Understanding how to facilitate continence for people with dementia in acute hospital settings: raising awareness and improving care – An ethnographic study

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Glossary and abbreviations

ASSIA	Applied Social Sciences Index and Abstracts Database
BNI	British Nursing Index
CerQUAL	Confidence in the Evidence from Reviews of Qualitative Research
CINAHL	Cumulative Index of Nursing and Allied Health Literature Database
EMBASE	Excerpta Medica Database
EPPI	Evidence for Policy and Practice Information and Co-ordinating Centre
ERIC	Education Resources Center Database
GRADE	Grading of Recommendations, Assessment, Development and Evaluation
HCA	Health care assistants
HCP	Health care professional / provider
MAU	Medical admissions unit
MEDLINE	Medical Literature Analysis and Retrieval System Online, or MEDLARS Online, Database
NHS	National Health Service
PLWD	People living with dementia
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PsycINFO	Psychological Information Database
QoL	Quality of life
REC	Research ethics committee
UK	United Kingdom
UI	Urinary incontinence
WA	Welsh Assembly

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Abstract

Background

The acute hospital setting has become a key site of care for people living with dementia. People living with dementia are one of the largest populations within our hospitals, with the Department of Health recognizing that 25-50% of all acute hospital admissions are also living with dementia. However, they are a highly vulnerable group within the hospital setting. Following an acute admission their functional abilities can deteriorate quickly and significantly. Detailed research is required to explore what constitutes “good care”.

Objective(s)

This study’s focus was a common but poorly understood aspect of everyday care for people living with dementia during an acute admission: continence care. We asked: What caring practices are observable when interacting with this patient group? How do ward teams respond to and manage continence needs? What informs these approaches? What are staff doing and why?

Design

This ethnography was informed by the symbolic interactionist research tradition, focusing on understanding how action and meaning are constructed within a setting. In-depth evidence-based analysis of everyday care enabled us to examine how ward staff responded to the continence care needs of people living with dementia and to follow the consequences of their actions. We carried out a mixed methods systematic narrative review to refine our approach to fieldwork and analysis.

Setting

This ethnography was carried out across 180 days, across 12 months in six wards within three hospitals across England and Wales, purposefully selected to represent a range of hospitals types, geographies and socio-economic catchments.

Participants

In addition to general observations, 108 participants participated directly in this study, contributing to 562 ethnographic interviews. Ten detailed case studies were also undertaken with people living with dementia.

Results

This study identified “pad cultures” as an embedded practice within these acute wards: the routine use of continence pads in the care of a wider group of people living with dementia (regardless of continence and independence) as a precautionary strategy, with the rationale to provide safeguards, ensure

containment, and prevent “accidents” or incontinent episodes, with an expectation that patients living with dementia not only wear pads, but that they could and should use the pad.

Conclusions

These pad cultures enabled wards to reduce unscheduled interruptions to the institutionally mandated timetabled work of these wards, but had significant impacts on people living with dementia, and in turn wider impacts on the person and their identities. Ward staff described feeling abandoned with the responsibility of caring for large numbers of people living with dementia, believing it was impossible to work in other ways to support their patient’s continence.

Limitations

Limitations identified included the potential for the Hawthorn effect to influence data collection.

Future Work

The findings are informing the development of education and training at the interactional and organisational level in collaboration with a specialist dementia care and continence teams.

Funding

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Plain English summary

At any one time, up to half of all acute UK hospital beds are occupied by a person living with dementia, typically for a condition unrelated to their dementia. However, such people are highly vulnerable within the hospital setting: their health can significantly and suddenly worsen during an admission. Change is needed to improve the care for people living with dementia during an acute hospital admission.

This study focussed on examining a common but poorly understood aspect of everyday care for people living with dementia during a hospital admission: their continence care. For 180 days, across 12 months, we observed care in six wards within three hospitals (two wards at each hospital) across England and Wales. We use the term “pad cultures” to describe the observed everyday and routine use of continence pads as a precautionary strategy in the care of people living with dementia (regardless of their continence and independence), a strategy viewed by staff as essential to provide safeguards, ensure containment, and prevent “accidents” or incontinence episodes, but with an expectation that patients living with dementia not only wear pads, but that they could and should use the pad.

These approaches meant ward staff could limit the unscheduled interruptions to wider ward care, and meant continence care could become reduced to keeping people in bed and at the bedside and to the “checking” and replacing of soiled or wet continence pads as part of other scheduled task-based organisation and delivery of bedside care. These pad cultures had significant impacts on the person and their identities. Ward staff described feeling abandoned with the responsibility of caring for large numbers of people living with dementia, believing it was not possible to work in other ways to support their patient’s continence.

Word count: 290

Scientific summary

Research Aims

The goals of this ethnographic study were to provide a detailed understanding and directly observed examples of the organisational and interactional processes that influence how acute hospital staff respond to the continence needs of people living with dementia.

Background

People living with dementia are one of the largest populations within our hospitals, with the Department of Health recognizing that between 25-50% of all acute hospital admissions are also living with dementia, with evidence suggesting approximately 50% of these remain undiagnosed during their admission. A diagnosis of dementia is associated with increased risk of unscheduled and emergency hospitalization, typically for admissions with potentially preventable conditions such as pneumonia, sepsis, urinary system disorders, and fractures. The prominence of the acute hospital setting and its impacts on people living with dementia, their families, and the nursing and care staff delivering bedside care, cannot be ignored.

People living with dementia are a highly vulnerable group within the acute setting, with their hospitalization associated with increased risk of deterioration, functional decline, and a range of adverse outcomes, including delayed discharge and institutionalization. They have a markedly higher short-term mortality compared to patients of a similar age with the same acute admitting condition, but without a dementia diagnosis. Acute hospitals have been described as “challenging” places for people living with dementia, with healthcare-related harm and adverse events experienced typically associated with “falls”, delirium, distress, functional decline and incontinence. These adverse events during an acute admission can all lead to further dependency and institutionalisation.

Continence care is a key part of everyday personal and intimate care to support people living with dementia during an admission. However, it is essential care which remains unexamined by the research and policy agenda. These forms of care work carried out on the bodies of others have been described as “dirty work”, “elimination work”, “body work” and “body labour”, are habitually regarded as low status, bordering on the polluted, and are often gendered, with higher status workers distancing themselves from bodywork. Despite its central role in supporting the maintenance of patient dignity, wellbeing, and quality of life (QoL), continence care is often described as “basic” rather than essential care or dignity work.

However, there is little empirical research examining the continence care people living with dementia receive during an acute hospital admission. Despite the growing population of people living with dementia and the importance of continence care, little is known about the appropriate management, organisational and interactional strategies for people living with dementia admitted within acute hospital wards.

