


SPECIAL ISSUE REVIEW

A research agenda for promoting continence for people living with dementia in the community: Recommendations based on a critical review and expert-by-experience opinion

Vanessa Burholt PhD, FAcSS, Professor^{1,2}  | Johanna Davies MSc, Research Assistant² | Michal Boyd PhD, RN, NP, ND, Associate Professor³ | Jane M. Mullins PhD, RGN, Research Assistant² | E. Zoe Shoemark MSc, Honorary Research Associate² | the Centre for Ageing, Dementia Research, Expert Review Group on Continence, Dementia

¹Faculty of Medical and Health Sciences, School of Nursing, University of Auckland, Auckland, New Zealand

²Centre for Innovative Ageing, College of Human and Health Sciences, Swansea University, Swansea, UK

³School of Nursing and Freemasons' Department of Geriatric Medicine, Faculty of Medical and Health Sciences, University of Auckland, Auckland, New Zealand

Correspondence

Vanessa Burholt, School of Nursing, Faculty of Medical and Health Sciences, The University of Auckland, 85 Park Road, Grafton, Private Bag 92019 Auckland, New Zealand. Email: vanessa.burholt@auckland.ac.nz

Funding information This article is based upon work conducted under the auspices of the Centre for Ageing and Dementia Research supported by funding from Health and Care Research Wales. Beti George undertook fund-raising activities and charitable donations' funded ERG meetings and a researcher's salary. Open Access Publishing was supported by Health and Care Research Wales Senior Research Leader fund.

Abstract

Aims and objectives: To identify research undertaken in the last decade addressing continence for people living with dementia (PLWD) in the community. To highlight gaps and develop recommendations for future research, taking into account the experiences and priorities of PLWD, caregivers and healthcare professionals.

Methods: A critical review with an Expert Review Group (ERG) comprising researchers, PLWD and facing continence issues, caregivers and other professional stakeholders. Findings are reported in line with the COREQ and Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews checklists.

Background: Caregivers rate the independent use of the toilet as the most important activity for PLWD to retain. However, in 2009 a review identified shortfalls in knowledge and praxis around promoting continence and managing incontinence for PLWD in the community. As absolute numbers of people with dementia are predicted to increase, it is imperative to examine whether these deficits have been addressed.

Results: Of 3,563 records identified, 57 full-text articles were reviewed. The ERG developed a conceptual model to summarise research evidence according to the extent of the challenge (neuropathology and clinicopathology, prevalence and incidence), gateways to continence services, effectiveness of interventions, outcomes and the potential influences of personal resources, socio-cultural factors and environmental contexts.

Conclusions: Research on (in)continence for PLWD in the community is under-developed and has not increased substantially over the last decade. ERG recommendations for future research included user involvement to identify appropriate quality indicators to assess the effectiveness of interventions.

Relevance to clinical practice: There is insufficient evidence on which to base decisions on continence care for PLWD in the community. Omission from continence care

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited and is not used for commercial purposes.

© 2020 The Authors. Journal of Clinical Nursing published by John Wiley & Sons Ltd

guidelines has the effect of marginalising and silencing this population. User involvement in clinical research and developing practice guidelines has the potential for positive systems change.

KEYWORDS

caregivers, community dwelling, continence, dementia, home care, social care

1 | INTRODUCTION

It has been estimated that in 2020, there will be 48.1 million people living with dementia (PLWD) worldwide, with the number expected to double to 90.3 million in 2040 (Prince et al., 2013). Dementia impacts on the quality of life of the people living with the disease, their family and caregivers and is the largest single contributor to disability and need for care among older adults (Prince et al., 2015). Experiencing urinary incontinence (UI) or faecal incontinence (FI) is common for PLWD particularly at the later stages of the disease (Wagg, 2019). Urinary incontinence is defined as the involuntary loss of urine and FI is the involuntary loss of solid or liquid faeces (Abrams et al., 2017).

Dementia (such as Alzheimer's disease [AD], dementia with Lewy bodies, vascular dementia and other forms of dementia) is accompanied by a progressive decline in cognitive abilities that interfere with the performance of social roles and activities of daily living (ADL). *Mild* dementia is described as a decline in memory and deterioration in judgement and thinking which is sufficient to interfere with everyday activities but not severe enough to be incompatible with independent living. *Moderate* dementia is characterised by memory loss that interferes with the management of routine ADL and potentially jeopardises independent living. With *severe* dementia, a person is unable to retain new information or recall previously learned activities (World Health Organization, 1993). Thus, the likelihood of experiencing continence issues increases as dementia progresses. With moderate to severe dementia, difficulties could include recalling previously learned information (e.g. the location of a toilet, what a toilet looks like and how to use it, and how to direct the penis for men) or decoding what sensations mean (e.g. the need to void), a decline in judgement (e.g. time required to get to and use the toilet, or what to do with faeces or soiled clothing if a toilet could not be reached in time), and how to maintain personal hygiene and cleanliness after voiding (Drennan et al., 2011).

Maintaining continence requires a functioning network of mechanisms that control the bladder and bowel. As dementia has an impact on the physiological functions of the body, it can contribute to bladder or bowel dysfunction (e.g. neurogenic detrusor dysfunction; Abrams et al., 2017). However, the precise nature of the pathological association between dementia and incontinence has not been established. Overall, incontinence is rarely solely due to the pathology of dementia and is more frequently the result of cognitive impairment as described above, or due to co-morbidity which is often overlooked because the person has dementia (Abrams et al., 2017).

What does this paper contribute to the wider global clinical community?

- Research on (in)continence for people living with dementia in the community is under-developed: there are gaps in knowledge about neuropathology, epidemiology and effectiveness of interventions.
- Clinicians and health practitioners working with people living with dementia do not have sufficient evidence on which to base decisions about the most appropriate continence care.
- Co-developed continence care guidelines for people living with dementia in the community are urgently required.
- User involvement is required to develop a Core Outcome Set to assess the effectiveness of future interventions.

Caregivers rate the independent use of the toilet as the most important ADL that they would like the PLWD to retain (Hauber et al., 2014). However, in 2009 a review identified several shortfalls in knowledge and praxis that impact on PLWD and incontinence in the community. The review found limited information on the prevalence of UI and FI in the population of PLWD at home, and lack of evidence-based guidance on promoting continence or managing incontinence at home: most research either excluded participants with dementia, or only included residents in institutions rather than in the community. It identified challenges associated with responding to the complex and evolving needs of PLWD in relation to promoting continence and managing incontinence that required assessment and regular review, generalist and specialist intervention and inter-agency working (Drennan & Cole, 2009). Around the same time, a systematic review found that rates of moving into aged care facilities were much greater for PLWD than for older people without dementia and that incontinence was consistently identified as a predictor for institutionalisation in this population (Luppa et al., 2010).

1.1 | Aim and objective

As absolute numbers of PLWD are predicted to increase, it is imperative to examine whether deficits in knowledge and praxis identified a decade ago have been rectified. This critical review aims to identify

research undertaken in the last decade addressing continence for PLWD in the community. It has been undertaken *with* PLWD, caregivers and other professional stakeholders, to take into account their experiences and priorities and understand continence issues in community contexts in which older people live and interact. The objective is to highlight current gaps in evidence and develop recommendations for future research.

2 | METHODS

2.1 | Critical review

Drawing on review processes well-suited to developing conceptual models or theory, a critical review of the evidence was conducted. A critical review is well-suited to providing insight into the dynamics underlying the findings of individual studies that often only capture single relationships (e.g. between carer distress and incontinence). A critical review simultaneously considers the complexity of the issue and integrates, interprets and synthesises information across studies while simultaneously drawing on expert-experience (Fingeld-Connett, 2014).

A critical review methodology does not neatly fit with a single EQUATOR checklist. As a qualitative approach has been used to synthesise user-experience and a review of evidence into a conceptual model, the Consolidated Criteria for Reporting Qualitative Studies (COREQ) checklist has been applied (Tong et al., 2007; Supporting Information, File 1). However, there are some elements of COREQ that are not relevant to a critical review. Moreover, COREQ does not address issues concerning the rigour of the review in terms of the records that were retrieved, assessed and included in the final review. In this respect, elements of the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) checklist have also been used (Tricco et al., 2018; Supporting Information, File 2).

2.2 | Identifying and selecting relevant studies

Relevant studies for the review were identified based on a social model of disability that is congruent with The International Classification of Functioning, Disability and Health (World Health Organization, 2001). Initial search terms were developed and revised to reflect key concept areas in the ICF model of disability and to ensure that the search generated a manageable volume of literature (Table 1). The primary search terms for the population (Group 1) were combined (AND) with each of the other groups (e.g. Groups 1 and 2; Group 1 and 3). ASSIA, BNI, CINAHL, PsycInfo, Cochrane, IBSS, Scopus and Inspec databases were searched. Records were screened (title and abstract) and full text of screened articles were read to ensure that they met the inclusion criteria (Table 2). Articles were also excluded if they were not published in English or were news articles and opinion pieces. The review was limited to articles

published between 1 January 2009 and 2 April 2019. Records that met the inclusion criteria were analysed to extract data and were charted in Microsoft Excel. Using a deductive approach, the first draft of a conceptual model was generated.

