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Abstract: The prevalence of faecal 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 six potential 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; 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. Evidence reviewed revealed that dementia was a known risk factor for FI, but how it affected uptake of different interventions or the dementia specific continence and toileting skills staff require, were not addressed. 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 worth trying and 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 in this population.



Dear Professor Morley

**What works to improve and manage fecal incontinence in care home residents living with dementia? A realist synthesis of the evidence.**

There is a long history of research into improving the continence care of older people living with dementia in long term settings. The challenge, as several JAMDA papers and Cochrane reviews have demonstrated is to deliver an intervention that is effective and, sustainable in care homes.

This paper has used a theory driven approach to reviewing the evidence, realist synthesis, to answer the question how interventions to reduce and manage fecal incontinence work, specifically for people living with dementia and in what circumstances. The work was funded by the National Institute of Health Research in recognition of the fact that being able to explain and understand “how” complex interventions work can be as important as judgement and summation.

Taking a realist approach has enabled us to provide a critical account of what needs to be in place for people living with dementia and fecal incontinence. It provides a plausible and rigorous account of the importance of defining incontinence in people living with dementia as a toileting behavior, designing interventions as integral to personal care and investing in developing the dementia care skills of the least qualified members of the workforce.

This paper accompanies an editorial by Professor Roe that you commissioned, following her presentation of this work at the Barcelona care homes conference.

We hope that you will consider it for publication.

Yours sincerely,

Marina Buswell  
FINCH research team

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## **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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Key Words: Fecal incontinence, older people, dementia, care homes, person centred care, residential care, nursing homes, care assistants, constipation

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# What works to improve and manage fecal incontinence in care home residents living with dementia? A realist synthesis of the evidence.

## Abstract

The prevalence of faecal 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 six potential programme 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 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.

## **Fecal incontinence in care home residents living with dementia**

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

Current evidence about FI in people in long term care settings is mixed, with some good evidence on risk factors,<sup>1, 13</sup> the impact of co-morbidity,<sup>14</sup> and the impact of different organizational contexts.<sup>3, 9, 10</sup> There are few intervention studies and little conclusive evidence of what is effective management of FI in people resident in care homes.<sup>15, 16</sup> 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 non-clinical manager in many countries. This paper 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.<sup>17</sup> 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 fecal incontinence could potentially be effective, how they might work, on what range of outcomes (i.e. organizational, resource use and patient level of care) and for whom (or why don't they work)
2. Establish evidence on the relative feasibility and cost of interventions to manage fecal incontinence

### **Realist review**

Realist review is a theory-driven approach to reviewing a range of published and unpublished literature, where 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.<sup>18-20</sup> Interventions to reduce and manage FI in care homes are always complex and their outcomes are context-dependent. Realist approaches emphasise understanding causation in terms of how interventions generate outcomes through the medium of human decisions and reactions that are themselves affected by social context.<sup>18, 20</sup> 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 assures rigor, even when contributing evidence may be of variable quality.

### **Methods**

The review had three linked phases: an initial scoping of the evidence to refine the question and build potential mid-range 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 protocol<sup>21</sup> and final report of the review.<sup>17</sup> Ethics approval was obtained via the University of Hertfordshire ethics committee: University of Hertfordshire protocol reference HSK/SF/UH00088.

Place Box 1 around here.

Review methods and reporting for the realist synthesis followed the RAMESES guidelines.<sup>20</sup> 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 theorises how interactions between 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) we hypothesised mechanisms (M) of interventions to explain the outcomes (O) (See Box 1 - CMO). We tested the CMOs against the relevant evidence to build context sensitive theory providing causal explanations for different settings, situations and participants (18) 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 one and in phase two these were expanded and refined (See Boxes 2 & 3 Examples of



literature search strategy). All strategies are available on request and available in the full report.<sup>17</sup> 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.

Place boxes 2 & 3 around here.

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 (i.e. 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, categorised thematically and analysed 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 were also 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 multiple areas of what needs to be in place to achieve improved resident outcomes for FI (e.g. continence, dependent continence, appropriate use of pads, comfort, personalised care, minimisation of distress, skin integrity). This made explicit the interactions between the environment, people and resources that may result in different CMO configurations and outcome patterns.

