Managing Faecal INcontinence in people with advanced dementia resident in Care Homes (FINCH) study: a realist synthesis of the evidence

Claire Goodman,[1]* Christine Norton,[2] Marina Buswell,[1] Bridget Russell,[1] Danielle Harari,[3,4] Rowan Harwood,[5] Brenda Roe,[6] Jo Rycroft-Malone,[7] Vari M Drennan,[8] Mandy Fader,[9] Michelle Maden,[10] Karen Cummings[11] and Frances Bunn[1]

[1]Centre for Research in Primary and Community Care, University of Hertfordshire, Hatfield, UK
[2]Florence Nightingale Faculty of Nursing and Midwifery, King's College London, London, UK
[3]Department of Ageing and Health, Guy's and St Thomas' NHS Foundation Trust, London, UK
[4]Division of Health and Social Care, King's College London, London, UK
[5]Health Care of Older People, Nottingham University Hospitals NHS Trust, University of Nottingham, Nottingham, UK
[6]Faculty of Health and Social Care, Edge Hill University, Ormskirk, UK
[7]School of Healthcare Sciences, Bangor University, Bangor, UK
[8]Centre for Health and Social Care Research, Faculty of Health, Social Care and Education, Kingston and St George's, London, UK
[9]Health Sciences, University of Southampton, Southampton, UK
[10]School of Health Sciences, University of Liverpool, Liverpool, UK
[11]Order of St John Care Trust, Witney, UK

*Corresponding author c.goodman@herts.ac.uk

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

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Scientific summary

The FINCH study

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Scientific summary

Background

Eighty per cent of care home residents in the UK are living with dementia. The prevalence of faecal incontinence (FI) in UK care homes is estimated to range from 30% to 50%. FI has a negative impact on a person's quality of life, dignity and comfort, and staff morale. There is a paucity of evidence on how to reduce and manage FI in care homes. For this realist synthesis, FI was initially defined as the involuntary loss of liquid or solid stool that is a social or personal hygiene problem. The aim was to provide a theory-driven explanation of the effectiveness of programmes that aim to improve FI in people with advanced dementia in care homes.

Objectives

- To identify which interventions could potentially be effective, how they work and on what range of outcomes.
- To establish what evidence there is on the relative feasibility and (when appropriate) cost of interventions to manage FI.

Review methods

The realist synthesis followed RAMESES (Realist And Meta-narrative Evidence Syntheses: Evolving Standards) guidelines (Wong G, Greenhalgh T, Westhorp G, Buckingham J, Pawson R. RAMESES publication standards: realist syntheses. *J Adv Nurs* 2013;**69**:1005–22). To define the scope of the review and establish candidate theories for further testing in the literature, we consulted on the principles of good practice in continence care for this population with five stakeholder groups and collated and summarised existing literature to identify theories that could explain what supported the reduction and management of FI for care home residents, when and with what outcomes. We systematically searched the published and unpublished evidence and tested possible links between context–mechanism–outcome (C–M–O) configurations within and across the evidence reviewed. To test and refine emergent propositions of what supports effective care in what circumstances for people living in care homes with dementia and FI, we discussed findings and implications for future research and practice with a purposive sample of stakeholders.

Data sources

Four separate searches were completed in phase 1, which were refined and expanded in phase 2. Databases searched included PubMed, Cumulative Index to Nursing and Allied Health Literature, The Cochrane Library, Scopus, SocAbs, Applied Social Sciences Index and Abstracts BiblioMap, Sirius, OpenGrey, Social Care Online and the National Research Register.

Data extraction

Bespoke data extraction forms based on the programme theories were populated according to what the evidence revealed about C–M–O configurations of the different programme theories and the patterns that cut across the evidence to either support or negate them. All members of the team were involved in data extraction and all papers were read by at least two members.

Results

The scoping phase identified six programme theories with related C–M–O configurations that could explain how to improve continence care for people living with dementia and FI. These were (1) clinician-led support, assessment and review, (2) ongoing teaching, review and feedback for care home staff on how to reduce and manage FI, (3) addressing the causes and prevention of constipation, (4) interventions that reflect the degree of cognitive and physical capacity of the resident, (5) a common understanding of the potential for recovery, reduction and management of FI and (6) when care of people living with dementia and FI is integral to the everyday work patterns of the care home and its staff. The scoping also identified the limitations of defining FI solely in terms of elimination without linking it to how a dementia diagnosis can affect toileting behaviours and recognition of the need to defaecate. Detailed data extraction was completed on 62 core papers with iterative searches of linked literature.

Dementia was identified as a risk factor for FI, but the evidence we reviewed did not address in sufficient detail the way in which dementia affects the uptake of different interventions or the dementia-specific continence skills that staff require. Most care home residents with FI will be doubly incontinent, which suggests that there is limited value in focusing solely on FI or on one possible cause of FI such as constipation. Clinical assessment, knowledge of the causes of FI, including nutrition, hydration, constipation, and pharmacological and behavioural approaches such as exercise, prompted voiding and strategies that recognise the individuals' preferences and priorities are necessary contextual factors. To achieve change in continence-related practice or resident outcomes, however, it is *how* staff can act on their knowledge and training and whether or not an intervention 'fits' into the everyday care work of a care home that are important. The valuing of the intimate and personal care work that care home staff provide to people living with dementia and the recognition of the challenges that arise when providing continence care, we propose, are what link evidence on best practice with care home staff's capacity to implement practices that are likely to reduce and manage FI in this population.

Limitations

The review and synthesis of key contextual factors were constrained by the limited evidence from the UK setting on supporting continence care in care homes. From the evidence we reviewed, we were unable to address our objective on the relative feasibility and (when appropriate) cost of interventions to manage FI or to consider how differences in care home staffing, staff experience and staff qualifications are linked to resident outcomes.

Family carers of people living with dementia and FI identified it as a limitation that FI and impact of dementia-specific behaviours on contamination of the shared environment, carer stress and risk of cross-infection were not addressed. Neither were we able to provide, from the evidence reviewed, a theory of how best to assess a person's need for continence aids, specifically pads (and what type), at different points in the dementia trajectory and as an aid in the daily management of FI.

Conclusions and implications for health care

This realist synthesis provides a theory-driven understanding of the conditions influencing how care home staff understand continence care and the conditions under which improvement is likely to be successful. Medical and nursing support for continence care is an important resource, but it is unhelpful to create a distinction between what constitutes continence care and what constitutes personal or intimate care. Valuing the work of unqualified and junior staff and providing ongoing support and reinforcement of good practice and education in ways that are meaningful to this workforce are important clinician-led activities. The focus on avoiding or treating constipation may be exacerbating FI, and careful thought

needs to be given to how the assessment and management of constipation is linked to other activities that promote bowel health and the reduction and management of FI.

Recommendations for research

Future research should assess how the functional abilities, behaviours and responses of the person living with dementia affect their ability to benefit from different care home sensitive interventions that address both faecal and urinary incontinence. In addition, future studies should include clear costings of time and resources used in any intervention.

Study registration

This study is registered as PROSPERO CRD42014009902.

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