Objectives

The focus of this study was to examine a common but poorly understood aspect of everyday care for people living with dementia during an acute admission, continence care. People living with dementia are a significant population within the acute setting; however, the research agenda has lagged behind and new approaches are needed to improve their care. Detailed research is required to identify the appropriate clinical, organisational, and educational strategies to deliver supportive continence care for people living with dementia within acute hospital settings. Such research is urged by patient advocacy groups as well as government inspectorates. In response, the research objectives were to provide detailed understandings of the organisational and interactional processes that influence the ways in which acute hospital staff organise and deliver continence care and how they respond to the continence needs of people living with dementia during an acute hospital admission. Our questions were: What caring practices are observable when interacting with this patient group? How do ward teams respond to and manage continence needs and what informs these approaches? What are staff doing and why?

This study set out to explore and establish how ward staff account for and make sense of the continence needs of people living with dementia, how staff respond to and rationalise these needs, and the consequences of staff actions over time. As a result, we have presented findings which provide an original and detailed understanding of the social and institutional forces that shape and influence everyday organisation and delivery of continence care within these acute wards for this significant patient population.

Methods

Our approach to ethnography was informed by the symbolic interactionist tradition, which aims to provide an interpretive understanding of the social world. This places an emphasis on interaction, understanding how action and meaning are constructed within a specific setting, while also acknowledging the mutual creation of knowledge by both the researcher and the researched. Ethnography allowed us to focus on how the wide range of social actors within these acute hospital settings, including the large number of ward staff that patients will come into contact with during an admission, actively respond to the continence care needs of people living with dementia through their actions, and the consequences of their actions.

Ethnography allows us to examine not only these elements, but importantly, the interplay between them. We carried out a mixed methods systematic narrative review to refine our approach to fieldwork and analysis. Our approach and subsequent analysis were also informed by understandings of the wider literature in the context of our systematic review, which focussed on synthesizing what is known about the organization and culture of the delivery of continence care across a range of settings (acute, long-term and community healthcare and home settings) and across different areas of continence care (faecal, urinary).

This ethnography was carried out across six acute wards within three hospitals across England and Wales, purposefully selected to represent a range of hospitals types, geographies and socio-economic catchments. A range of variables was identified that may influence the phenomena, to inform purposive and maximum variation sampling to select sites. Across these sites, 180 days of observational ethnographic fieldwork were carried out in those areas of acute hospitals known to admit large numbers of people with dementia for acute conditions: General Medical Wards (including acute wards for older people) and Medical Assessment Units (MAU or variants thereof). Approximately 500,000 words of observational fieldnotes were collected, written up, transcribed, cleaned and anonymised by the ethnographers (KF and AN). To provide a detailed contextual analysis of the events observed, the expertise involved, and the wider conditions of patient care, we also carried out ethnographic (during observation) interviews with ward staff (562), and also with 10 case study participants and their family members, observing care at the bedside throughout their admission (and in some cases following discharge).

Ethics Committee approval for the study was granted by the NHS Research Ethics Service via the Wales Research Ethics Committee 3 on 19th April 2018 (18/WA/0033) with approval from the Health Research Authority and Health and Care Research Wales granted on 5th September 2018 (IRAS 239618 / Protocol 4804). The research project was approved for the purposes of the Mental Capacity Act 2005 (section 31).

Results

Our detailed analysis provides understandings of the complex social relations that occurred within these wards, the ways in which the organisation and delivery of continence care at the bedside connected closely with and was informed by wider institutional expectations, policies, and priorities, which in turn, shaped the personal impacts of continence care for both patients living with dementia and ward staff. Given the scope of our data set, within this report, we focus on presenting the 5 major themes that emerged within our analysis: 1) Continence as significant, visible and public phenomena, 2) Continence communication, 3) Rationales of safety, 4) Pad cultures and 5) Impacts of continence care.

1) Continence as significant, visible and public phenomena

Continence was a significant, visible, and public phenomena, representing a considerable aspect of the care for people living with dementia within the everyday bedside care routines predominantly carried out by health care assistants (HCA), but also significant within the routines of nursing. Considerations of privacy were often overridden by the recording practices and required documentation of these wards. This could also lead to close monitoring and control of the person living with dementia at the bedside.

2) Continence communication

Despite its apparent centrality within the everyday work of these wards, communication was significant primarily in the silencing of continence and the work of continence care. The discomfort surrounding continence care for ward staff could be seen within the strategies of communication and the language used within these wards during bedside care for people living with dementia, but also extended to staff discussions of continence within team meetings. Euphemisms particularly for genitalia, bodily functions, urine and faecal matter were notable during intimate personal care, with euphemistic and infantilised vocabulary used to communicate intimate continence and personal care to people living with dementia. Importantly, there was little evidence that staff were able to check the person’s comprehension or to vary language to suit the individual.

Within these wards there was the explicit requirement that people living with dementia must communicate urgency and request continence care at the bedside using institutionally recognised forms of communication, through verbal requests and using the personal call button to seek help. Permission was also required to leave the bedside and walk to a toilet, even if the person was able to do so independently. For people living with dementia, the communication of an urgent continence care need was often not verbalized (through either difficulties in communication or embarrassment), but rather was embodied, and could only be identified in the body and via changes in behaviour. It was unusual for staff to respond to these non-verbal means of communicating or to recognise an underlying continence care need.

3) Rationales of safety

Ensuring safety and minimizing risks often featured within discussions of continence care for people living with dementia. A person living with dementia leaving or repeatedly attempting to leave the bed or bedside was always interpreted by ward staff as a risk to be managed and ward staff typically focussed on the immediate behaviour with the goal typically to contain and reposition the patient within the bed or bedside chair. This focus on immediate risks of falling may reduce one risk, but meant staff typically did not recognise immediate continence needs, or other potential impacts on the person or the reduced opportunities for independence and rehabilitation, such as regaining the ability to walk.

4) Pad cultures

We identified "pad cultures" as the routine use of continence pads in the care of a wider group of people living with dementia (regardless of continence and independence) as a precautionary strategy, essential to provide safeguards, ensure containment and preventing "accidents" or incontinence episodes, but with an expectation that patients living with dementia not only wear pads, but that they could and should use the pad. These cultures enabled wards to reduce unscheduled interruptions and ensure containment at the bedside. This approach meant continence care could become reduced to containment practices and the "checking" and replacing of soiled or wet pads as part of other scheduled task-based bedside care during a shift.

Ward staff described continence care as a "heavy" burden, and a "heavy load", which expressed not only the physically demanding nature of this care, but also the experience of isolation and of feeling abandoned with the responsibility of caring for large numbers of people living with dementia, who required highly supportive care.