Searches retrieved 1500 potentially relevant sources: empirical studies, policy and staff guidance documents, book chapters and theses. A total of 287 sources were examined during the project and we systematically extracted data from 62 core papers selected based on their relevance to the developing theories. Agreement was reached by consensus within the team. Bespoke data extraction forms were populated by all members of the project team with all papers read independently by at least two people. Data were extracted on type of literature (e.g. intervention study, observational study, policy document etc.), country, setting, methods, study outcomes, and which theory areas they related to. Quality assessments were completed for the eight intervention studies using a modified version of the Cochrane risk of bias tool.<sup>22</sup>

Data extraction captured the evidence on CMO configurations of different theories and patterns that were supported or negated. The emergent propositions of what supports effective care for people living in care homes with dementia and FI were tested, refined and validated by finally discussing findings and implications for future research and practice among the project team and with a purposive sample of stakeholders (from phase 1).

## **Results**

Six broad theory areas were identified that could explain how to improve continence care for people living with dementia and FI in care homes. 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. The key findings from group interviews and evidence for the different CMOs are presented.

### **Stakeholder group interviews and literature scoping**

Whilst all stakeholders highlighted how distressing FI could be for both residents and staff and how important it was to know the resident, there were differences in emphasis among different groups. For example, doctors focused on the issues such as 'regular assessment' and nutrition and hydration, whereas direct carers and family focused on approaches that stressed knowing the resident's biography, and that promoted empathy and clarity/leadership within the care home. These findings were summarised by stakeholder groups' accounts of what is effective summarised as possible C-M-O configurations. The detailed tables are available in the full report.<sup>17</sup>

Evidence from the scoping review was summarised in four broad narratives:

1) A cumulative programme of work in continence research in nursing homes in the United States by Ouslander, Schnelle et al<sup>23-37</sup> demonstrated how interventions have been progressively refined over time with an increasing emphasis on the involvement of care home staff in training and structured programmes of prompted voiding. There was, however, a lack of evidence or guidance about how to implement these approaches in settings with limited access to doctors or how a person's dementia will have an impact on implementation.

2) A wider care home literature on what needs to be in place when introducing new interventions to improve care for people with dementia in care homes that were predicated

on person centred approaches. This included interventions such as person-centred care, medicine management, therapy interventions<sup>38, 39</sup> and non-pharmacological approaches to the reduction and management of behavioural and psychological symptoms of dementia (BPSD).<sup>40-46</sup> The relevant learning from these studies was that training, learning, mentoring and post-training support are important but do not of themselves lead to staff engagement and motivation to change practice or care routines.

3) Guidance and review articles relevant to the management of FI in older people living in care homes/long term care.<sup>47-58</sup> This work emphasised the importance of assessment, nutrition, hydration and the diagnosis of faecal impaction. The underlying narrative being that clinical assessment was essential, but how this was achieved lacked detail, particularly in care home settings for people living with dementia. The scoping highlighted a gap in the research between studies focussed on solely dementia care and those focussed solely on continence care. This gap is picked up later in the paper where we assess how included continence studies measured and considered dementia.

4) Absorbent products for FI: Although extensively used in care homes for the management of FI we found very few studies that have compared the different designs of absorbent products.<sup>59-64</sup> The emphasis has been mainly on testing pads with patients with urinary incontinence (UI) and the studies did not consider how dementia affects the person's use of continence aids nor their use for FI.

## ***Outcomes***

From the stakeholder interviews and across the different types of literature the reduction of distress and improvement in symptoms were important measures of effectiveness but there

was little consensus on what might be other important outcomes (see Supplementary online sources S-Table 1). Cost related outcomes in particular are not well defined or measured.

### ***Clarifying definitions of fecal incontinence and dementia***

The scoping identified the need for a more dementia focussed definition of FI that sees it as an aspect of ‘toileting difficulties’ that may be experienced by people living with dementia.

