try out possible solutions and review progress. At a general level, these reinforce the conception of organisational context not as a background to action but as an interacting element in the change process. In the specific context of PIE implementation on these NHS wards, the degree of system turbulence expressed in staffing shortages, ward closures and remodelling created an environment in which high work pressures and future uncertainty meant that the investment required for improvement was not forthcoming.

Research implications

The combined and interactive effect of advanced older age, dementia exacerbated by delirium, chronic health problems and acute events presents enormous challenges for staff in providing quality care. There is a pressing need for further research to identify more precisely the skill mix and resources necessary to provide person-focused care to this frail patient group across the spectrum of need. Specifically, what skill mix, training and resources are necessary to provide the appropriate 'balance of care' to respond to this complexity?

Implementing innovations to change practices in complex organisations, such as acute wards, requires a more in-depth understanding of contextual factors that have an impact on the capacity of organisations to absorb and embed new practices. Longitudinal research is needed that examines the dynamic between interventions and the environments in which they are inserted. In particular, we require understanding of what are 'receptive change' contexts to secure quality improvement. This suggests a parallel line of investigation to that focusing on application of theories to the development and implementation of interventions to improve quality. More specifically, in the NHS context, there is need for research on the impact of different organisational cultures on innovation and service improvement.

Funding

Funding for this study was provided by the Health Services and Delivery Research programme of the National Institute for Health Research.

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 11/1017/18. The contractual start date was in February 2013. The final report began editorial review in March 2017 and was accepted for publication in July 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 Godfrey 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).

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 editors: www.journalslibrary.nihr.ac.uk/about/editors

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