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Review Article

What Works to Improve and Manage Fecal Incontinence in Care Home Residents Living With Dementia? A Realist Synthesis of the Evidence



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The prevalence of fecal incontinence (FI) in care homes is estimated to range from 30% to 50%. There is limited evidence of what is effective in the reduction and management of FI in care homes. Using realist synthesis, 6 potential program theories of what should work were identified. These addressed clinician-led support, assessment, and review; the contribution of teaching and support for care home staff on how to reduce and manage FI; addressing the causes and prevention of constipation; how cognitive and physical capacity of the resident affects outcomes; how the potential for recovery, reduction, and management of FI is understood by those involved; and how the care of people living with dementia and FI is integral to the work patterns of the care home and its staff. Dementia was a known risk factor for fecal incontinence (FI), but how it affected uptake of different interventions or the dementia specific continence and toileting skills staff require, were not addressed in the literature. There was a lack of dementia-specific evidence on continence aids. Most care home residents with FI will be doubly incontinent; there is, therefore, limited value in focusing solely on FI or single causes, such as constipation. Medical and nursing support for continence care is an important resource, but it is unhelpful to create a distinction between what is continence care and what is personal or intimate care. Prompted toileting is an approach that may be particularly beneficial for some residents. Valuing the intimate and personal care work unqualified and junior staff provide to people living with dementia and reinforcement of good practice in ways that are meaningful to this workforce are important clinician-led activities. Providing dementia-sensitive continence care within the daily work routines of care homes is key to helping to reduce and manage FI for this population.

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Fecal Incontinence in Care Home Residents Living With Dementia

Approximately 80% of residents in nursing or care homes have dementia or memory problems,^{1–6} and the prevalence of FI is estimated to range from 30% to 50%.^{1–3,6–8} Dementia is an independent risk factor for FI.^{2,9,10} FI is defined as the involuntary loss of liquid or solid stool that is a social or personal hygiene problem.¹¹ FI is distressing, humiliating, and potentially stigmatizing for any adult. Managing another adult's excrement is outside the usual expectations, and can engender emotions of disgust and distaste.¹²

Current evidence about FI in people in long-term care settings is mixed, with some good evidence on risk factors,^{1,13} the impact of comorbidity,¹⁴ and the impact of different organizational contexts.^{3,9,10} There are few intervention studies and little conclusive evidence of what is effective management of FI in people resident in care homes.^{15,16} Care homes are the main providers of long-term care for older people in many developed countries and accommodate those who require help with personal care and are unable to be supported in their own home due to medical, functional, or mental health problems. They include settings that have on-site nursing provision and those that do not. They are often administered by a nonclinical manager in many countries. This article reports the main findings of a realist review and synthesis of evidence for the management of FI in older people with dementia in care homes.¹⁷ The definition of care homes includes nursing homes, residential homes, aged long-term care, assisted living facilities, and dual-registered homes.

The objectives of the review were to

1. Identify which interventions to reduce and manage FI could potentially be effective, how they might work, on what range of outcomes (ie, organizational, resource use, and patient level of care), and for whom (or why they do not work)
2. Establish evidence on the relative feasibility and cost of interventions to manage FI

Realist Review

Realist review is a theory-driven approach to reviewing a range of published and unpublished literature, whereby evidence is assessed and used based on its relevance in terms of contributing to (and testing and refining) an emerging understanding about the different aspects of an intervention and how it may work.^{18–20} Interventions to reduce and manage FI in care homes are always complex and their outcomes are context-dependent. Realist approaches emphasize understanding causation in terms of how interventions generate outcomes through the medium of human decisions and reactions that are themselves affected by social context.^{18,20} The often-repeated statement used to explain realist review is that it makes explicit “what works, for whom, in what circumstances?” The focus on causal mechanisms and necessary conditions for success ensures rigor, even when contributing evidence may be of variable quality.

Methods

The review had 3 linked phases: an initial scoping of the evidence to refine the question and build potential midrange theories about what determines “good” care in the reduction and management of FI (scoping searches and stakeholder interviews); an in-depth review phase to test and refine the proposed theory areas (continuous literature searching, retrieval, inclusion/exclusion, data extraction, review, and appraisal); and a final testing, refining, and validation phase (theory testing, refining, and stakeholder review). Further details are available in the protocol²¹ and final report of the review.¹⁷ Ethics approval was obtained

via the University of Hertfordshire ethics committee: University of Hertfordshire protocol reference HSK/SF/UH00088.

Review methods and reporting for the realist synthesis followed the RAMESES (Realist And Meta-narrative Evidence Syntheses: Evolving Standards) guidelines.²⁰ An iterative approach was used to define the scope of the review and identify potential candidate theories for testing in the literature. Context–Mechanism–Outcome configurations (CMOs) were used as a tool to understand what is going on in interventions. This does more than describe barriers and enablers, it theorizes how interactions among the environment, the people, and the resources may result in different patterns of outcomes. We asked, “what does good continence care looks like?” and used multiple sources of evidence within key contexts (C) and we hypothesized mechanisms (M) of interventions to explain the outcomes (O) (see [Box 1](#)). We tested the CMOs against the relevant evidence to build context-sensitive theory providing causal explanations for different settings, situations, and participants of what supported the reduction and management of FI for residents in care homes when and with what outcomes. Published and unpublished evidence was systematically searched and used to test possible CMOs within and across the evidence reviewed. Four separate searches were undertaken in phase 1, and in phase 2 these were expanded and refined (see [Boxes 2 and 3](#)). All strategies are available on request and available in the full report.¹⁷ Databases searched included PubMed, CINAHL, The Cochrane Library, Scopus, SocAbs, ASSIA, BiblioMap, Sirius, OpenGrey, Social Care online, and the National Research Register without date restrictions up to March 2015.

Five stakeholder group interviews were conducted with a purposively selected sample of care home managers, care home staff, service user representatives, practice educators, academics, clinicians (ie, doctors, nurses, and allied health professionals) with specialist interest in FI, continence specialists, and commissioners and providers of continence services (n = 44), as well as incorporating our own prior knowledge of this field. Interviews were used to explore assumptions and theories of what was important for the effective care of people living with FI and dementia. Interviews were recorded, transcribed, categorized thematically, and analyzed on how different participants described what good continence care looked like, what needed to be in place to achieve it, and how effectiveness could be measured. Field notes also were taken to capture *how* participants discussed different issues within the group, where there appeared to be uncertainty and consensus. Data from the scoping searches and interviews were used to develop narratives, tables, and summary diagrams that captured

Box 1. Definitions of realist terms and how they have been applied throughout the review

- Context (C): Context can be broadly understood as any condition that triggers and/or modifies a mechanism; the background situation, for example, clinical assessment, provision of training, resident's diet and hydration, or cost of continence aids.
- Mechanism (M): A mechanism is the generative force that leads to outcomes. It may denote an action or reasoning of the various “actors” (ie, care home staff, residents, relatives, and health care professionals). Identifying the mechanisms goes beyond describing “what happened” to theorizing “why it happened, for whom, and under what circumstances.”
- Outcomes (O): Intervention outcomes; for example, reduction in episodes of FI, reduction in resident distress, family caregiver satisfaction with care, staff confidence, costs. An outcome of one CMO configuration may be the context of another CMO configuration.

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