Toileting difficulties are the ‘voiding of urine or faeces either following an unsuccessful effort or with no apparent attempt to use an acceptable facility.’<sup>65</sup> This conceptualisation reframes continence in the social and environmental context. How the original definition of ‘involuntary loss’ translates to people with dementia and FI in studies is unclear, with the frequency of FI episodes classed as constituting FI differing between studies. Fecal incontinence in this broader definition is recognised as having multiple causes that may include constipation, cortical atrophy, neuropsychological, sensory disability, physical disability – mobility and dexterity, medication effects – sedatives, antidepressants, diuretics, psychological factors – personality, habits, life experience and mood. All of which are further compounded by the care home design including distance to the toilets, obstacles, visual access, signage and the actions and attitudes of others.

The original review brief was to look at *advanced* dementia however the lack of continence studies addressing dementia, inconsistency in how dementia is assessed and recorded for care home residents, coupled with the lack of consensus as to how to define “advanced dementia” in relation to continence care, meant that the distinction between dementia and advanced dementia was not useful. Moreover, as FI in care home residents is almost always

associated with UI,<sup>66</sup> there was limited value in focusing solely on FI in people living with dementia (PLWD) and so UI evidence was also considered.

### **Theory Testing**

The six theory areas were tested with the evidence from the 62 included sources. The detailed data extraction forms noted for which theory area(s) the source had relevant evidence (confirming or disconfirming), and multiple CMO configurations specific to the source. Table 1 gives an overview of the type of evidence by broad research themes and shows the diversity of evidence used. We now present the evidence by theory area.

Place Table 1 around here

#### ***Theory 1: Clinician led support, assessment and review will achieve observable***

##### ***improvements in FI***

This area reflects the assumptions and training of clinicians. Twenty-one sources were relevant to this area.<sup>8, 30, 37, 50, 67-83</sup> Evidence suggested that when clinicians (specifically geriatricians) apportion time and energy to working with care homes they can drive improvements in the prevention and management of FI. However, studies did not specify exactly what the clinicians' role entailed. Nor was it clear if the improved outcomes applied to people living with dementia or if having dementia impacted on someone's ability to benefit. This approach is much influenced by the seminal study of Tobin and Brocklehurst,<sup>69</sup> which concluded that most FI was due to fecal impaction and could be resolved with 'simple measures'. However a study 20 years on by Akpan et al<sup>71</sup> found that FI was not resolved in their sample of nursing home patients and suggested that either the original study does not apply to current nursing home populations (who are now significantly older, with more co-

morbidities and severe cognitive impairment) or findings are not being implemented, or both.

Review and guidance literature (that was summarized in the scoping review) notes the high prevalence of FI in physically and cognitively impaired patients and describes available physical examination and diagnostic tests. Details on how to take a history and complete examinations in PLWD are not provided. Difficulties achieving the ideal level of investigation and assessment, especially in long-term care facilities were noted. Current literature does not address the complexity of delivering interventions for PLWD who have FI.

***Theory 2: Ongoing teaching, review and feedback to staff on assessment and how to reduce and manage FI***

The importance of clinician assessment is linked to the assumption that giving staff access to the appropriate training, education and facilitation will result in a change in practice. This area is important to consider as so many care-home interventions employ a training, education or facilitation approach. Sixteen sources were relevant to this area with some detailed accounts of implementing interventions through training and education.<sup>29, 30, 73-75,</sup>

83-93

Two papers reporting the use of distance coaching and coursework in US nursing homes<sup>29, 30</sup> found qualified support for using this approach to encourage staff (mostly nurses) to implement prompted voiding. One third of nursing homes dropped out of the program. However, for those completing the courses there was improvement in knowledge (average pre-test to post test score improvement, independent *t*-test) – course 1 participants (N=15) 57% to 73% (P=0.01) and course 2 (N=35) participants 57% to 85% (P < 0.001). Although the