2.3 | Convening an ERG

Expert review group members were contacted through existing networks and the aims of the review were discussed informally (JM, JD). Contacts that indicated an interest in taking part were sent an invitation and terms of reference. The resulting Expert Review Group (ERG) comprised academics (2), PLWD (4), caregivers (6), practitioners and policy stakeholders (3). The researchers (JM, JD) were experienced in involvement PLWD in research. Separate groups were convened to discuss the model (see below) to enable members to have sufficient support and time to contribute. These groups involved (a) academics and PLWD, (b) academics and caregivers and (c) academics, policy and practice stakeholders.

A draft diagram organising the scoped literature was developed (JM, JD), discussed and refined by the ERG during the first meetings. After each meeting, the researchers used the feedback from the ERG to revise the model. The groups met four times to consider the new drafts of the model, to identify inconsistencies, the weight of the evidence, weaknesses and gaps and to make further amendments to the drafts. The iterative process continued through drafting the article (VB) until the ERG felt that the model resonated with both the review findings, personal experiences and professional knowledge. This approach to model development is common when members of a panel have extensive knowledge of a topic (though lived experience) and/or where they have undertaken primary research on the topic (Hsieh & Shannon, 2005).

3 | RESULTS

After removing duplicates, a total of 911 records were screened. Of these, 829 were excluded after reviewing the title and abstract. Eighty-two articles met the inclusion criteria for the review. Five articles were not available for full-text assessment. The full text of 77 articles was examined in more detail. On closer examination, 20 further articles were excluded. A total of 57 articles were included in the review (Figure 1).

The model developed by the ERG (Figure 2) was used as the framework to structure the review: the research evidence in summarised in themes aligned to the conceptual model. Gaps in research are addressed in a critical reflection in the discussion. The model encapsulates continence and dementia across the scientific spectrum, that is from the neuropathology of dementia and incontinence, through to experiential outcomes and context for PLWD, caregivers and families.

For each element in the model, the ERG noted the potential for differences between types of dementia (e.g. in prevalence)

Group	Key concepts	Search terms (or)
1	Dementia	dementia*, Alzheimer*, cognitive impairment
AND	Continence	continen*, incontinen*, toilet, voiding, stoma, catheter
AND	Place	communit*, home
2	Functioning and disability	mobility, immobile*, dexterity*, frail*, medicat*, dehydrat*, fluid intake, nocturnal, role*
3	Personal resources	gender, sex*, race*, ethni*
4	Social environmental context	carer*, famil*, relative*, kin, relation*, stigma, ageism, agism, stereotyp*, stress*, burd*, abuse, neglect*, safeguard*
5	Physical environmental context	design, environment*, toilet*, bath*, home*, adapt*, public toilet*, convenience*, home care, social care
6	Psychological outcomes	identit*, depression, resilience, coping, recogni*, unrecogni*, mood, wellbeing, well-being, mental health, supress*, feeling*, ignore, isolation, loneliness digni*

TABLE 1 Search strategy

TABLE 2 Inclusion and exclusion criteria based on the population, concept and context framework

	Inclusion criteria	Exclusion criteria
Population: Adults with dementia or cognitive impairment	<p>Studies about:</p> <ul style="list-style-type: none"> adults living with any type of dementia (e.g. Alzheimer's disease, vascular dementia, dementia with Lewy Bodies) or mild, moderate or advanced cognitive impairment kin/non-kin caregivers to people living with dementia (PLWD) or cognitive impairment professional care/service providers to PLWD or cognitive impairment 	<p>Focus on:</p> <ul style="list-style-type: none"> Children and young people Disease-specific studies, for example cancer, stroke or diabetes
Concept: urinary or faecal incontinence	<p>Studies about:</p> <ul style="list-style-type: none"> Urinary or faecal incontinence Functional toileting challenges Medications for urinary incontinence (UI) and faecal incontinence (FI), for example antimuscarinics 	<p>Studies about:</p> <ul style="list-style-type: none"> Interventions for UI or FI incontinence as a result of other conditions, for example trauma or stroke
Context: living in the community in a country with high human development	<p>Studies conducted in:</p> <ul style="list-style-type: none"> Home or community Transitioning between home to short term care Countries in the upper quartile (above 47) of the Human Development Index (HDI) 	<p>Focus exclusively on:</p> <ul style="list-style-type: none"> Hospital, care home, nursing home setting Countries in other quartiles of the HDI

and cognitive trajectories (e.g. effectiveness of strategies to promote continence or manage incontinence), issues that were rarely addressed in the articles reviewed. The model is also intended to draw attention to inter-relationships between domains. For example, the potential for personal resources and socio-cultural factors (e.g. norms, values and beliefs) to impact in the effectiveness of interventions. Environmental contexts (e.g. rural or urban location and area disadvantage) may also influence access to clinical, health, social care and continence services and subsequent support.

3.1 | Extent of the challenge

The precise nature of the pathological association between dementia and incontinence has not been established. Incontinence might be associated with frontal lesions that disinhibit the bladder control centre in AD and frontal-temporal dementia. In dementia with Lewy bodies and Parkinson's disease with dementia, detrusor hyperactivity may be due to lesions of the nigrostriatal dopaminergic neurons (Idiaquez & Roman, 2011) or autonomic dysfunction (Stubendorff et al., 2012). Dementia also interrupts neurological pathways

between the brain and the bowel resulting in problems with FI, especially for PLWD with Lewy bodies (Orimo, 2017). Prospective clinicopathological studies are required in order to correlate type of dementia and continence issues to neuropathological evaluation at autopsy.

The prevalence of incontinence for PLWD in the community is unclear. A systematic review suggested prevalence of UI is in the range of 10%–34% Mini-Mental State Examination (MMSE <24). In Hong Kong, the prevalence of UI for PLWD living in the community recruited from a memory clinic was 33% (Miu et al., 2010), while in Germany, 84% of PLWD and receiving home care services experienced UI (Suhr & Lahmann, 2017). Compared to research on UI, there are fewer studies that have estimated prevalence of FI for PLWD living in the community. These suggest a prevalence of between 0.9% and 27% (Drennan, Rait, et al., 2013).

Studies combining UI and FI demonstrate variation in prevalence. In Australia, the prevalence of UI or FI (prior to the onset of acute illness) in a sample of PLWD that attended an emergency department was 34% (Schnitker et al., 2016). In Canada, 34% of women living with dementia were incontinent at the time they first received home care services (Cloutier & Penning, 2017).

In terms of the incidence of UI and FI for PLWD in the community, analysis of routinely collected data from general practices in the United Kingdom (UK) demonstrated that after adjusting for age, sex and comorbidity, the rate ratio of UI, comparing those with dementia to those without, was 3.2 in men and 2.7 in women. For FI, the rate ratio was 6.0 in men and 4.5 in women (Grant et al., 2013). In US home hospice clients, a primary diagnosis of dementia was associated with an increased hazard of FI (HR = 1.34 [1.24–1.46]) compared to participants with cancer (Chughtai et al., 2019).

Four studies examined the association between UI or FI and stages of dementia or changes over time. A study of more than 1,000 dyads of PLWD and their caregivers in eight European countries, compared toileting (i.e. going to the toilet for bowel and urine elimination; cleaning self after elimination and arranging clothes) and continence (i.e. the physiological process of elimination from bladder and bowel) for different levels of dementia. It concluded that toileting was predominantly intact in mild stages of dementia with around 80% of participants managing without assistance, but deteriorated in more advanced stages with only around 30% of people with severe dementia managing alone. However, continence was impaired to a great extent at early stages of dementia with around 40%–60% of participants with mild or moderate dementia needing partial or complete assistance (Giebel et al., 2014). In the United States, 45% of PLWD who responded to an advert experienced UI which did not significantly change over a 7 month period (Sloane et al., 2017). In France, a study of people referred to dementia care centres with mild to moderate dementia suggests that the pattern of loss of basic ADL reflected the complexity of these activities. Toileting activities and continence (combined) were the penultimate activity to be lost (before feeding), with 15% of women and 14% of men experiencing loss in this area (Lechowski et al., 2010).

Some studies have attempted to associate particular forms of UI with types of dementia. In Korea, a study of people with AD and UI (excluding those with severe dementia, and indwelling catheter or taking anticholinergic medication) found that urge UI was most common, followed by stress UI (the latter more common in women than men). More than half (58%) of UI was accounted for by detrusor overactivity (Lee et al., 2014). Urge UI is the most common form of incontinence for people with AD (Lee et al., 2014).