5) Impacts of continence care

This characterization of the dependency of people living with dementia within these wards had wider and significant impacts on the person and their identities. These impacts were intrinsically linked to "pad cultures". Placing a person into "pads" and institutional gowns during bedside care could lead to the reclassification of people living with dementia (and could become applied to a wider group of older people) grouped together within a given bay or ward area as being highly dependent. The everyday use of institutional gowns was also a response to the routine failure of "pads" as a containment technology, failure which meant clothing also needed to be routinely changed along with pads. Thus, the requirements and failures of the pad technology itself, were expected, normalized, and prioritized. This could also extend to recognition and understandings of individual behaviour. Walking to the bathroom could become understood by staff as "wandering", no longer a sign of continence, capacity, and capability, but a potential risk of "falls" and recognised by staff as a potential sign of confusion or resistance to ward care. Distress at experiencing intimate continence care from strangers, often carried out in silence or without adequate warning, could also become quickly perceived as "aggression". Forms of embodied communication of continence care needs could be viewed as transgressive or as a form of behaviour constituting a feature of their dementia, rather than an expression of urgent and underlying need.

Conclusions

This study identified "pad cultures" as an embedded practice within these acute wards. We recognise that the use of continence pads was often required to support people living with dementia in response to incontinence in the person. However, "pad cultures" refers to the routine use of continence pads in the care of a wider group of people living with dementia (regardless of continence and independence) as a precautionary strategy, essential to provide safeguards, ensure containment and preventing "accidents" or incontinence episodes, but with an expectation that patients living with dementia not only wear pads, but that they could and should use the pad. These cultures enabled wards to reduce unscheduled interruptions to the timetabled work of these wards, and to ensure containment at the bedside. This approach meant continence care could become reduced to containment practices and the "checking" and replacing of soiled or wet pads as part of other scheduled task-based organisation and delivery of bedside care during a shift.

These pad cultures had significant impacts on people living with dementia and ward staff. These practices informed wider understandings and characterizations of people living with dementia (individuals and groups cohorted together) within these wards as being highly dependent, which had wider and significant impacts on the person and their identities. In turn, ward staff described continence care as a "heavy" burden, and a "heavy load", which expressed not only the physically demanding nature of these pad cultures, but also the experience of isolation and of feeling abandoned with the responsibility of caring for people living with dementia without support. Staff also often expressed the view that although they wanted to support their patient's continence, they believed it was not possible to work in other ways.

Funding

The study was funded by the National Institute for Health Research Health Services and Delivery Research programme.

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Chapter 1: Context

There is increasing recognition that action is required to improve the experience and outcomes of people living with dementia admitted to hospital for an additional acute condition.[1–5] The Alzheimer's Society has identified widespread poor care for people living with dementia in the acute setting, with the quality of care received varying widely.[6] This variation means that people living with dementia are "likely to experience poor care at some point along their care pathway".[79(p19)]

Prevalence of people with dementia in the acute setting

The acute hospital setting has become a key site of care for people living with dementia, now one of the largest populations (25-50%) within acute wards,[6,8–12] representing high levels of unscheduled and emergency admissions (77%).[13] A diagnosis of dementia is associated with increased risk of hospitalization,[14] with potentially preventable conditions such as pneumonia, sepsis, urinary system disorders, and leg fractures[10,15] often the principal cause of admission.

Estimates are likely to be low due to underreporting or late diagnosis of dementia in this population.[2] Screening studies suggest that within the acute setting, approximately 50% of those affected by dementia remain undetected and undiagnosed[16] and do not yet have a formal diagnosis in their medical records,[10,17,18] with recent figures suggest this rises to two thirds[19,20] and three quarters[12,21,22] of older people (patients over 65 years) during an acute hospital admission. A high prevalence of delirium (15.5%), undiagnosed delirium (72%),[23] and co-morbid mental health disorders amongst[17] this patient population, with medication and co-morbid chronic conditions such as diabetes,[18] also potentially impact on cognitive function during an admission.

Impact on patient outcomes

People living with dementia are a highly vulnerable group and their hospitalization is associated with increased risk of deterioration,[14,17] functional decline and a range of adverse outcomes[22,24] including delayed discharge[25] and institutionalization.[26] They also have a markedly higher short-term mortality,[7,9,26,27] compared to similar patients without a dementia diagnosis.

Acute hospitals have been called "challenging"[27] and "dangerous"[28] places for older people and for people living with dementia. Healthcare-related harm and adverse events experienced by people living with dementia are typically associated with falls, delirium, incontinence, and functional decline.[29] Associated iatrogenic impacts[30] of an admission include incontinence,[31] reduced mobility,[32–34] increased agitation,[35] delirium,[36–39] longer admissions,[40] and distress.[41–45] These adverse events can result in further dependency, institutionalisation, and potentially death during their acute admission.[30]

Calls for transformation

In response to this evidence, there has also been recognition by policymakers of the urgent need to improve care for people living with dementia in hospitals, particularly for admission to general hospitals for an unrelated condition.[27] A "transformation of dementia services" has been called for within the Department of Health national strategy, "Living Well with Dementia"[4] and by the Dementia Action Alliance.[46] In partnership with the NHS Institute for Innovation and Improvement, a key objective within their Call to Action[46] is to design services around the person with dementia through the creation of dementia-friendly hospitals. These objectives are supported and reinforced by a wide range of policy recommendations. The Prime Minister's Challenge on Dementia[47] renewed the focus on dementia-friendly health and care, with the goal of every person with dementia obtaining the safest, best care in acute hospitals.

However, although acute hospitals have an increasing range of initiatives[8], even within institutions where high quality acute care is identified, this is limited to specific wards, failing to reach across an organisation[8]. Overall, it is acknowledged that hospitals struggle to respond to the needs of an ageing population with increasing hospital admissions amongst this group.[48]

The social organization and interactional context of care

Research draws attention to the social and organisational context of care in influencing frontline delivery within acute wards, with much research focused on the care of older people and people living with dementia. Meta-ethnography[49] identifies that, despite nurses' aspirations for a high standard of psychosocial care, this was largely dependent on ward-level social and organisational conditions.

National Institute of Health Research studies report strong associations between ward cultures and care quality. Patterson et al.[50] found that positive patient and carer assessments of acute care for older patients were associated with higher staff ratings of a positive climate for care, findings mirrored in a second NIHR study that experiences of working in wards directly influences patient experiences.[51] The impact of different shifts on work goals and priorities;[52] a culture of reactivity;[53] austere ward environments and cultures that emphasize routines and few opportunities for communication that restricted both patients and staff, and were associated with staff moral distress and burnout.[52,54,56]. A systematic review of qualitative studies highlights the importance of relational work in delivering care quality within acute wards[55] and the nursing role's significance in identifying and promoting dignity for older people with dementia.[56] However, given the increasing delegation of "hands-on" care to HCAs, an important focus needs to be this less privileged[57] and marginalized group who can also influence how care is organized and delivered.[57,58.]