authors discuss issues around feasibility of implementing this approach and clearly recorded and calculated costs of the training intervention, there was insufficient detail provided to understand which elements of the training were working for particular nursing homes or staff groups. Lack of “*time to do training*” was cited as a barrier, even though webinar timings were adapted to suit course participants. The wider care home literature<sup>41, 43, 44, 93</sup> highlighted similar issues around “*substantial time commitment*” required for training and mentoring. Results from a qualitative study on the implementation of psychosocial interventions in care homes to reduce anti-psychotic prescribing<sup>43</sup> suggest, that whilst knowledge, skills and time may be important contextual factors for implementing interventions in care homes, a key mechanism comes from activities that foster the development of a shared understanding of the problem and an enhanced status of the work. An example CMO from this study; a training program (to reduce anti-psychotic drug use in care homes) was delivered to all staff AND family members (C) this triggered a shared understanding about behaviors staff find challenging and the approaches that can be used to improve these (M) with the outcome (O) that staff groups and family work together to provide care to the resident and reduce the use of anti-psychotic drugs.

Evidence suggests offering more training for care staff on FI with structured guidelines and facilitation will not lead to better management or reduction of FI if it does not account for key contexts such as the work pressures of the care home or consider if staff have the autonomy to act. A recent study<sup>89</sup> testing the hypothesis “*that faecal incontinence can be prevented, cured, or ameliorated by offering care staff knowledge of best practice*” had difficulty recruiting nursing homes and found changes in the rates of FI were not sustained.



It was concluded *“For the main study, empowering RNs [Registered Nurses] in the nursing role and helping them find ways to best organize the work on their own unit and give feedback to the rest of the care staff will be important.”* Analysing evidence shows how contexts can be linked to outcomes by theorising potential mechanisms. Training interventions may be successful or unsuccessful depending on context and complex interactions of culture and practice.

***Theory 3: Knowledge on causes, management and prevention of constipation for older people with dementia***

A commonly held belief, supported with early empirical work<sup>94</sup> is that successful management of constipation, could lead to a reduction in FI for older people in institutionalized care. This theory area overlaps with Theory 1 (clinician led support and review). The key difference is that a focus on management of constipation, as a significant contributory factor of FI, will lead to overall improvement in FI.

Sixteen sources provided relevant evidence.<sup>8, 10, 23, 25, 33, 50, 72, 76, 77, 79, 80, 88, 90, 95-97</sup> A 1996 study<sup>23</sup> found that prompted voiding had increased continent bowel movements. They suggested the increase in physical activity and fluid intake resolved fecal impaction. Ten years later the same team warned, however, that overuse of laxatives as prophylactic treatment for constipation can result in FI<sup>25</sup>. Other studies<sup>68, 90</sup> found reduction in laxative induced FI did not arise due to better understanding of causes of constipation but from change in care home practice to routinely dispensing laxatives that had been prescribed *pro re nata* (PRN). More recent work by Saga<sup>96, 97</sup> found that a preoccupation of nursing staff with constipation and a person's bowel being empty meant care home staff accepted FI and used pads to

cope with the consequences. Evidence suggests that while knowledge of constipation and its causes is important, there could be unintended consequences, such as over use of laxatives and acceptance of use of pads.

***Theory 4: Interventions that reflect degree of cognitive and physical capacity of a resident – personalized care planning***

This theory area encapsulates the patient-centered care (PCC) approach that values individualization, empathic understanding and creating relationships to provide psychological needs: comfort, identity, inclusion, attachment and occupation, thereby promoting wellbeing and minimizing distress for people living with dementia. In this framing FI or its treatment is an aspect of health that may impact on the toileting difficulties people can experience.<sup>65</sup>

Thirty-one sources had evidence relevant to this area.<sup>23, 25, 33, 43, 44, 50, 67, 70, 73, 74, 80, 83, 88, 90-93, 96-</sup>

