# Editorial: Management of Faecal Incontinence in older people with dementia resident in Care Homes: A realist synthesis – The FINCH Study

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Many nursing homes provide continuing care and support for older people with dementia (1). Care home residents may have three or more health conditions, with an estimated 80% in the United Kingdom having dementia without a confirmed or documented diagnosis, up to a third of whom may be at an advanced stage (2, 3). In this editorial the term care home is used and includes registered homes providing nursing, social and/or continuing aged care. Advanced dementia is variably defined but usually includes complete loss of memory and recognition, severe dependency for activities of daily living, (such as bathing, dressing, toileting and feeding), poor or absent communication, incontinence, poor mobility, difficulty swallowing and weight loss (4). The prevalence of faecal incontinence (FI) in care homes ranges from 30% to 50% (5, 6,7,8,9,10), with dementia being an independent risk factor for FI (6,11, 12). FI four times higher in people with confirmed dementia compared to matched community samples (13). FI has a negative impact on dignity, comfort, quality of life and staff morale. There is a paucity of evidence on how to manage FI in older people with advanced dementia in care homes despite practice guidelines for managing FI being available.

Recent philosophical and methodological developments have challenged the dominant medical focus on randomized trial evidence, especially for complex clinical problems and interventions. Randomised controlled trials and conventional systematic reviews, give high degrees of confidence about causal relationships between treatments and outcomes. But generalisability may be uncertain, and non-trial evidence is difficult to use. Realist review and synthesis attempts to address this, by asking the question what works, for whom, under what circumstances, and why? Hypotheses, called Context-Mechanism-Outcome configurations (CMOs) are proposed and evidenced from a variety of study designs in the literature. The focus on mechanisms and necessary conditions for success allows for rigour, even when raw contributing evidence is of variable quality. The process is guided by a multi-disciplinary external steering committee and interviews with relevant stakeholders. This approach was used to investigate the problem of managing FI incare homes for people with advanced dementia (the National Institute for Health Research FINCH study).

To address the lack of evidence on FI in care homes the recently published FINCH study comprised a realist review and synthesis (14). The objectives were to identify interventions or elements that could potentially be effective, how they work and the range of outcomes. To identify barriers and facilitators to their uptake, acceptability and implementation in managing FI in people with advanced dementia in care homes. Also, to establish evidence on feasibility and cost of interventions to manage FI. The full report is available (14) and a paper from the realist review by Buswell et al (15) is published in this current issue of JAMDA.

For the review FI was not considered an inevitable consequence of aging or dementia. It was defined as the involuntary loss of liquid or solid stool that is a social or hygienic problem (16) and "the voiding of urine or faeces either following an unsuccessful effort, or with no attempt to employ an acceptable facility (e.g. toilet, commode)" (17). Six theories related to how to improve continence care for people living with dementia and FI in care homes were identified. These were: 1. Clinician led support, assessment and review; 2. Ongoing teaching, review and feedback to care 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. Common understanding of the potential for recovery and reduction of FI; 6. Integrating care for people living with dementia and FI into everyday work patterns of the care home and staff.

Results from an RCT (18) found people with more cognitive impairments were most responsive to prompted voiding. It was suggested, as they were unable to self-initiate drinking or toileting requests prompting protocols compensated for this and led to a higher degree of responsiveness compared to other residents with incontinence. Findings from qualitative research, found tension between patient-centred care (PCC) and care home priorities: the need for residents to appear clean and well-groomed was given priority over PCC (19). A realist approach can incorporate evidence from other areas, including urinary incontinence, other aspects of dementia care and what is known of the nursing home or care home context. For example, Saga et al (20) looked specifically at causes of FI while Stokes (17) investigated toileting difficulties for people with dementia. The work of Schnelle and colleagues for over 30 years has investigated single component, then multi-component complex interventions for prompted voiding and timed voiding taking into account, equipment, resources, education and training of staff, as well as quality control issues and implementation (14, p71). In our review, of the 20 continence studies that included people with dementia only 16 had an assessment of their dementia or confirmed diagnosis. Only one study considered the impact of dementia and the influence it had over the disease trajectory on interventions to improve UI in care homes (21).

The main findings of this realist review are that FI in care home residents is almost always in association with urinary incontinence. Solely focusing on resolving constipation can exacerbate FI via laxative induced diarrhoea. How the current status of dementia and subsequent trajectory affects a person's ability to benefit from different interventions for FI is unknown. Few studies have compared different designs of absorbent products for FI or considered the particular needs of people with dementia in care homes. Continence care is usually delivered by lowest paid frontline care staff in care homes and understanding that this is part of personal and intimate care is crucial. There is a mismatch of worlds - the research evidence world and the real world of direct care delivery. Personal and intimate care should assure privacy, respect, dignity and personhood. A particular ethical or moral issue when caring for people with FI and advanced dementia is the digital rectal examination recommended within guidelines for the management of FI (22). The findings of FINCH suggest that in practice digital rectal examination is not warranted for this specific client group and must be done selectively and traded against any potential distress it may cause.

In summary the overall findings are; very few intervention studies have investigated FI for people with dementia living in care homes. Many studies identify dementia as a risk factor for FI. Clinician led assessment and review are important foundations for good continence care and there is conflict between common understanding and care home work practices. Support of care staff to act on their training and knowledge to improve continence outcomes for people living with dementia is essential. Continence care is part of intimate care (14, 23). Providing intimate and personal care for people with dementia requires particular skills to minimise distress and maximise their comfort. The implications for policy and practice are that interventions which give staff support and authority to act on their training would result in care focused on the person with dementia. Interventions that fit with the culture and work of the care home generate staff confidence that dependent continence (that is with support from care staff and / or treatment) can be achieved for people with dementia. Finally, interventions should recognise that continence care, is part of intimate and personal care and is in essence a valuable activity requiring specific dementia care skills.

1235 words

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