Despite people living with dementia representing a significant population within the acute setting, ward cultures can mean delivering care appropriate to their needs is often viewed as "a disruption to core business";[59] they can be viewed as a group who do not belong within the acute setting[60] and should be transferred to other services.[61] Older people and family carers recognize that developing good relationships with staff powerfully informs and shapes their experience of a hospital admission.[62] Acute ward staff can fail to promote the identity and wellbeing of people living with dementia in their care, and may not recognise or respond to opportunities to deliver recommended person-centred care,[63] with patients viewed as "complex" or "demanding" receiving less personalised care.[56] As a result, the acute setting remains a potentially harmful location for this patient group.

Continence care: body work and 'dirty work' of the ward

Continence care is part of everyday intimate care to support people living with dementia, which has been described variously as "dirty work", "elimination work", "body work", and "body labour". These forms of paid work carried out on the bodies of others[64] and their wastes are habitually regarded as low status, bordering on the polluted,[65] and are often gendered.[65] This work poses a serious threat to formal caregivers' sense of self and status, with higher status workers distancing themselves from bodywork.[65–67] It is also invisible work,[66] with body workers hiding "dirty work" from others, e.g. by drawing screens around the bed[68] protecting the dignity of both the patient and the worker. Supporting patients to use the toilet supports the maintenance of dignity, wellbeing, and QoL, a core nursing role.[69] Despite this, continence care is often described as "basic" rather than "essential" care.[70]

Dementia, incontinence and stigma

A diagnosis of dementia is associated with significant levels of stigma, and powerfully impacts on opportunities for social inclusion.[71] Incontinence is also a powerfully stigmatizing, particularly within care settings,[72,73] discrediting an individual's social identity and elicits fear, stereotyping, and social control.[74,75]

The continued stigma, shame, social isolation, and loss of integrity experienced by people living with incontinence is linked to a cultural disgust with urine and faeces.[76] Incontinence in older people can be viewed as a loss of control, a sign of incompetence incompatible with adulthood, putting them on the path to becoming a "nonperson".[77] Thus, loss of continence has consequences that go far beyond the physical impairment, to cast strong doubt on a person's social competence,[78] disrupting privacy as incontinence "threatens to expose the incompetence of the body to others".[79]

This stigma is further impacted by intersections of gender, race, and ethnicity.[80,81] For example, older women with dementia are exposed to a "triple jeopardy"[72] of age, sex, and condition. Reviews examining the experiences of older women with incontinence identified microaggressions from others (subtle and insidious acts of aggression such as impatience intended to make the individual feel inferior) leading to social isolation.[80]

Continence and dementia in the hospital setting

Urinary incontinence is one of the most commonly reported symptoms experienced in the last year of life, experienced by an estimated 72% of people living with dementia at this stage.[82] Key predictors of are the severity of cognitive impairment and degree of immobility.[83] Thus, incontinence is typically a feature during the moderately severe and advanced stages of dementia.[84] Importantly, this does not reflect the continence status of the majority of people living with dementia admitted to acute wards, generally in the early and moderate stages of the disease, when incontinence should not be a typical feature of their dementia. Yet in the acute setting, a UK national audit found 71% of patients over 65 (33% of whom had a diagnosis of dementia and 44% impaired mobility) were classified as incontinent of urine.[85] Similarly, a screening study of emergency admissions of patients over 70 with cognitive decline, found 47% were classified as incontinent,[14] with 86% identified as requiring supervision and assistance with toileting.[84]

Within the acute setting, people living with dementia are at high risk of "functional incontinence", when their cognitive impairment, mobility problems, or medication (associated with their admitting condition) means they cannot reach the toilet in time,[84,86] as a result of their environment rather than their dementia.[87] A small number of international audits in acute settings have identified that people living with dementia who are continent at admission are at significant risk of developing incontinence during admission, with this becoming permanent at discharge.[88–90] An estimated 17%[90] to 36%[88] of previously continent people living with dementia will be clinically incontinent following an acute hospital admission. Carers report high dissatisfaction in continence care (60%) for people living with dementia during an acute admission, with hospital-acquired incontinence frequently reported as the key long-term impact post-discharge.[10]

These high rates of hospital-acquired incontinence are associated with a number of hospital organization and treatment factors. A primary provisional diagnosis of delirium, dementia, or cognitive impairment are the most significant risk factors,[89] more than doubling the risk of hospital-acquired incontinence.[91] Increased length of stay,[88] advanced age (85+ years),[89,91] gender (women identified as more at risk),[91] and reduced mobility and physical functioning,[107] also increase risk. The use of continence pads, urinary catheters,[90] and chair restraints,[91] and symptoms of drowsiness, daily pain, and sleep problems,[91] have all been associated with increased risk of acquired incontinence following discharge. However, continence care, including new-onset incontinence among older adults and people living with dementia during their hospitalization, is a significant and understudied phenomenon.

Continence care for people living with dementia in acute hospital wards is a continued concern for policymakers,[92] families, and carers.[10,93–95] The systemic failure within the NHS in providing older and vulnerable patients with dignified continence care is widely highlighted in service reviews and inquiries.[93,94,96–98] Lack of dignity and privacy was a recurrent theme.[92,96,97]

Dementia guidelines emphasise that incontinence is often treatable.[99] However, the small number of qualitative studies examining continence care for older patients in the acute setting identify containment (use of disposable pads and catheterisation) as key strategies,[100,101] corroborated by national audits.[102]

Incontinence is highly discrediting[74,79] and combined with dementia, increases stigma and attacks social status.[73,103] A disparity exists between policy recommendations to improve care and actual implementation. Although incontinence care plans are common in care homes (83%), only 37% of Trusts have an integrated incontinence care pathway[102] and only 18% have a continence nurse specialist[50], with low levels of continence training for ward staff.[48,101] Despite the growing population of people living with dementia and the significance of continence care in the acute setting,[104] little is known about the appropriate management, organisation and interactional strategies for people living with dementia admitted to hospital.[8]

The current paucity of evidence[85] fails to support this population's continence needs in this key site of care.[104] This presents a significant NHS challenge[8] and new approaches are needed. Our research question is therefore "How do ward staff respond to the continence care needs of people living with dementia being cared for within acute hospital wards, and what are the experiences of continence care from the perspectives of patients, their carers, and families?"

Chapter 2: Research objectives

This in-depth ethnographic study aims to establish an empirically-based conceptual and theoretical foundation to inform the development of innovative interventions in service organization, delivery and training that will improve clinical care for people living with dementia, a large, growing, but often overlooked population within acute hospital wards. This study focuses on an important, poorly understood feature of everyday care for people living with dementia: continence care.