<sup>109</sup> Evidence suggested managerial support and endorsement were needed to embed PCC within a care home.<sup>92</sup> There was not, however, a shared understanding of what PCC involves in care home settings.<sup>92</sup> Lawrence et al<sup>43</sup> found that a person centered working style, and focus on residents as individuals with differing needs and preferences, could develop in settings where staff were encouraged to form bonds with residents rather than taking a task oriented approach. Studies that addressed the dementia specific issues of providing personal and intimate care to care homes residents<sup>91, 107</sup> offer transferable learning about what needs to be in place to reduce distress and minimize resistance to care. This work showed promise, but noted that “organisational factors”<sup>107</sup> and “facility wide culture change”<sup>91</sup> were important for implementation. One Australian study<sup>99</sup> illustrated the

tension that care home staff may experience when asked to implement PCC if, for example, the need for residents to appear clean and well-groomed was given priority over individualized approaches to care, such as prompted toileting.<sup>100</sup> To achieve outcomes, such as reduced resident distress, using a more reflective personalized approach requires both empathy and permission for staff to work in this way.<sup>34</sup>

Of 43 studies which addressed continence care in some form, only twenty included people living with dementia, of those, only sixteen assessed the severity of the dementia (a detailed summary of these twenty studies can be found in the full report)<sup>17</sup>. It is striking that, apart from the acknowledgement that dementia is a risk factor for FI and that this increases with immobility, only three sources specifically address dementia behaviors and FI within an intervention: two studies conducted in the early 1990's in an Alzheimer's disease unit focused on improving environmental clues (signage and removing the visual barrier to the toilet in patient's rooms). The studies provided some evidence that appropriate visual cues can encourage toilet visits for older people living with dementia in aged care facilities, but this may not translate to appropriate toilet use.<sup>104, 110</sup> The third source is a practice tool for direct care staff of people with dementia resident in care homes with a section specifically addressing continence care, including pictures of how best to help people use the toilet. Examples include, how to communicate non-verbally or what to do if someone 'freezes' and refuses to sit.<sup>111</sup>

***Theory 5: Establish a common understanding of the potential for recovery, reduction and management of FI for people with dementia***

This theory area posits that it is what staff belief about the potential for improvement or reduction in episodes of FI that determines the kind of continence care a person with dementia may receive.

Twenty-two sources contributed to this theory area.<sup>8, 33, 43, 50, 67, 69, 73, 75, 79, 85, 87, 91, 93, 96, 97, 99,</sup>

<sup>105, 107, 108, 112-114</sup> All were also associated with the theory areas around clinician led assessment and review, ongoing teaching, review and feedback and PCC approaches. In one multi-component prompted voiding study in a care home<sup>33</sup> people with cognitive impairment responded particularly well to the intervention. This suggests older people living with dementia can benefit from toileting assistance and prompting. A study in Norwegian nursing homes found that some staff have negative perceptions about the possibility of improving FI in PLWD and felt that it was not worth pursuing interventions other than pads.<sup>97</sup> This suggests a lack of shared understanding around the potential for reduction of FI is an important context that triggers a resistance in staff uptake of learning in FI care. Thus should be acknowledged and addressed in interventions, but may not be the key factor.

***Theory 6: Integral to the everyday work pattern and environment, “fit”***

Recurring narratives from the care home research reviewed under the other theory areas underlined the need for new approaches to care to fit within existing structures of authority and working practices in the care home. Forty-one sources were relevant to this theory area.<sup>8, 26, 29, 30, 43, 44, 68, 70, 71, 73, 74, 76, 78-80, 84-88, 90, 92, 93, 98-100, 104-110, 114-121</sup> Burgio and Engel<sup>84, 85</sup>

investigating behavioral treatments for UI and FI (in the 1990's) concluded “*the only two*

*mechanisms by which toileting programs are likely to succeed: one is by increasing the number of trained personnel and the other is by redistributing staff time...*<sup>85</sup> This indicates this theory is not new but has not been previously explored with particular reference to residents who are living with dementia or how continence related care is framed in the day to day work of care home staff. For staff to believe that change is possible enough time, encouragement and support are required.

How the “fit” with working practices was expressed ranged from whether the intervention was embedded in team working, related to normal working practices of staff and if staffs’ continence work was embedded in their daily work. Rovner and colleagues<sup>119</sup> identified physicians completing documentation, and being involved in ongoing discussion with staff, as the potential reason their intervention was sustained (for nine months after the end of the study period). The intervention was a work priority for all staff and ongoing involvement of the clinician endorsed the activity.