3.2 | Gateways to continence support

Access to services, support and products to promote continence or manage incontinence in the community is generally governed by primary care which is accessed more frequently by PLWD, than acute hospital care (Mullins et al., 2016). General practitioners are usually responsible for the diagnosis, treatment and specialist referral as appropriate. Studies suggest that clinicians and healthcare practitioners should initiate conversations about promoting continence and managing incontinence because PLWD and/or caregivers may be reluctant to raise the issue. For example, spouses may be fearful that incontinence will lead to institutionalisation, and adult children may want to respect a parent's desire for privacy (Bliss et al., 2013; Drennan et al., 2011; Gove et al., 2017; Mullins et al., 2016). This can lead to concealment of the issue or caregivers' problem-solving alone (Drennan et al., 2011).

Appropriate doctor or nurse-led screening, assessment and care planning can help avoid therapeutic nihilistic approaches (e.g. Poulos et al., 2017; i.e. that nothing can be done to promote continence for PLWD) or making assumptions that 'containment' is the most appropriate response. Healthcare practitioners should undertake an assessment of the root causes and impact of UI or FI to gauge the appropriate intervention or management strategy (Drennan et al., 2017). International guidelines recommend that assessments also address contributory causes such as infection, pharmacological side effects and reduced mobility (Orme et al., 2015; Wagg et al., 2015).

Evaluations of structured assessments conducted by physicians and/or nurse practitioners suggest that these are useful in identifying cognitive impairment and incontinence, triggering automated orders for simple procedures and the provision of condition-specific educational material for the older person and caregivers (Lichtenstein et al., 2015; Locatelli et al., 2017; Reuben et al., 2013; Roth et al., 2012; Wenger et al., 2009, 2011). However, the reviewed structured assessment studies did not take into account comorbidities, that is incontinence in the presence of dementia. This is problematic, because the value of certain types of tests for people with moderate to severe dementia (e.g. cystometry and urethral pressure profiles) is uncertain (Häggglund, 2010). Although structured assessments perform well in terms of achieving quality indicators extracted from routinely collected data, studies have yet to assess the usefulness of the information and support provided to PLWD and their caregivers, or effectiveness in promoting continence or managing incontinence at home.

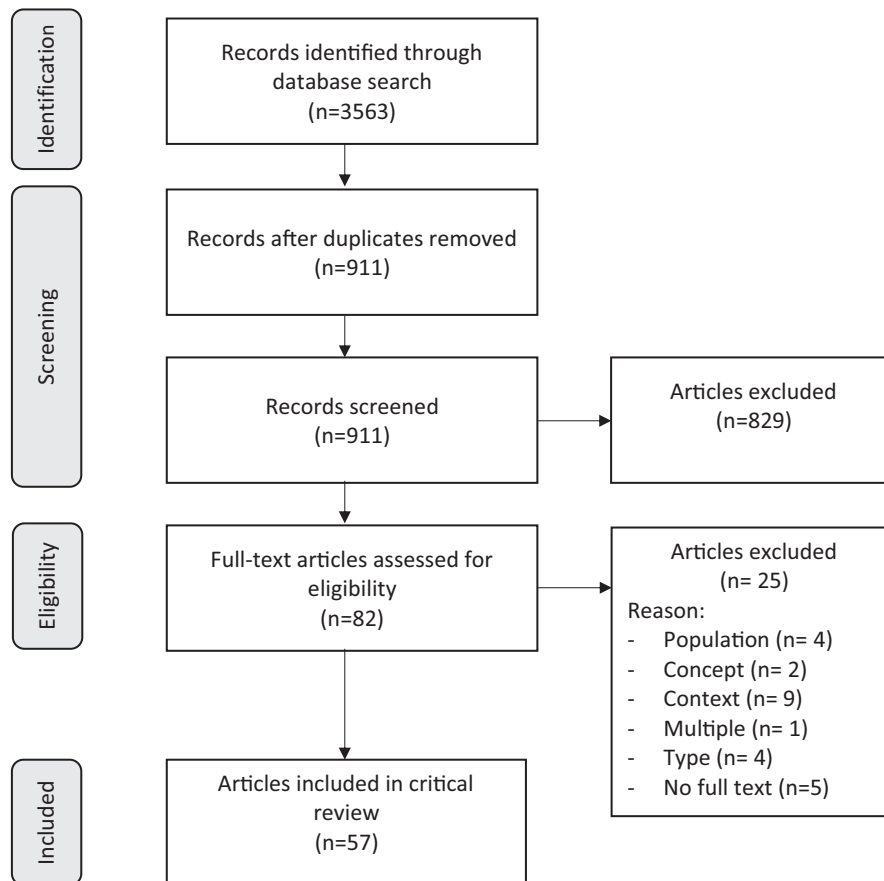


FIGURE 1 Flow diagram for article selection

Overall, most continence guidelines do not address dementia (Orme et al., 2015) or have been developed in institutional settings rather than in the community (Drennan, Norrie, et al., 2013; Wagg et al., 2015). Guidance on assessment and care planning is often patchy and inconsistent. In England, a review of practical guidelines from continence services (covering the provision of products, eligibility criteria and mechanisms of delivery) found that most did not explicitly address the needs of PLWD and caregivers: only one-third specifically mentioned dementia and only three documents provided a specific care plan (Drennan, Norrie, et al., 2013).

3.3 | Interventions: Promoting continence and managing incontinence

International continence guidelines recommend a stepwise approach to the provision of continence care for PLWD at home, progressing from the least to most invasive interventions (i.e. from environmental and lifestyle interventions, behavioural therapies through to pharmacological intervention and surgery; Alzheimer Europe, 2014; Orme et al., 2015; Wagg et al., 2015). On the other hand, guidelines for people with neurological diseases recommend treatment are tried on an individual basis (NICE, 2012).

International continence guidelines boldly suggest that 'most people with a dementia diagnosis living in the community can potentially be managed in a similar way to any other community-dwelling adults in line with current guidelines' (Abrams et al., 2017, p. 1315). However, there is limited evidence to back up this assertion. A systematic review on non-pharmacological and non-surgical conservative prevention or management interventions for PLWD in the community identified only three studies (Drennan et al., 2012). Two of these were pilot studies, and all three were methodologically flawed. All studies focused on UI with educational and advice to be implemented by a caregiver. None of the interventions addressed FI examined cost implications, or the impact on quality of life of PLWD or caregivers.

3.3.1 | Containment

Containment products should be made available to PLWD, if needed, alongside other forms of intervention (Alzheimer Europe, 2014). However, the ERG noted that containment through the use of continence products is often the first and/or only solution offered.

Eligibility for continence products may depend on producing frequency or volume charts that require incontinence pads to be weighed on domestic scales (Drennan, Norrie, et al., 2013).