Specific objectives are to:

- Provide a detailed understanding and directly observed examples of the organisational and interactional processes that influence how acute hospital staff respond to continence management and toileting needs of people living with dementia. What are staff doing and why: what caring practices are observable when interacting with this patient group, how do staff respond to and manage continence needs and what informs these approaches?

- Provide a detailed understanding and concrete examples of the ward routines that impact on continence care for this group. Specifically, examine the assessment, classification, and management of patient toileting needs and their place within ward handovers, routines and schedules.

- Examine and describe the experiences of incontinence, toileting and catheterisation care in the ward from the perspectives of people living with dementia and their carers.

- Explore the relationship between continence needs and patient dignity to add to understandings of how continence care impacts upon person-centred care, patient dignity, the potential for dehumanization, family experiences, and staff morale.

- Identify factors associated with the improved care of this patient population that are actionable, specifically what clinical care needs to look like to improve the quality and humanity of continence care for people living with dementia and their carers within acute hospital settings. This may include enhanced awareness of risk of incontinence interventions and clinical management options.

- Identify low-cost factors at the organization level, e.g., staff training, ward practices and routines, that can lead to actionable change, and to explore barriers and facilitators to implementing changes.

- Provide a detailed foundation of knowledge to inform a longer-term programme to develop and evaluate interventions providing new or enhanced approaches to delivery of continence care to people living with dementia.

- Dissemination and delivery of new knowledge to frontline providers of acute hospital care to people living with dementia, managers, service commissioners, and the research community.

Little empirical research examines continence care for people living with dementia to inform practice in the acute setting. A systematic review finds a lack of evidence-based nursing interventions to manage continence care for people living with dementia. It cannot be assumed that interventions from long-term care can be transferred unproblematically to the acute setting.[85] We conducted a mixed methods systematic review and thematic synthesis of the literature alongside ethnographic fieldwork to establish an empirical foundation from which interventions in acute care settings can be established.

Chapter 3: Methodology

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This study utilized an ethnographic approach alongside a mixed method review. It focussed on the routine work of continence care for people living with dementia admitted to acute hospital settings within the wider context of the everyday care carried out by nurses and HCAs. We provide a detailed understanding of social and institutional forces shaping and influencing continence care. Our ethnographic approach enables us to understand how staff respond to continence care needs of people living with dementia and to follow the consequences of their actions. We examined how staff account for and make sense of the needs of people living with dementia in these contexts.[106]

Ethnography provides a sophisticated toolkit for exploring the complexities of the everyday, forging better understandings of daily meaning-making[107] within organisational structures and settings. It delivers detailed understandings of organisational culture, organisational change, and the interrelationships between different elements within an organisation. Within healthcare settings, ethnography allows researchers to take into account perspectives across the clinical experience, exploring the perceptions of patients and carers; medical, nursing and care teams; and wider auxiliary, administrative, and managerial staff.[108,109] It is particularly useful to examine research questions and topics where measurement is either not easy or inappropriate, where the aim is to access the unspoken and tacitly understood, and where the topic is complex and highly sensitive.[110]

Our approach to ethnography is informed by the symbolic interactionist tradition, which aims to provide an interpretive understanding of the social world. This places an emphasis on interaction, understanding how action and meaning are constructed within a specific setting, also acknowledging the mutual creation of knowledge by both researcher and researched.[111] The study aimed to deliver understandings of everyday continence care for people living with dementia within the acute hospital setting, focusing on how the wide range of social actors within these settings (the large number of ward staff they will come into contact with during an admission) actively respond to the needs of people living with dementia, through their actions, and following the consequences of their actions. Ethnography allows us to examine these elements, and importantly, the interplay between them. It examines "up close and in person how work is organized and how the organizing organizes people".[107(p.1)]

Ethnography at its core is the in-depth study of a small number of cases. Exploring people's actions and accounts within their natural everyday settings allows ethnographers to collect relatively unstructured data from a range of sources; observation, informal interviews, and documentary evidence.[112] Ethnographers "hold that an appreciation of the extraordinary-in-the-ordinary may help to understand the ambiguities and obscurities of social life".[107(p.2)] This approach provides a depth of understanding and theory generation.[113] A long tradition of ethnography within healthcare settings[111] provides many examples of ethnographic studies with significant impacts on policy and practice.[114–117]

Our aim in utilizing ethnography was to explore the otherwise unnoticed details of everyday life, what was tacitly acknowledged but rarely discussed around ordinary, and in the case of continence care, hidden activities. Starr notes the importance of examining organizational infrastructure and the "hidden mechanisms"[118(p.377)] constructed and embedded in the technical and procedural work carried out within it. The articulation work of people within organisational and institutional settings was examined: how people within them account for and make sense of their actions. An ethnographic approach allowed us to explore both the front stage performance and also the backstage work practices,[119] while always maintaining the dignity and privacy of both patients and staff.

Within any organization there are groups whose everyday work is unrecognised formally, often unnoticed and invisible.[118] In the hospital setting this includes carers, nurses, healthcare assistants (HCAs), and auxiliary staff, including domestic services. In the context of our research questions, ethnography can examine how social and institutional forces shape and influence the work of health care providers (HCPs)[120] and the everyday routine behaviours of individuals, both within and across multi-disciplinary teams.[121]

This study focusses on the routine work of continence care for people living with dementia admitted to acute hospital settings within the wider context of the everyday care carried out by nurses and HCAs within them and provides detailed understanding of the social and institutional forces that shape and influence continence care. Our ethnographic approach enables us to understand how staff respond to the continence care needs of people living with dementia and to follow the consequences of their actions. We examine how staff make sense of the needs of people living with dementia in these contexts.[106] In presenting our findings, utilisation of ethnographic "thick description" enables the reader to connect concepts, policies, and practice to detailed empirical examples.[122] This approach allows the reader to develop not only a strong connection to the social world of these wards but also an understanding of the complex social relations within them, the personal impacts of continence care on patient, carers, and ward staff, and how this connects with wider issues in the organisation and delivery of care within these institutional settings.[122]

Prior to data collection, in January 2018, DE and JH carried out a mixed methods systematic review and thematic synthesis of the literature to identify successful strategies in care settings that could inform innovations in continence care for people living with dementia in the acute hospital setting. This approach bridges the gap between research, policy and practice[123(p.2)] and is useful in examining the complexities of health service settings. The synthesis generated was used to refine our approach to fieldwork and analysis, and to inform the development and feasibility of interventions.