Saga<sup>97</sup> noted that a resident’s need for assistance was a trigger or “protective” factor for FI, with staff being more proactive in supporting the achievement of dependent continence in patients who needed help transferring from a bed to a chair.

An Australian study on continence care in care homes depicted continence care as *‘Caring against the odds’* and was characterized by four major sub-categories: (1) *working in a highly regulated work environment*; (2) *encountering ethically challenging situations*; (3) *highly dependent residents*; and (4) *a devalued role.*” (p5).<sup>99</sup> This analysis goes beyond earlier statements about needing time and demonstrates that an important context is whether the intervention explicitly addresses care home specific patterns of working.

## Discussion

Dementia is a risk factor for faecal incontinence and in care home residents is almost always present in conjunction with urinary incontinence. The testing of different program theories of what needs to be in place to reduce or manage FI established that solely focusing on resolving constipation can exacerbate FI. It also demonstrated the importance of making the link between continence care and intimate care of people living with dementia. Continence care is delivered by lowest paid frontline care staff in care homes. Understanding how their contribution affects uptake of practices that are likely to be beneficial (for example assessment, working with clinicians, regular toileting) is key. The review highlighted two areas of dissonance in how research on FI has been undertaken. Firstly, a limited engagement in the research with how living with dementia affects a person's ability to benefit from continence led interventions and secondly, a mismatch between what researchers consider achievable, and the real world of direct care delivery.

How the dementia 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 the particular needs of people with dementia in care homes. Clinical, educational and PCC approaches may be uncontentious. Constipation should never be ignored but may not be as important an etiology, as the use of laxatives in long term care settings. Activities such as clinical assessment and a focus on PCC need to support the development of a 'common understanding' among clinicians, staff, families and residents. Use of the evidence of what reduces and manages FI needs to both fit with working

practices of the care home, and recognises the dementia care skills the least qualified staff might need.

### Strengths and weaknesses

A strength of this synthesis is that it provides a comprehensive account of what influences, supports and inhibits practices that can promote better reduction and management of fecal incontinence of people living with dementia in care homes. It developed and tested a theoretical understanding of what supports the reduction and management of FI in long term care settings. We tested and debated the relevance and resonance of the emergent findings with stakeholders at each stage of the review. From the outset the paucity of evidence on what is effective was known but in realist terms, even when the desired outcomes were not achieved it was possible to learn from the evidence and develop a theoretical understanding of what needs to be in place. The inclusion of a wider literature (e.g. around bathing, and reduction of antipsychotic prescribing) that has similar preoccupations and challenges has demonstrated recurring preoccupations around containment (in this case of behavior), the significance of care home routines on uptake of interventions and how living with dementia reframes how everyday clinical problems and activities are assessed and addressed. The findings suggest that FI related interventions that fail to tailor practices to fit with care home working, or don't provide ongoing support to staff on dementia informed continence care will probably have limited impact.

In the validation phase family carers highlighted that the review did not address the amount of time and resource given to cleaning up after episodes of FI, nor concerns about cross infection arising from, for example, people living with dementia engaging in smearing or

parcelling of faeces. It is a limitation that the evidence was insufficient to address the use of continence aids for FI or relative costs of different management approaches (e.g. prompted toileting, use of pads). However, it reinforced the finding that the reduction and management of FI cannot be separated from the everyday work of cleaning and clearing up or residents' actions that arise from living with dementia.

## Conclusions

This review provides an emergent conceptual model that articulates what are likely to be the minimum requirements for continence interventions targeting people living with FI and dementia in care homes. It has done this by setting out the evidence for the different possible context-mechanism-outcome configurations that need to be in place and has argued that interventions are more likely to achieve the outcomes of interest when continence care is reframed as integral to intimate and personal care work for older people with dementia. Personal and intimate care requires a set of skills that can ensure care is responsive to the individual resident's preferences and needs. These need to be formalised in job descriptions, taught to those who give this care (junior/inexperienced staff), and valued and supported by senior staff. Care home staff across different disciplines and grades need to have the opportunity to reflect on practice and learn from each other about how to promote continence. Where reflective practice is already part of care home practice, continence, FI, intimate and personal care and dementia care can and should be explicitly linked.