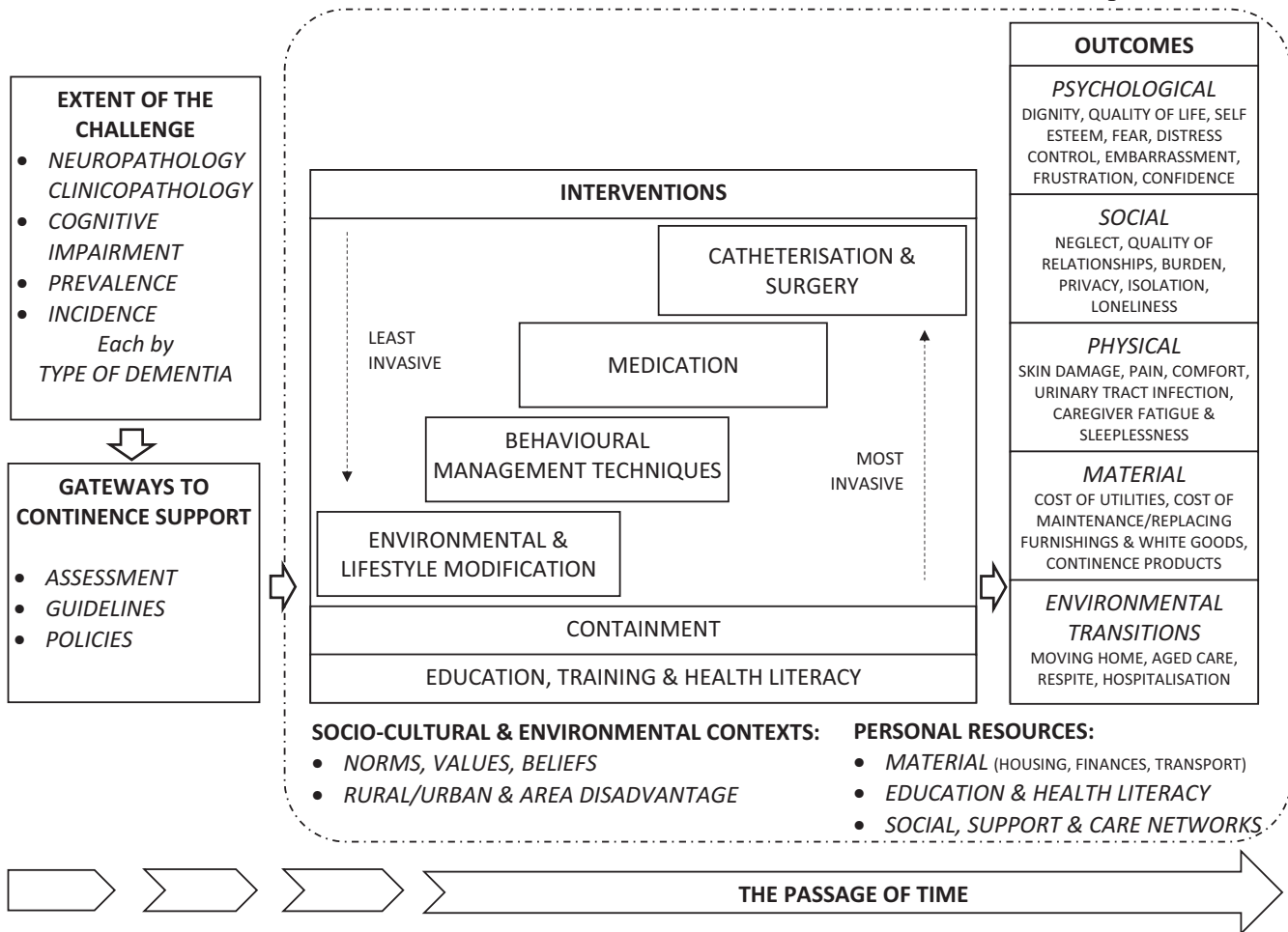


FIGURE 2 Expert Review Group's conceptual model of research areas relevant to continence for people living with dementia in the community

Caregivers in Germany have criticised health professionals' focus on the documentation of faecal matter and urine, while failing to take into account the experiences of PLWD and their caregivers (Messer, 2012 cited in Gove et al., 2017). In England, the process of achieving a supply of incontinence products is frequently described as inadequate or unmanageable for PLWD and caregivers, with guidelines rarely account for difficulties associated with memory impairment and remembering to order products (Drennan, Norrie, et al., 2013; Drennan et al., 2011).

Variability in eligibility for free continence products means that PLWD and caregivers often fund these themselves. Caregivers have reported difficulties finding information about products and identifying the most suitable for PLWD (Drennan et al., 2011). The purchase or provision of products that are the wrong fit is frequently mentioned as a challenge (Cole, 2017). It has been suggested sample packs should be made available (ERG) so that products can be tried before buying to test fit, performance and acceptability (Bliss et al., 2013; Drennan et al., 2011).

Containment products should adequately contain urine/faeces without leakage and should be acceptable and manageable for the PLWD and/or caregiver. The range of products available

includes insertable continence pads, 'pull up' style absorbent pants, mattress/chair protectors and, for men, penile sheaths. 'Pull-ups' are often more acceptable than insertable incontinence pads for PLWD (Drennan et al., 2011, 2017). Although penile sheaths may be used for UI in some men with Neurogenic Lower Urinary Tract Dysfunction caused by dementia they require good technique in order to retain hygiene and avoid skin damage (Drake et al., 2016). Overall, there is an absence of randomised trials comparing different types of containment products. There are no studies comparing the use of containment products to other strategies (e.g. environmental or behavioural modification) on in combination with other strategies for PLWD in the community (Häggglund, 2010).

3.3.2 | Education, training and health literacy

Information and education on promoting continence and managing incontinence should be provided in a simple and understandable format, in order for PLWD and caregivers to make an informed choice about what is most appropriate for their context and situation (Bliss et al., 2013). A lack of appropriate information may lead

to counterproductive 'self-help' strategies, for example limiting activities outside of the home or adopting unhealthy practices, such as restricting fluid intake (Cole, 2017). There are very few studies on the effectiveness of educational material or training interventions to improve health literacy and care outcomes.

The content and form of delivery of information are important. Descriptions of incontinence used by PLWD and caregivers may include colloquial terms (Bliss et al., 2013; Cole, 2017) and the term 'incontinence' may need defining. While one study noted that a majority of caregivers preferred printed material to online material on continence care and dementia (Bliss et al., 2013), there is likely to be a wide variation in preference, for example, by age and educational level.

Caregivers may encounter barriers to attending face-to-face training or support groups due to transport issues, competing demands from work, or inability to leave the home (without respite care; Bliss et al., 2013). However, opportunities to discuss experiences and practices with others in a similar situation may help caregivers feel connected, validate their practices or help them find alternative and successful strategies (Bliss et al., 2013; Forbes et al., 2011; Hetherington, 2012).

3.3.3 | Environmental and lifestyle modifications

Certain activities can promote a healthy bowel and bladder and promote continence for PLWD. These include establishing a balanced diet and an adequate liquid intake (Bliss et al., 2013; Drennan et al., 2017); maintaining food safety and hand hygiene to avoid food poisoning and the resulting loss of control over bowel motions (Drennan et al., 2017); and undertaking general exercise, such as walking (Drennan et al., 2017).

Providing opportunities to use a toilet may help maintain continence (Drennan et al., 2017). However, outside the home toileting opportunities are often dependent on the availability of public toilets (Bliss et al., 2013; Drennan et al., 2017). PLWD and caregivers may adopt 'toilet mapping' to plan trips based on the location of these facilities (Cole, 2017). The provision of public toilets in the community fall outside the remit of the healthcare or social care services and the importance of these facilities are often overlooked (Drennan & Cole, 2009).

Interventions within the home are intended to correct for functional incontinence by improving the chances of successfully navigating to and using the toilet. For example, aids to make toileting easier, assistance in toileting (e.g. with clothing) or encouraging sitting instead of standing to urinate (for men) to avoid spillage may be beneficial (Cole, 2017; Drennan et al., 2017). Particular types of environmental interventions may address specific forms of cognitive impairment.

The inability to locate the toilet (spatial disorientation and/or perceptual deficits) may be improved through visual cues (e.g. pictures of toilets on walls and/or doors; van Hoof et al., 2010). However, in practise few caregiver use cues and some PLWD find visual cues

(e.g. a picture of a toilet in key locations) unacceptable and remove them (Drennan et al., 2011).

An inability to reach the toilet fast enough due to motor problems, reduced mobility and balance may be improved by providing a commode, urinal or bedpan. Making access to the toilet straightforward, and/or installing a raised toilet seat or grab bars in the toilet room may also help. The need for assistance using the toilet (due to reduced mobility and coordination) may benefit from an automated toilet with bidet function. Reduced judgement or awareness about where to urinate or defecate (due to confusion) may be improved by removing waste baskets and other items resembling toilet bowls. In response to perceptual deficits, a 'texture path' made of carpet from the bedroom to bathroom may help with disorientation. For caregivers' comfort, protective bedding, and twin beds or a second bedroom may protect a partner from incontinence and nocturnal restlessness (van Hoof et al., 2010). While these environmental interventions may be pragmatic, none of the solutions cited in a review by van Hoof et al. (2010) are evidence-based. Instead, they are derived from think pieces or non-peer-reviewed practical guides, rather than robust studies demonstrating feasibility, acceptability or effectiveness for PLWD and caregivers in the community.

Some small-scale studies have used alarms systems to alert the PLWD or caregivers about the need to use the toilet. In one study, examining the effectiveness of self-initiated voiding a woman with vascular dementia ($N = 1$) was taught to associate an auditory signal with urinating. This intervention reduced urinal leaks from 1.5 per week to zero (de Codt et al., 2015). Another study ($N = 3$) assessed the effectiveness of using an auditory and vibrating alarm that sounded when the PLWD started to urinate. At the sound of the alarm, caregivers prompted the PLWD to stop urinating and accompanied them to the toilet. The intervention helped reduce large urinary accidents and also prompted self-initiated toileting, which had been minimal before the study (Lancioni et al., 2011). Despite promising outcomes, neither of these studies included insights from PLWD. Further robust testing in trials would be required to confirm whether these approaches were suitable for reducing UI, and whether alarms are perceived to be acceptable in public spaces.

3.3.4 | Behavioural management techniques

There are no recent systematic reviews regarding the effectiveness of behavioural techniques for promoting continence or managing incontinence for PLWD in the community (Abrams et al., 2017). A decade ago, a systematic review by Hägglund (2010) found insufficient evidence for the effectiveness of time voiding or habit training, and limited scientific evidence on the effectiveness of promoted voiding to reduce UI for PLWD.

Concerns have been raised over the usefulness of bladder training for people with moderate or severe dementia, due to memory difficulties impacting on the recall of instructions. However, there are no robust studies that test this assumption (Hägglund, 2010). In the UK, caregivers have reported that in the early stages of

dementia, prompting successfully reduced instances of incontinence (Drennan et al., 2011).

Caregivers could utilise behavioural modification techniques to help with challenges, such as resistance to using absorbent pads or toileting before going out, voiding in inappropriate place, handling faeces, refusing to clean after voiding, and disposing of toilet paper or incontinence pads inappropriately (Bliss et al., 2013; Drennan et al., 2017; Gove et al., 2017). However, we did not identify any studies looking at the effectiveness of techniques to manage these challenges in the community.