Chapter 4: Data sources

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Ethnographic fieldwork

Multiple sites were used within this ethnography (both across and within hospital sites) as an exercise in "mapping terrain". The goal was not "representation" or "comparison", but "identification", to reveal the social processes surrounding continence care for people living with dementia within the acute setting. Thus, it was important to observe both interaction and performance; how continence care work was organised and delivered, and how it was communicated between different actors. This moves beyond traditional examination of verbal communication, to exploring tacit and non-verbal interaction, the multiple complex, nuanced but everyday interactions and strategies that occur around continence care, which often "communicat[e] many messages at once, even of subverting on one level what it appears to be 'saying' on another".[125(p.24)] Many such interactions were concealed, part of backstage talk, veiled language, euphemism, and informal conversations within these settings. Our approach remedies a common weakness in many qualitative studies: what people say in interviews may differ from what they do or their private justifications to others, an issue exacerbated when the topic under discussion is taboo or concealed from everyday public life.[126] Our approach allowed us to respond to this, and to examine the impacts of the organisation and delivery of continence care on people living with dementia and those caring for them over time.

This ethnography was carried out in six wards within three hospitals across England and Wales, purposefully selected to represent a range of hospitals types, geographies and socio-economic catchments. Across these sites, 180 days of observational ethnographic fieldwork were conducted in areas of acute hospitals known to admit large numbers of people living with dementia for acute conditions: General medical wards (including acute wards for older people) and MAU (or variants thereof). Approximately 500,000 words of observational fieldnotes were collected, written up, transcribed, cleaned and anonymised by the ethnographers (KF and AN). To provide a detailed contextual analysis of the events observed, the expertise involved, and the wider conditions of patient care, we also carried out ethnographic (during observation) interviews with ward staff (n=562) over multiple occasions. Case study participants who were living with dementia (n=10) and their family members and carers (n=20) also took part in ethnographic interviews (n=30) during their admission (and in some cases following discharge). Given the scope of our data set, within this report, we focus on presenting our analysis of the observational data examining a key feature of continence care within these wards: the use of continence "pads" in everyday bedside care, the impacts on people living with dementia and ward staff, and their influence on shaping ward cultures. In order to present the analysis of other aspects of continence care (for example, catheter care) and data sets (staff interviews and case studies following people living with dementia and their families) fully, these will be published separately.

Multi-sited ethnography defines the object of study via a number of techniques or tracking strategies and within the fieldwork we recognised the importance of focussing on the “busy intersections”[127:(p.28)] and of seeking out sites of tension where a large number of interests and identities are expressed. It is at these points that identity and culture become articulated, enacted, and constructed. We aimed to provide a detailed understanding of the clinical and interactional work and processes that influence ward teams, their response to pressing continence needs of patients living with dementia, and the organisation of continence care for multiple patients within and across shifts. We also explored the work of other clinical staff (this included specialist registrars, consultants, allied health professionals, and staff with managerial responsibilities) and auxiliary staff (including domestic services) when involved in the care of people living with dementia and their continence. We observed their actions and accounts to explore how individuals, teams, and institutions, prepare for, respond to, communicate, and organise continence care within these settings, and the cultures that are both produced and maintained by these approaches.

At each hospital (n=3), we conducted 30 days of observation within each ward (n=2) over a period of eight weeks of detailed fieldwork. Care was observed within and across day and night shifts, weekdays, weekends, and where possible also public holidays. Observations ranged in duration from two to six hours and were reactive to events within the wards during observation. These periods of observation were followed by a further eight weeks of follow-up data collection (case study interviews and additional observation) so that (where possible) we could examine the implications of continence care practices for discharge and long-term care trajectories. Fieldwork always preserved patient dignity (this study did not need to go “behind the screen” to observe intimate care) and the goal of our observational strategy was to provide an in-depth evidence-based analysis of the management and context of continence care within these wards:

- Used non-participant observation, concentrated on the visible work of nurses and health care assistants (HCAs) who are responsible for continence care. Other healthcare staff were also included as they are involved in wider continence assessment and decision-making for this patient group.
- Focussed on ward routines where continence care took place or was prompted, including observation rounds, personal care routines, medication rounds, meal times.

- Focussed on responses to personal alarms, calls for assistance and decisions to prioritize or defer, to examine the classification, urgency and management of patient continence care needs when it disrupted ward routines and schedules.
- Examined communication and language around continence care, and everyday interactions and strategies used within the wards between staff, with people living with dementia and with their families.
- Focussed on ward practices of assessment and management of continence care for people living with dementia by ward staff (nurses and HCAs), the medical teams and other staff when they were involved in continence care, assessment, and decision-making.
- Observed shift handovers to examine everyday ward classification practices of continence and incontinence and explore how these informed the organisation and planning of patient care within shifts and how these classifications entered risk assessment and discharge planning.
- Examined the technical and procedural work around continence care management (e.g., types and use of pads), assessment, and recording.
- Focussed on observing conversations with carers, as opportunities for sharing information about continence and how these might best be managed, and decisions about discharge and place of discharge.
- Collected routine ward data at the time of data collection, providing context and an understanding of the workload around both everyday care routines and continence care within these wards

This enabled us to provide detailed understandings of organisational and interactional care processes impacting on the responses to and the management and delivery of continence care for this patient group.

Working within acute wards required the researchers to adopt a range of observational practices and strategies. Observation time was spent standing, rarely sitting, reflecting the pace of work of the teams and the wider hospital staff within them. Our practice involved standing in the corridor, usually close to an alcove, sink, trolley, or equipment that was already blocking part of the walkway, where there was space to stand out of the way of the team, and from where areas of the ward and the events within them were visible. We also shadowed and walked with individual members of staff and teams as they worked within the ward. The built environment of the observed wards was highly variable, ranging from a central hub with satellite bays, to long corridors, sometimes with windows onto bays and rooms, other times without. The researchers positioned themselves accordingly in the corridors to maximise visibility while minimising obstruction.

Our strategy was of comprehensive note taking with notes written up as more detailed accounts. The researchers wrote extensively during these periods of observation, using A4 spiral bound notepads. Writing was typically carried out with the notebook in hand, writing as we were standing or walking. The fieldnotes recorded took the form of a running record of events and incidents including details and near verbatim text of conversations and interactions. The opposite side of the notebook remained clear of fieldnotes and was used to insert thoughts and any additional points or queries to follow up on or expand later. Note-taking was clearly visible to all within the wards (staff and patients) who then had natural opportunities (as well as being offered opportunities by the team) to ask questions about our notes. Staff were granted access to look at the fieldnotes taken if they requested it.