There is good evidence that appropriate diet, fluid intake and increased mobility help as part of improving FI. The ways in which these strategies are introduced or improved for



those residents with dementia should incorporate both the preferences of the person with dementia and consideration of how the activities and routines of the care home support this.

Further research is needed that considers how different care routines and practices can be aligned with interventions to enhance continence care for this population.

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Table 1: Description of evidence sources by broad research themes

<p><b>Evidence on continence care (but not FI specifically) and dementia in a care home setting – 3 sources</b><sup>67, 104, 110</sup></p> <p>Two intervention studies from the 1990's about environmental effects on incontinence problems in Alzheimer's patients living in a specialist care facility and, a book for direct care staff of people with dementia resident in care homes with a section specifically addressing continence care.</p>
<p><b>Evidence on UI in a care home setting, but not dementia or FI – 21 sources</b><sup>8, 15, 26, 29, 30, 68, 84-88, 98-100, 105, 114-117, 122, 123</sup></p> <p>Sources from 1989 – 2015. Eight intervention studies (one RCT), nine observational, four qualitative interview studies and a review.</p>
<p><b>Evidence on FI and/or bowel health (also covering constipation) in a care home setting , but not dementia – 15 sources</b><sup>10, 23, 25, 33, 50, 69-72, 78, 89, 90, 96, 97, 101</sup></p> <p>Sources from 1986– 2015 focussing on FI, bowel problems (including constipation) and diarrhoea in care homes. Five intervention studies (one RCT), seven observational studies and three reviews.</p>
<p><b>Evidence from interventions specifically for people with dementia, but not continence interventions, in care home settings– 12 sources</b><sup>44, 73, 74, 83, 91-93, 102, 103, 106, 107, 124</sup></p> <p>Sources from 2003 – 2015 covering psychosocial interventions, morning care, bathing, eating and drinking and person-centred care interventions. Seven intervention studies (three cluster RCTs and one RCT), four reviews and an observational study.</p>
<p><b>Evidence on 'implementation' of interventions in a care home setting – 7 sources</b><sup>43, 75, 76, 79, 80, 108, 120, 121</sup></p> <p>Sources from 2000 – 2015 covering implementation in care home settings, three intervention studies, two observational study, one review and one book (2 chapters).</p>
<p><b>Evidence from specific novel interventions to manage continence/bowel health in a care home context – 4 sources</b><sup>77, 95, 109, 125</sup></p> <p>Studies from 2000 – 2013, that address residents in care homes with dementia or make reference to the application to the person with dementia. Four intervention studies (one RCT).</p>

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Table 1: Description of evidence sources by broad research themes

<p><b>Evidence on continence care (but not FI specifically) and dementia in a care home setting – 3 sources</b><sup>67, 104, 110</sup></p> <p>Two intervention studies from the 1990's about environmental effects on incontinence problems in Alzheimer's patients living in a specialist care facility and, a book for direct care staff of people with dementia resident in care homes with a section specifically addressing continence care.</p>
<p><b>Evidence on UI in a care home setting, but not dementia or FI – 21 sources</b><sup>8, 15, 26, 29, 30, 68, 84-88, 98-100, 105, 114-117, 122, 123</sup></p> <p>Sources from 1989 – 2015. Eight intervention studies (one RCT), nine observational, four qualitative interview studies and a review.</p>
<p><b>Evidence on FI and/or bowel health (also covering constipation) in a care home setting , but not dementia – 15 sources</b><sup>10, 23, 25, 33, 50, 69-72, 78, 89, 90, 96, 97, 101</sup></p> <p>Sources from 1986– 2015 focussing on FI, bowel problems (including constipation) and diarrhoea in care homes. Five intervention studies (one RCT), seven observational studies and three reviews.</p>
<p><b>Evidence from interventions specifically for people with dementia, but not continence interventions, in care home settings– 12 sources</b><sup>44, 73, 74, 83, 91-93, 102, 103, 106, 107, 124</sup></p> <p>Sources from 2003 – 2015 covering psychosocial interventions, morning care, bathing, eating and drinking and person-centred care interventions. Seven intervention studies (three cluster RCTs and one RCT), four reviews and an observational study.</p>
<p><b>Evidence on 'implementation' of interventions in a care home setting – 7 sources</b><sup>43, 75, 76, 79, 80, 108, 120, 121</sup></p> <p>Sources from 2000 – 2015 covering implementation in care home settings, three intervention studies, two observational study, one review and one book (2 chapters).</p>
<p><b>Evidence from specific novel interventions to manage continence/bowel health in a care home context – 4 sources</b><sup>77, 95, 109, 125</sup></p> <p>Studies from 2000 – 2013, that address residents in care homes with dementia or make reference to the application to the person with dementia. Four intervention studies (one RCT).</p>