Other techniques may be required in response to behavioural and psychological disturbances that are directly associated with the provision of incontinence support (Drennan et al., 2017). Some PLWD may react aggressively in response to intimate support associated with incontinence and toileting: they may want to protect relatives from having to deal with excreta or urine, or they may be unable to communicate their wishes (Cole, 2017). In some cases, prompting may lead to conflict if PLWD perceives that they are being infantilised (Drennan et al., 2011). In other cases, the stigma association with incontinence leads to embarrassment and shame, and maybe manifest in the concealment of soiled clothes or pads, or inappropriate disposal of incontinence products or clothes (Drennan et al., 2017; Hetherton, 2012).

3.3.5 | Medication

There are no specific data on drug management for PLWD and incontinence, and it is recommended that medication should be used with care and reviewed regularly to ensure that is safe and effective (Orme et al., 2015). There is insufficient evidence for pharmacological treatment with oestrogen for UI or laxatives for FI for PLWD, as no systematic reviews of drug effectiveness had been carried out with this population (Hägglund, 2010).

In the UK, analysis of administrative records demonstrated that 15% of PLWD were prescribed drug treatment for UI compared with 18% of people without dementia. However, the median time to first prescription was shorter for PLWD than for people without dementia (16 vs. 21 months for men and 19 vs. 30 months for women; Grant et al., 2013). In a US study, PLWD were more likely to be taking antimuscarinics (e.g. solifenacin or trospium) for UI (6%) than those with normal cognition (4%; Green et al., 2017).

Acetylcholinesterase inhibitors (e.g. donepezil or galantamine) are often prescribed for PLWD to improve memory. However, the mechanism of these drugs is diametrically opposed to antimuscarinics. In summarising the evidence, the 6th International Consultation on Incontinence concluded that drug interactions may have clinical consequences for some, but not all people taking both medications (Abrams et al., 2017). The Urological Association and American Geriatric Society urge caution in prescribing acetylcholinesterase inhibitors in tandem with antimuscarinics. Despite this warning, 27% of participants in a US study were taking both medications (Green et al., 2017).

3.3.6 | Catheterisation and surgery

Catheters are not an accepted treatment for UI and should be considered only for persons with urine retention, or possibly during end of life care (Hägglund, 2010). However, analysis of administrative records in the UK demonstrated that the median time to first use of prolonged catheterisation (from the time of diagnosis of UI) was less for PLWD than for people without dementia (18 vs. 25 months for men and 26 vs. 41 months for women). After adjusting for age sex and comorbidity, the rate ratio of prolonged catheterisation was 1.6 in men and 2.3 in women comparing PLWD to those without (Grant et al., 2013). Studies are required to evaluate the use of intermittent catheterisation for PLWD who experience difficulties emptying the bladder (Hägglund, 2010), especially in the later stages of dementia during which a person may attempt to remove a catheter if they do not understand what it is and/or it causes discomfort.

There are no studies on aggressive surgery for PLWD and incontinence. The 6th International Consultation on Incontinence was unable to determine whether surgery should be offered to PLWD (Abrams et al., 2017).

3.4 | Outcomes

Outcomes of (un)successfully promoting continence or managing incontinence for PLWD were described in terms of the impacts on psychological well-being, social relationships, physical health, finances and environmental transitions.

In terms of psychological well-being, dignity and quality of life for PLWD and caregivers were affected by incontinence (Drennan et al., 2017; Gove et al., 2017; Suhr & Lahmann, 2017). Perversely, practices that preserved well-being for PLWD impacted adversely on caregivers. For example, concealing soiled clothing or pads to preserve own dignity can have an unintended negative impact on caregiver stress, or environmental quality (e.g. odours).

The difficulties associated with promoting continence and managing in continence often requires around the clock vigilance by caregivers. UI and fatigue are associated with 'caregiver burden' (Kamiya et al., 2014), and sleeplessness from constant watchfulness can contribute to exhaustion, potentially jeopardising caregiving in the community (Gove et al., 2017; Hetherton, 2012).

Embarrassment, shame and distress for both PLWD and caregivers were associated with episodes of incontinence (Cole, 2017; Drennan et al., 2011, 2017; Gove et al., 2017; Mullins et al., 2016; Rolnick et al., 2013). The ERG suggested that fear over the loss of control of continence had an impact on self-esteem and confidence. These outcomes were frequently linked to social relationships and the reactions of others to continence issues.

With regard to social relationships, the perception of being a burden changed the relationship dynamic between the PLWD and caregiver (Cole, 2017; Drennan et al., 2011, 2017; Gove et al., 2017; Hetherton, 2012; Mullins et al., 2016). Embarrassment associated with incontinent episodes in public places or at friends' homes

contributed to fewer social engagements. The ERG noted that reduced social engagement increased social isolation and loneliness.

Dementia and continence issues also impact on financial resources. In addition to the cost of incontinence pads (when these have not been provided through a free service), the financial consequences of incontinence and dementia included laundry costs, replacement of spoiled furniture (including beds), carpets, mattresses, cleaning materials and deodourisers (Messer, 2012 cited in Drennan et al., 2011; Gove et al., 2017; Hetherington, 2012). In some countries, waste products, such as disposable continence pads, may require payment for collection (Messer, 2012 cited in Gove et al., 2017).

Environmental transitions are also associated with dementia and continence issues. Promoting continence is especially pertinent during changes in residence for the PLWD, for example to receive respite care or during hospitalisation. An Australian study found that more than one-third (34%) of PLWD who were continent before admission had UI at discharge from hospital, and 2% were discharged doubly incontinent (Furlanetto & Emond, 2016). Similarly, in the UK, caregivers have noted that previously continent PLWD are frequently discharged from respite or hospital incontinent and/or using pads (Drennan et al., 2011). This may be due to inadequate assessment, the misuse of incontinence aids that discourage independent toileting and inadequate staff training (Furlanetto & Emond, 2016).

4 | DISCUSSION

Research on (in)continence for PLWD in the community is under-developed and is consistently overlooked as a topic of study. There are gaps in research evidence from scientists from a range of disciplines (i.e. neuropathology, clinical, social, psychology and policy perspectives). This is concerning, as demand for care for PLWD in the community will rise exponentially over the coming decades. Currently, the knowledge about neuropathology, epidemiology, effectiveness of interventions, and the experiences and outcomes for PLWD, (and their caregivers and families) in the community is poor.

The precise nature of the neuropathological association between dementia and incontinence has not been established, which limits the development of effective therapeutic approaches. Additionally, there are few studies but wide variation in reported prevalence and incidence of UI/FI for PLWD in the community. This is explained, in part, by the lack of uniformity in the measurement of cognitive impairment/dementia and incontinence, and the different samples selected for study. There is no recent research on the prevalence or incidence of incontinence for various forms of dementia which is extremely important as the clinical course of each shows a high degree of inter-individual variability. Without these data, it is impossible to model future costs of continence care for PLWD in the community; an important consideration given that many policies focus on community ageing in place for as long as possible.

Research addressing the effectiveness of interventions to promote continence or manage incontinence for PLWD is under-developed (Kolanowski et al., 2018) and has not increased substantially

over the last decade. Studies tend to be small scale and are often methodologically flawed. A majority of research in this field has been undertaken in institutional settings (care homes and hospitals). Consequently, we have limited information on which to base guidelines for care pathways to achieve the best continence care for PLWD in the community.

While there are some guidelines for continence care for PLWD, these often draw on research conducted in care homes—which does not necessarily translate into the community setting (Drennan et al., 2012). Due to the current paucity of evidence on the effectiveness of assessment and interventions, the ERG felt that there is an immediate need to co-develop guidelines that take into account the perspectives of clinicians, healthcare practitioners, PLWD and caregivers, until evidence from robust intervention studies becomes available (see also, Drennan et al., 2012; Hägglund, 2010).

The experiences of PLWD and their caregivers in the community in relation to continence care is an under-researched area (Cole, 2017). User involvement was rarely considered in the intervention studies cited in this review. Consequently, it is impossible to ascertain whether they are acceptable to PLWD or caregivers. Furthermore, lack of user involvement has impacted on the quality of resources intended for PLWD and caregivers. For example, information has not been appropriately tailored to their needs (Drennan, Norrie, et al., 2013) and there is no research that has considered the design and/or textiles used in garments and pads for containment (although garments have been designed for use in care homes, Iltanen-Tähkävuori et al., 2012). The ERG noted that eco-friendly products that are biodegradable and reduce carbon emissions are becoming increasingly important consideration for them, but this issue has yet to be tackled through co-designed research and development of products.