Ethnographic interviews with ward staff

To provide a detailed understanding of the influences on HCPs response to continence care, ethnographic (during observation) interviews focussed on and were predominantly carried out with nursing (across all grades), HCAs, also including clinical staff, from a range of disciplines (including foundation year doctors, junior doctors, registrars, consultants, physiotherapists, occupational therapists, pharmacists and specialist dementia teams), staff with co-ordinating responsibilities (ward clerk and discharge co-ordinators), and auxiliary staff (including domestic services) where appropriate. These interviews (n=562) with ward staff over multiple occasions during and across shifts as staff cared for people living with dementia within each ward, had a broad focus on the organisation and delivery of everyday care and continence care. These short ethnographic interviews allowed us to question routine practices, rationales, and decision making, to understand what staff were doing and why:

- What was the articulation work within those settings, how did staff account for and make sense of their actions?
- What were their experiences and training of working with people living with dementia and continence care, what informed their practices?
- What aspects of caring were defined as difficult, demanding or rewarding and what was their confidence in caring for this patient group?
- What were the barriers and enablers to supporting people living with dementia?
- What was the recognition and rewards of providing care for this group from patients, relatives, colleagues, managers?

Case studies:

A series of cases (total sample=10) were recruited with the goal to follow individuals living with dementia and their family carers from initial admission in the acute ward through to discharge (home, long-term care) and to follow their short-term care pathways. However, we were not able to seamlessly identify and follow people through an admission. The organisation of hospital admissions, with patients admitted, transferred and discharged on these wards 24 hours a day, meant identifying and tracing a patient was not always possible, requiring the availability of the nurse in charge of the ward to access systems on behalf of the researcher. These obstacles meant we recruited 10 case studies rather than our objective (12), but these represented a range of diagnostic, prognostic, and socio-demographic factors, including patients with a range of continence care needs, reflecting our aims of including people with diverse experiences.

The goal of our approach was to support people living with dementia and their families to share their experiences of an admission, which meant the case studies include limited data specifically on continence care, and contribute to our wider understandings of the experiences and perspectives of an acute admission and its consequences for people living with dementia and their families. In order to fully represent their experiences, this analysis will be published separately.

Sampling

Sampling in ethnography requires a flexible, pragmatic approach, using a range of variables that may influence the phenomena, and what is known based on the available literature. Probability sampling is inappropriate, instead non-probability sampling was used to provide analytically rather than statistically generalizable findings.[128,129] Using this approach, the number of sites and participants in the sample was judged not on the basis of size, but by the nature and scope of the study aims, the findings of our syntheses, the quality and appropriateness of the sample, and the achievement of theoretical saturation of data had been achieved.[129]

Sampling of hospitals and ward sites

Hospital settings are well suited to an ethnographic approach.[130,131] We identified a range of variables that may influence the phenomena using purposive and maximum variation sampling to include 3 sites that represented hospitals types, geographical location, expertise, interventions and quality. Within these hospitals, we included site of care (assessment units and general medical wards) which receive a high volume of patients living with dementia who required acute medical attention, and had a wide range of continence care needs. Detailed descriptions of these hospital sites and profiles of participating ward can be found in Appendix 1.

Sampling within each acute hospital site

Whilst our sites (acute hospitals and wards) were standardized, with sequential and systematic data collection, there was some variation within each site. We applied theoretical sampling *within* sites to achieve robust analytic concepts within the analysis, rather than sites and people. Informed by grounded theory, sensitizing concepts from the ongoing analysis fed into each stage of data collection, expanding the research process to capture emerging relevant aspects into the ongoing analysis. The focus was on “discovery”, ensuring the grounding of emerging concepts within data and the reality of the settings.[132]

Sampling and recruitment of staff for observation and interviews

We followed the routine and everyday work of nurses and HCAs. We use purposive sampling to include a wide range of clinical grades and roles across the ward settings. In addition, we included other clinical staff, staff with co-ordinating responsibilities and auxiliary staff where involved in the care of people living with dementia and continence care.

Sampling and recruitment of patients for observation

It was not possible to predict the type of patients available within acute hospital wards during the fieldwork period. However, we were confident from our previous research (NIHR HS&DR 13/10/80) that people living with dementia would be a significant population within them. Details of the populations within these wards are found in Appendix 1.

Ethical approvals

Ethics Committee approval for the study was granted by the NHS Research Ethics Service via the Wales Research Ethics Committee 3 on 19th April 2018 (18/WA/0033) with approval from the Health Research Authority and Health and Care Research Wales granted on 5th September 2018 (IRAS 239618 / Protocol 4804). The research project was approved for the purposes of the Mental Capacity Act 2005, confirming that it met the requirements of section 31 of the Act in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project. Recruitment for the study was managed and recorded through the Central Portfolio Management System beginning on 11th October 2018 and ending on 31st October 2019. 108 participants were recruited to the study.

The safety of all participants was a key priority at each stage of the study. Before commencement, the ethics of observing care, and of reporting where necessary what was observed, were frequently discussed with the hospital sites and our carers group. In meetings with the NHS REC that approved this study it was clarified that while neither of the researchers (KF & AN) had a clinical duty of care (being academics without clinical qualifications or professional affiliation), they would be bound to safeguard any patient participants observed during the project.

Prior to commencement, both researchers, experienced in both hospital ethnography and conducting research with people living with dementia, renewed their Good Clinical Practice certification and superseded their existing Protection of Vulnerable Adults level 1 certification by completing Level 1, 2 and 3 Adult Safeguarding training. They were made aware of safeguarding and whistleblowing procedures at each site, and had a named member of staff (the site PI or senior nurse on shift) to contact if malpractice or behaviour putting vulnerable patients at risk was observed. Both underwent full Occupational Health checks, held honorary contracts with the NHS Health Boards and Trusts, and had up to date Disclosure and Barring Service certification and NHS research passports.

Several months in advance of the period of observation at each ward the research team visited the wards to discuss with relevant staff the study aims and to introduce the study to ward staff. These meetings were repeated 24 hours before observations started and in handover meetings in week one of observations and to individuals throughout the study, to ensure ward staff were aware of the study, to answer questions, and to recruit staff to the study.

Over the course of the observations, the researchers saw many aspects of everyday practice which would not be considered "best practice", or in the interests of the individual patient. However, the examples presented within this report were not isolated but formed part of systemic and established everyday routine practice within every ward at each hospital site. We never observed individual malicious behaviour, or isolated incidents of deviance placing a vulnerable adult at risk. Instead, we observed how the everyday routine organisation and delivery of continence care itself often placed the vulnerable person living with dementia at risk, as a part of the routine and established cultures of these hospitals and the wards within them. At no point did the researchers feel any individual or ward team were acting in a way that required escalating or whistleblowing.

The researchers did, however, frequently intervene to support people living with dementia and their families and carers where necessary to protect the comfort of the patient. People living with dementia would frequently tell the researchers (as can be seen in examples presented below) that they wanted to go to the bathroom, that they were in pain, or shared concerns (about home, family or pets, or how to pay for their care). In response to disclosures, the researcher (with permission from the patient) would inform ward staff and ensure that this was attended to by the ward team.