*S-Table 1: Resident, staff and organisation outcomes categorised by research/stakeholder perspective*

Resident Outcomes	Staff Outcomes	Organisation Outcomes
<b>Outcomes proposed by stakeholders</b>		
Continence (dependent) Recognition/use of toilet Minimisation of leakage Skin integrity Comfort Minimisation of distress Dignity	Increased knowledge (about continence/dementia) Confidence Work satisfaction Change in attitudes to ageing and dementia	Costs Resource use e.g. continence products and laxatives Use of health services Reputation Workforce turnover
<b>Outcomes from the continence literature</b>		
Frequency Stool weight and presentation Odour Skin integrity and hygiene Behavioural change/symptoms of distress Acceptability of intervention to residents Improved continence	Staff adherence to protocol Staff knowledge Observed change in practice Acceptability of intervention to staff	Resources used : staff time and equipment used
<b>Outcomes from the PCC literature</b>		
Expressed and observed distress in residents QoL and Quality of Care measures Improvement in neuropsychiatric symptoms	Behaviour change of staff Sense of personal accomplishment Evidence of staff leading decision making & increasing confidence Staff knowledge	Culture change
<b>Outcomes from the Care Home Implementation literature</b>		
Acceptability	Staff engagement/attrition from intervention	Costs

<p>Residents' independence /dignity/choice</p>	<p>Change in practice reported/observed</p> <p>Evidence of change in documentation/Recording</p> <p>Acceptability</p> <p>Improved staff knowledge</p> <p>Staff confidence</p> <p>Breadth of staff discussion, engagement &amp; encouragement of leadership team</p>	
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<ul style="list-style-type: none"><li>• <b>Context (C):</b> 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, cost of continence aids</li><li>• <b>Mechanism (M):</b> A mechanism is the generative force that leads to outcomes. It may denote an action or reasoning of the various ‘actors’, i.e. 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.”</li><li>• <b>Outcomes (O):</b> Intervention outcomes e.g. 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.</li></ul>
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Box 1: Definitions of realist terms and how they have been applied throughout the review.

Scoping searches
<ol style="list-style-type: none"><li>1. Continence-related research in care homes, dementia and continence, older people and continence, implementation research in care homes, and person-centred dementia care</li><li>2. Fecal incontinence, care homes and incontinence pads</li><li>3. Literature on interventions to promote nutrition and hydration (eating and drinking) for people living with dementia in care homes. This was to test whether this body of work included outcomes related to continence and FI</li><li>4. Scope the learning disability (intellectual difficulty) literature for continence related research</li><li>5. All types of evidence including empirical studies on FI, policy documents, staff guidance, book chapters and theses</li></ol>
Databases searched: PubMed and Cochrane Library

Box 2: Literature searching - Scoping search areas

Searches 1a and 1b searched for evidence on care home research, continence or FI, which included people living with
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dementia, and care home research covering implementation or patient centered care (PCC) which included people with dementia.

Search 2 continence literature in care homes that may be about factors associated with FI such as the use of incontinence pads or constipation.

Search 3 research in CHs for people with dementia that concerned nutrition and or hydration in the CH population. We were interested in outcomes relevant to FI or urinary continence as well as learning on implementation.

Search 4 literature on continence care for people with learning disability

Databases searched: MEDLINE, EMBASE, CINAHL, PsychINFO, The Cochrane Library, Joanna Briggs

*Box 3: Second literature search areas*