Experiential data are also vital as there may be divergence between caregivers/PLWD and healthcare professionals and researchers in the perception of challenges associated with incontinence. For example, members of the American Academy of Family Physicians ranked UI as one of the most challenging comorbidities for health professionals to manage for PLWD. However, they did not rank it highly as a challenge for caregivers in the community, perceiving instead that fatigue, selecting a care home and anger were priority issues (Stewart et al., 2014). Thus, health professionals often misunderstand key domestic issues (Cole, 2017). Additionally, outcomes that were important to PLWD and caregivers (e.g. Figure 2) were rarely measured in intervention studies. Reductions in 'wet episodes' (see Orme et al., 2015) are used as primary outcomes measures more frequently than psychological or social outcomes that reflect the quality of life of PLWD and caregivers.

As dementia progresses caregivers may need to take a more active role including performing more intimate continence support. Healthcare professionals often assume that caregivers will undertake what is required of them, when certain practices may not be acceptable. For example, the use of suppositories for constipation can be challenging when a PLWD does not understand what is happening and can lead to agitation and conflict (Drennan et al., 2011). There may also be issues around acceptability of intimate forms of

support associated with gender and relationships (e.g. sons helping mothers, husbands helping wives) which need to be taken into account (Drennan et al., 2011).

The stigma associated with both dementia and incontinence increases the risk of it shaping behaviours, for example by reducing social interaction of PLWD and their caregivers, or by avoiding or delaying seeking help from healthcare providers (Cole, 2017; Messer, 2012 cited in Gove et al., 2017; Hetherton, 2012). Although the risk of institutionalisation is increased for PLWD and incontinence, the specific management challenges for caregivers that contribute to the decision to move are unclear (Cole, 2017; Risco et al., 2015).

Finally, there were very few studies that took into account social-cultural and environmental context or personal resources (see Figure 2), such as the potential for differences between socio-economic groups, geographic location or ethnicity/culture in continence care for PLWD. These issues need to be addressed in research to ensure that continence care is accessible, effective, culturally appropriate and acceptable.

4.1 | Strengths and weaknesses

The critical review has weaknesses, as it is not as rigorous as other forms of review. For example, there is no expectation of a formal assessment of the quality of studies. Furthermore, the structure of the review and model development relies heavily on the experience and expertise of the ERG. While this is a strength of the method, as gaps in research evidence (e.g. eco-friendly containment products) would not have been identified without the involvement of experts-by-experience, it is also potentially a limitation. The ERG experiences may be structured and shaped by the healthcare systems, policy frameworks and physical settings in which they are embedded (i.e. in Wales, UK) and may not be generalisable to other countries. Furthermore, the articles reviewed were from a variety of countries in the upper quartile (above 47) of the Human Development Index in which policies and healthcare systems differ. Although the results are not necessarily generalisable directly to other settings, there are no obvious areas of divergence. The resulting review is a summary of literature alongside a subjective interpretation of gaps in evidence and is intended to be the starting point for further research.

5 | CONCLUSION

Based on the reviewed evidence and personal experiences, the ERG has made the following recommendations to help shape the future research agenda. Robust research is required to examine and establish:

1. The association between dementia pathology, cognitive impairment trajectories and UI/FI for each type of dementia.

2. The prevalence and incidence of UI and FI for PLWD in the community.
3. The effectiveness of containment, education and training, environmental/lifestyle, behavioural, pharmacological and surgical interventions.

In order to establish the effectiveness of interventions to promote continence or manage incontinence in the community and the co-ordinated delivery of services that meet needs during a changing illness trajectory and in multiple contexts, we need to know what constitutes good continence care from the perspective of PLWD, caregivers and families (Pickett et al., 2018). This has yet to be achieved in research on dementia and continence care in the community and the ERG recommend:

4. User involvement in future research to ensure that PLWD and caregivers' perceptions and experiences are taken into account. Co-produced research and user involvement is a priority in the following contexts:
5. To identify appropriate quality indicators and benchmarks that characterise good continence care. These indicators would form part of a Core Outcome Set that could be used to assess the effectiveness of future interventions.
6. To identify the most promising strategies to incorporate into assessments and guidelines to promote continence and manage incontinence for PLWD.
7. To develop interventions that meet the needs of PLWD and caregivers in the community.

6 | RELEVANCE TO CLINICAL PRACTICE

Clinicians and health practitioners working with PLWD do not have sufficient evidence on which to base decisions on the most appropriate care management. Omitting PLWD from assessment and continence care guidelines may be the result of implicit or unconscious bias and contributes to a nihilistic approach that nothing (other than containment) can be done (FitzGerald & Hurst, 2017). The lack of instructions for healthcare practitioners to initiate discussions about continence with PLWD, coupled with the public's reluctance to discuss the taboo subject, has the effect of marginalising and silencing this population. In turn, the decreased visibility and voice of PLWD facing continence issues (also manifest in the lack of data on prevalence) do little to challenge the status quo and the scant research attention paid to the issue. Adopting recommendations made by the ERG concerning user involvement in clinical nursing research, and developing practice guidelines, has the potential to bring about positive systems change.

ACKNOWLEDGEMENTS

We are grateful to Beti George, a Welsh television and radio broadcaster, who initiated this critical review. Beti's partner David Parry

Jones was a writer and broadcaster who died from Alzheimer's disease in 2017. Beti has continued to raise awareness of dementia through the Welsh media, for example the BBC programme *David and Beti: Lost for Words* was broadcast across the UK. We would like to thank the members of the Centre for Ageing and Dementia Research ERG on Dementia and Continence for their contributions, including Beti George; Ann Yates, Director of Continence Services, Cardiff and Vale University Health Board, St Davids Hospital, Cardiff; Louise Barraclough, Manager, Community Continence Services, Swansea Bay University Health Board; and those who wish to remain anonymous.

CONFLICT OF INTEREST

The authors declare that there are no conflicts of interest.

AUTHOR CONTRIBUTIONS

VB designed and directed the review. JD and JM conducted the literature search and JD exported the results into the database. JD reviewed all articles and initially screened articles based on title and abstract. JD and JM convened the ERG and led discussions. JD and VB reviewed full-text articles and contributed to the data extraction table. The ERG, VB and JD contributed to the synthesis and interpretation of the results. JD and JM created the initial model, and VB created the revised model. VB led on writing the manuscript, JD contributed first drafts of sections of the review. MB, EZS, JD and JM contributed to the manuscript providing critical feedback on intellectual content which shaped the article.

ORCID

Vanessa Burholt  <https://orcid.org/0000-0002-6789-127X>

REFERENCES

- Abrams, P., Cardozo, L., Wagg, A., & Wein, A. (Eds.). (2017). *Incontinence 6th edition*. ICI-ICS International Continence Society. Retrieved from https://www.ics.org/publications/ici_6/Incontinence_6th_Edition_2017_eBook_v2.pdf
- Alzheimer Europe. (2014). *Improving continence care for people with dementia living at home*. Alzheimer Europe. Retrieved from <https://www.alzheimer-europe.org/content/download/79312/491695/file/Final%20version%20of%20the%20continence%20care%20report.pdf>
- Bliss, D., Rolnick, C., Jackson, J., Arntson, C., Mullins, J., & Hepburn, K. (2013). Health literacy needs related to incontinence and skin damage among family and friend caregivers of individuals with dementia. *Journal of Wound, Ostomy & Continence Nursing*, 40(5), 515–523. <https://doi.org/10.1097/WQN.0b013e3182a3ff24>
- Chughtai, B., Thomas, D., Russell, D., Bowles, K., & Prigerson, H. (2019). Prevalence of and risk factors for urinary incontinence in home hospice patients. *European Urology*, 75(2), 268–271. <https://doi.org/10.1016/j.eururo.2018.10.027>
- Cloutier, D. S., & Penning, M. J. (2017). Janus at the crossroads: Perspectives on long-term care trajectories for older women with dementia in a Canadian context. *The Gerontologist*, 57(1), 68–81. <https://doi.org/10.1093/geront/gnw158>
- Cole, L., & Drennan, V. M. (2017). Living with incontinence: The experience of people with dementia. *Dementia*, 18(5), 1826–1839. <https://doi.org/10.1177/1471301217731171>
- de Codd, A., Grotz, C., Degaute, M. F., Tecco, J. M., & Adam, S. (2015). Management of demented patients with urinary incontinence: A case study. *Clinical Neuropsychology*, 29(5), 707–722. <https://doi.org/10.1080/13854046.2015.1062561>
- Drake, M. J., Apostolidis, A., Cocci, A., Emmanuel, A., Gajewski, J. B., Harrison, S. C. W., Heesakkers, J. P. F. A., Lemack, G. E., Madersbacher, H., Panicker, J. N., Radziszewski, P., Sakakibara, R., & Wyndaele, J. J. (2016). Neurogenic lower urinary tract dysfunction: Clinical management recommendations of the Neurologic Incontinence committee of the fifth International Consultation on Incontinence 2013. *Neurology and Urodynamics*, 35(6), 657–665. <https://doi.org/10.1002/nau.23027>
- Drennan, V. M., & Cole, L. (2009). Promoting continence and managing incontinence with people with dementia living at home: One more challenge for integration. *Journal of Integrated Care*, 17(1), 15–25. <https://doi.org/10.1108/14769018200900004>
- Drennan, V. M., Cole, L., & Iliffe, S. (2011). A taboo within a stigma? A qualitative study of managing incontinence with people with dementia living at home. *BMC Geriatrics*, 11, 75. <https://doi.org/10.1186/1471-2318-11-75>
- Drennan, V. M., Greenwood, N., Cole, L., Fader, M., Grant, R., Rait, G., & Iliffe, S. (2012). Conservative interventions for incontinence in people with dementia or cognitive impairment, living at home: A systematic review. *BMC Geriatrics*, 12(1), 77. <https://doi.org/10.1186/1471-2318-12-77>
- Drennan, V. M., Manthorpe, J., & Iliffe, S. (2017). Meeting the needs of older people living at home with dementia who have problems with continence. *Quality in Ageing and Older Adults*, 18(4), 246–253.
- Drennan, V. M., Norrie, C., Cole, L., & Donovan, S. (2013). Addressing incontinence for people with dementia living at home: A documentary analysis of local English community nursing service continence policies and clinical guidance. *Journal of Clinical Nursing*, 22(3–4), 339–346. <https://doi.org/10.1111/j.1365-2702.2012.04125.x>
- Drennan, V. M., Rait, G., Cole, L., Grant, R., & Iliffe, S. (2013). The prevalence of incontinence in people with cognitive impairment or dementia living at home: A systematic review. *Neurology and Urodynamics*, 32(4), 314–324. <https://doi.org/10.1002/nau.22333>
- Finfgeld-Connett, D. (2014). Use of content analysis to conduct knowledge-building and theory-generating qualitative systematic reviews. *Qualitative Research*, 14(3), 341–352. <https://doi.org/10.1177/1468794113481790>
- FitzGerald, C., & Hurst, S. (2017). Implicit bias in healthcare professionals: A systematic review. *BMC Medical Ethics*, 18(1), 19. <https://doi.org/10.1186/s12910-017-0179-8>
- Forbes, D., Ward-Griffin, C., Kloseck, M., Mendelsohn, M., St-Amant, O., DeForge, R., & Clark, K. (2011). 'Her world gets smaller and smaller with nothing to look forward to': Dimensions of social inclusion and exclusion among rural dementia care networks. *Online Journal of Rural Nursing & Health Care*, 11(2), 27–42. <https://doi.org/10.14574/ojrnhc.v11i2.18>
- Furlanetto, K., & Emond, K. (2016). "Will I come home incontinent?" A retrospective file review: Incidence of development of incontinence and correlation with length of stay in acute settings for people with dementia or cognitive impairment aged 65 years and over. *Collegian*, 23(1), 79–86. <https://doi.org/10.1016/j.colegn.2014.09.013>
- Giebel, C. M., Sutcliffe, C., Stolt, M., Karlsson, S., Renom-Guiteras, A., Soto, M., Verbeek, H., Zabalegui, A., & Challis, D. (2014). Deterioration of basic activities of daily living and their impact on quality of life across different cognitive stages of dementia: A European study. *International Psychogeriatrics*, 26(8), 1283–1293. <https://doi.org/10.1017/S1041610214000775>
- Gove, D., Scerri, A., Georges, J., Houten, P., Huige, N., Hayder-Beichel, D., Leichsenring, K., & Morris, V. C. (2017). Continence care for people with dementia living at home in Europe: A review of literature

- with a focus on problems and challenges. *Journal of Clinical Nursing*, 26(3–4), 356–365. <https://doi.org/10.1111/jocn.13582>
- Grant, R. L., Drennan, V. M., Rait, G., Petersen, I., & Iliffe, S. (2013). First diagnosis and management of incontinence in older people with and without dementia in primary care: A cohort study using the health improvement network primary care database. *PLoS Medicine*, 10(8), e1001505. <https://doi.org/10.1371/journal.pmed.1001505>
- Green, A. R., Segal, J., Tian, J., Oh, E., Roth, D. L., Hilson, L., Dodson, J. L., & Boyd, C. M. (2017). Use of bladder antimuscarinics in older adults with impaired cognition. *Journal of the American Geriatrics Society*, 65(2), 390–394. <https://doi.org/10.1111/jgs.14498>
- Hägglund, D. (2010). A systematic literature review of incontinence care for persons with dementia: The research evidence. *Journal of Clinical Nursing*, 19(3–4), 303–312. <https://doi.org/10.1111/j.1365-2702.2009.02958.x>
- Hauber, A. B., Mohamed, A. F., Johnson, F. R., Cook, M., Arrighi, H. M., Zhang, J., & Grundman, M. (2014). Understanding the relative importance of preserving functional abilities in Alzheimer's disease in the United States and Germany. *Quality of Life Research*, 23(6), 1813–1821. <https://doi.org/10.1007/s11136-013-0620-5>
- Hetherington, N. (2012). Living with people who have dementia and faecal incontinence. *End of Life Journal*, 2(2), 1–8.
- Hsieh, H.-F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, 15(9), 1277–1288. <https://doi.org/10.1177/1049732305276687>
- Idiaquez, J., & Roman, G. C. (2011). Autonomic dysfunction in neurodegenerative dementias. *Journal of the Neurological Sciences*, 305(1), 22–27. <https://doi.org/10.1016/j.jns.2011.02.033>
- Iltanen-Tähkävuo, S., Wikberg, M., & Topo, P. (2012). Design and dementia: A case of garments designed to prevent undressing. *Dementia*, 11(1), 49–59. <https://doi.org/10.1177/1471301211416614>
- Kamiya, M., Sakurai, T., Ogama, N., Maki, Y., & Toba, K. (2014). Factors associated with increased caregivers' burden in several cognitive stages of Alzheimer's disease. *Geriatrics & Gerontology International*, 14(Suppl. 2), 45–55. <https://doi.org/10.1111/ggi.12260>
- Kolanowski, A., Fortinsky, R. H., Calkins, M., Devanand, D. P., Gould, E., Heller, T., Hodgson, N. A., Kales, H. C., Kaye, J., Lyketsos, C., Resnick, B., Schicker, M., & Zimmerman, S. (2018). Advancing research on care needs and supportive approaches for persons with dementia: Recommendations and rationale. *Journal of the American Medical Directors Association*, 19(12), 1047–1053. <https://doi.org/10.1016/j.jamda.2018.07.005>
- Lancioni, G. E., Singh, N. N., O'Reilly, M. F., Sigafos, J., Bosco, A., Zonno, N., & Badagliacca, F. (2011). Persons with mild or moderate Alzheimer's disease learn to use urine alarms and prompts to avoid large urinary accidents. *Research in Developmental Disabilities*, 32(5), 1998–2004. <https://doi.org/10.1016/j.ridd.2011.04.011>
- Lechowski, L., Van Pradelles, S., Le Crane, M., D'Arailh, L., Tortrat, D., Teillet, L., & Vellas, B. (2010). Patterns of loss of basic activities of daily living in Alzheimer patients: A cross-sectional study of the French REAL cohort. *Dementia and Geriatric Cognitive Disorders*, 29(1), 46–54. <https://doi.org/10.1159/000264632>
- Lee, S. H., Cho, S. T., Na, H. R., Ko, S. B., & Park, M. H. (2014). Urinary incontinence in patients with Alzheimer's disease: Relationship between symptom status and urodynamic diagnoses. *International Journal of Urology*, 21(7), 683. <https://doi.org/10.1111/iju.12420>
- Lichtenstein, B. J., Reuben, D. B., Karlamangla, A. S., Han, W., Roth, C. P., & Wenger, N. S. (2015). Effect of physician delegation to other healthcare providers on the quality of care for geriatric conditions. *Journal of the American Geriatrics Society*, 63(10), 2164–2170. <https://doi.org/10.1111/jgs.13654>
- Locatelli, I., Monod, S., Cornuz, J., Büla, C. J., & Senn, N. (2017). A prospective study assessing agreement and reliability of a geriatric evaluation. *BMC Geriatrics*, 17. <https://doi.org/10.1186/s12877-017-0546-9>
- Luppa, M., Luck, T., Weyerer, S., König, H. H., Brähler, E., & Riedel-Heller, S. G. (2010). Prediction of institutionalization in the elderly. A systematic review. *Age and Ageing*, 39(1), 31–38. <https://doi.org/10.1093/ageing/afp202>
- Miu, D. K. Y., Lau, S., & Szeto, S. S. L. (2010). Etiology and predictors of urinary incontinence and its effect on quality of life. *Geriatrics & Gerontology International*, 10(2), 177–182. <https://doi.org/10.1111/j.1447-0594.2009.00574.x>
- Mullins, J., Bliss, D. Z., Rolnick, S., Henre, C. A., & Jackson, J. (2016). Barriers to communication with a healthcare provider and health literacy about incontinence among informal caregivers of individuals with dementia. *Journal of Wound, Ostomy and Continence Nursing*, 43(5), 539–544. <https://doi.org/10.1097/WON.0000000000000263>
- National Institute for Health and Clinical Excellence (NICE). (2012). *Management of urinary incontinence in neurological disease: Management of lower urinary tract dysfunction in neurological disease (Clinical guideline CG148)*. Retrieved from <http://guidance.nice.org.uk/CG148>
- Orimo, S. (2017). Autonomic symptoms in dementia with Lewy bodies. In K. Kosaka (Ed.), *Dementia with Lewy bodies: Clinical and biological aspects* (pp. 111–128). Springer. https://doi.org/10.1007/978-4-431-55948-1_9
- Orme, S., Morris, V., Gibson, W., & Wagg, A. (2015). Managing urinary incontinence in patients with dementia: Pharmacological treatment options and considerations. *Drugs & Aging*, 32(7), 559–567. <https://doi.org/10.1007/s40266-015-0281-x>
- Pickett, J., Bird, C., Ballard, C., Banerjee, S., Brayne, C., Cowan, K., Clare, L., Comas-Herrera, A., Corner, L., Daley, S., Knapp, M., Lafortune, L., Livingston, G., Manthorpe, J., Marchant, N., Moriarty, J., Robinson, L., van Lynden, C., Windle, G., ... Walton, C. (2018). A roadmap to advance dementia research in prevention, diagnosis, intervention, and care by 2025. *International Journal of Geriatric Psychiatry*, 33(7), 900–906. <https://doi.org/10.1002/gps.4868>
- Poulos, C. J., Bayer, A., Beaupre, L., Clare, L., Poulos, R. G., Wang, R. H., Zuidema, S., & McGilton, K. S. (2017). A comprehensive approach to reablement in dementia. *Alzheimer's & Dementia: Translational Research & Clinical Interventions*, 3(3), 450–458. <https://doi.org/10.1016/j.trci.2017.06.005>
- Prince, M., Bryce, R., Albanese, E., Wimo, A., Ribeiro, W., & Ferri, C. P. (2013). The global prevalence of dementia: A systematic review and metaanalysis. *Alzheimer's & Dementia: the Journal of the Alzheimer's Association*, 9(1), 63–75.e62. <https://doi.org/10.1016/j.jalz.2012.11.007>
- Prince, M., Wimo, A., Guerchet, M., Ali, G.-C., Wu, Y.-T., & Prina, M. (2015). *World Alzheimer report 2015. The global impact of dementia: An analysis of prevalence, incidence, cost and trends*. Alzheimer's Disease International. Retrieved from <https://www.alz.co.uk/research/WorldAlzheimerReport2015.pdf>
- Reuben, D. B., Ganz, D. A., Roth, C. P., McCreath, H. E., Ramirez, K. D., & Wenger, N. S. (2013). Effect of nurse practitioner comanagement on the care of geriatric conditions. *Journal of the American Geriatrics Society*, 61(6), 857–867. <https://doi.org/10.1111/jgs.12268>
- Risco, E., Cabrera, E., Jolley, D., Stephan, A., Karlsson, S., Verbeek, H., Saks, K., Hupli, M., Sourdet, S., & Zabalegui, A. (2015). The association between physical dependency and the presence of neuropsychiatric symptoms, with the admission of people with dementia to a long-term care institution: A prospective observational cohort study. *International Journal of Nursing Studies*, 52(5), 980–987. <https://doi.org/10.1016/j.ijnurstu.2015.02.013>
- Rolnick, S., Bliss, D. Z., Jackson, J. M., Arntson, C., Mullins, J., & Hepburn, K. (2013). Healthcare providers' perspectives on communicating incontinence and skin damage information with patients with dementia and their family caregivers: A descriptive study. *Ostomy—wound Management*, 59(4), 62–67.

- Roth, C. P., Ganz, D. A., Nickels, L., Martin, D., Beckman, R., & Wenger, N. S. (2012). Nurse care manager contribution to quality of care in a dual-eligible special needs plan. *Journal of Gerontological Nursing*, 38(7), 44–54. <https://doi.org/10.3928/00989134-20120606-10>
- Schnitker, L. M., Beattie, E. R., Martin-Khan, M., Burkett, E., & Gray, L. C. (2016). Characteristics of older people with cognitive impairment attending emergency departments: A descriptive study. *Australasian Emergency Nursing Journal*, 19(2), 118–126. <https://doi.org/10.1016/j.aenj.2016.04.002>
- Sloane, P. D., Schifeling, C. H., Beeber, A. S., Ward, K. T., Reed, D., Gwyther, L. P., Matchar, B., & Zimmerman, S. (2017). New or worsening symptoms and signs in community-dwelling persons with dementia: Incidence and relation to use of acute medical services. *Journal of the American Geriatrics Society*, 65(4), 808–814. <https://doi.org/10.1111/jgs.14672>
- Stewart, T. V., Loskutova, N., Galliher, J. M., Warshaw, G. A., Coombs, L. J., Staton, E. W., Huff, J. M., & Pace, W. D. (2014). Practice patterns, beliefs, and perceived barriers to care regarding dementia: A report from the American Academy of Family Physicians (AAFP) national research network. *Journal of the American Board of Family Medicine*, 27(2), 275–283. <https://doi.org/10.3122/jabfm.2014.02.120284>
- Stubendorff, K., Aarsland, D., Minthon, L., & Londos, E. (2012). The impact of autonomic dysfunction on survival in patients with dementia with Lewy bodies and Parkinson's disease with dementia. *PLoS One*, 7(10), e45451. <https://doi.org/10.1371/journal.pone.0045451>
- Suhr, R., & Lahmann, N. A. (2017). Urinary incontinence in home care: A representative multicenter study on prevalence, severity, impact on quality of life, and risk factors. *Aging Clinical and Experimental Research*, 30(6), 589–594. <https://doi.org/10.1007/s40520-017-0816-6>
- Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), 349–357. <https://doi.org/10.1093/intqhc/mzm042>
- Tricco, A. C., Lillie, E., Zarin, W., O'Brien, K. K., Colquhoun, H., Levac, D., Moher, D., Peters, M. D. J., Horsley, T., Weeks, L., Hempel, S., Akl, E. A., Chang, C., McGowan, J., Stewart, L., Hartling, L., Aldcroft, A., Wilson, M. G., Garrity, C., ... Straus, S. E. (2018). PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and explanation. *Annals of Internal Medicine*, 169(7), 467–473. <https://doi.org/10.7326/M18-0850>
- van Hoof, J., Kort, H. S. M., van Waarde, H., & Blom, M. M. (2010). Environmental interventions and the design of homes for older adults with dementia: An overview. *American Journal of Alzheimer's Disease & Other Dementias*, 25(3), 202–232. <https://doi.org/10.1177/1533317509358885>
- Wagg, A. (2019). Aging in place: Implications for continence care for older people. *European Urology*, 75(2), 272–273. <https://doi.org/10.1016/j.eururo.2018.11.017>
- Wagg, A., Gibson, W., Ostaszkievicz, J., Johnson Iii, T., Markland, A., Palmer, M. H., Kuchel, G., Szonyi, G., & Kirschner-Hermanns, R. (2015). Urinary incontinence in frail elderly persons: Report from the 5th International Consultation on Incontinence. *Neurourology and Urodynamics*, 34(5), 398–406. <https://doi.org/10.1002/nau.22602>
- Wenger, N. S., Roth, C. P., Martin, D., Nickels, L., Beckman, R., Kamberg, C., Mach, J., & Ganz, D. A. (2011). Quality of care provided in a special needs plan using a nurse care manager model. *Journal of the American Geriatrics Society*, 59(10), 1810–1822. <https://doi.org/10.1111/j.1532-5415.2011.03599.x>
- Wenger, N. S., Roth, C. P., Shekelle, P. G., Young, R. T., Solomon, D. H., Kamberg, C. J., Chang, J. T., Louie, R., Higashi, T., MacLean, C. H., Adams, J., Min, L. C., Ransohoff, K., Hoffing, M., & Reuben, D. B. (2009). A practice-based intervention to improve primary care for falls, urinary incontinence, and dementia. *Journal of the American Geriatrics Society*, 57(3), 547–555. <https://doi.org/10.1111/j.1532-5415.2008.02128.x>
- World Health Organization. (1993). *The ICD-10 classification of mental and behavioural disorders: Diagnostic criteria for research*. World Health Organization. Retrieved from <https://apps.who.int/iris/handle/10665/37108>
- World Health Organization. (2001). *International classification of functioning, disability and health: ICF*. World Health Organization.

SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

How to cite this article: Burholt V, Davies J, Boyd M, Mullins JM, Shoemark EZ, . A research agenda for promoting continence for people living with dementia in the community: Recommendations based on a critical review and expert-by-experience opinion. *J Clin Nurs*. 2020;00:1–14. <https://doi.org/10.1111/jocn.15537>