The researchers were sometimes the only member of "staff" spending uninterrupted time within a specific area of a ward and so would regularly ask patients if they needed anything. Sometimes when ward staff were absent or could not be called quickly to a bay, the researchers provided immediate support. For example, were a patient at immediate risk of physical danger, they would call staff and, if necessary, intervene. Similarly, they would fetch cups of tea, pour glasses of water, and carry out other simple requests within these wards when required and permitted. While the researchers accept this may have, on occasion, contaminated the purity of their data, the welfare of those within the field of observation was always their priority.

Between sites, the emergent analysis was regularly presented to the research team, including nurses, clinicians and Trust leads, people living with dementia, and family carers, and while it was agreed that the care observed could be detrimental or distressing to a person living with dementia, it was also recognised as routine, and recognisable as the everyday practice of acute ward staff.

While, in isolation, some of the descriptions of continence care presented within this report may appear to breach patient's rights, we hope to have demonstrated in our analysis that these are not isolated incidents but rather the everyday reality of care delivery each person living with dementia will experience during admission within the acute hospital. We also show that nurses and HCAs likewise experience distress, with little organisational support or recognition of the care required to respond to the continence needs of people living with dementia in ways other than those outlined here. The cultures of these institutions prioritised risk reduction and timetabled routines over the comfort or preferences of patients living with dementia. The actions taken by nurses and HCAs in response to continence needs presented in this report were taken in good faith, attempting to protect the patient and the ward, and to respond to the policies and perceived expectations of the wider institution. We hope the evidence presented here highlights the challenges faced by ward staff as they deliver care in the acute environment, and the need to better support both patients living with dementia and staff within this setting.

Chapter 5: Modes of analysis / interpretation

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Data collection (in-situ observations and interviews) and analysis was informed by the analytic tradition of grounded theory,[132] a flexible approach for ethnographic research.[126] This approach utilises theoretical sampling and the constant comparative method, whereby data collection and analysis are interrelated[133,134] and conducted concurrently.[133,135] The flexibility and responsiveness of this approach was of particular significance, enabling us to increase the "analytic incisiveness"[126(p160)] of the study. Preliminary analysis of data continued in parallel with data collection at later sites, informing the focus of further stages of data collection and subsequent concurrent analysis. The constant comparative method means that the coding of data into categories was a recurrent process. Data was examined in the context of previous fieldwork and analysis, which informed further strategies of data collection within subsequent sites, producing more focused stages of analysis.[126] The analytic concepts emerging were then further tested and refined to develop robust analytic concepts that transcend the local contexts of individual wards and sites, and identify broader structural conditions[136] influencing continence care for people living with dementia within the acute setting.

Findings from our mixed methods review informed the ethnography in various ways, with a focus on initiating the process of early thinking and theorizing during data collection and analysis. The review aimed to increase our theoretical sensitivity to key areas of importance to explore during data collection, including communication, language, and the importance of non-verbal cues. The review was conducted alongside data collection at the first site, with data at this site analysed as it was collected. The review and its findings were used to stimulate questions during the ongoing iterative analytic process. This affirmed our focus on issues of continence-related communication, language, privacy and dignity, combined with known routines and strategies of bedside care.

Strauss and Corbin[134] caution that in grounded theory, literature should not impede "discovery", emphasising the importance of using it actively to identify potential areas to inform theoretical sampling; thus we explicitly sought opportunities to identify examples of individualised care planning and assessments, with the goal to improve the continence of PLWD during an acute admission and the use of promoted strategies such as "prompting" and other continence routines and schedules identified within the review.

Grounded theory strengthens the ethnographic aims of achieving theoretical interpretation of data, whilst the ethnographic approach prevents a mechanistic and rigid application of grounded theory.[126] Ethnography can treat everything within a setting as data, leading to the ethnographer collecting large volumes of unconnected data and a heavily descriptive analysis.[129] Our approach provides a middle ground where the ethnographer uses grounded theory to provide a systematic approach to data collection with the analytic goal of developing theory to address the interpretive realities of the range of actors within these ward settings.[126] Data collection strategies explicitly supported "theoretical saturation",[132] where further data collection was no longer adding to the development of analytic concepts.

Analysis involved developing and testing of analytic concepts and categories. The strategies we used for their development included careful reading of the data, looking for patterns and relationships, noting surprises, inconsistencies, and contradictions across the range of perspectives gathered. Line-by-line coding is inappropriate for field notes; rather, coding was selective involving whole events or scenarios.[117] Initially this produced a collection of "sensitizing concepts"[137] and analytic memos, which informed the later development of more refined and stable analytic concepts. At this stage KF and AN re-examined the raw data informed by the subsequent phases of analysis (re-coding where necessary) looking for examples and events to test the analysis. Emerging analytic concepts were tested and refined to develop (in collaboration with the wider research team) stable concepts that identified broader structural conditions[134] influencing continence care.

Throughout this process, we drew on multiple perspectives (sociological, policy, clinical, patient and carer) to inform our analysis. This included the use of our mixed methods systematic review, with the narrative syntheses generated (see findings) informing data collection strategies and the analysis. Credibility checks included presenting emergent analysis to ward staff (participating sites) and to people living with dementia and carers (see Chapter 9) for discussion throughout this process.

Field notes of observation and near verbatim text were handwritten then transferred into word files following data collection.[138,139] All audio recordings of observations and interviews (ethnographic and in-depth) were written up in word files or transcribed verbatim by a professional transcription service. All sites, individuals, and data collected was anonymised and sorted in line with the UK General Data Protection Regulations as part of the Data Protection Act (2018), and the NHS England Data Protection Policy (2014). Storage of the data is managed by the Cardiff University Information Security Framework.

Chapter 6: Findings from mixed methods review and thematic synthesis

This chapter focuses on the mixed methods systematic review and thematic synthesis. Sections of this chapter have been reproduced from Edwards et al.[140] under licence CC-BY-4.0 (https://creativecommons.org/licenses/by/4.0/).

Methods

This systematic review uses methods informed by the Evidence for Policy and Practice Information and Co-ordinating Centre (EPPI).[141,142] A scoping exercise in January 2018 was followed by a targeted, in-depth, review and synthesis. The protocol has been registered in the PROSPERO (CRD42018119495).

Scoping exercise

The scoping exercise asked "What is known about the management and practices of continence care (continence care, incontinence care, toileting, and catheter care) for people living with dementia (PLWD) in acute, long-term community healthcare, and home settings?" Two databases were searched (MEDLINE and PsycINFO) from inception to January 2018 for citations that focused on, or contained an element relating to, each of the following inclusion criteria:

1. People living with dementia, Alzheimer's disease or cognitive impairment
2. Acute, long-term and community healthcare and home settings
3. Urinary or faecal continence/incontinence, or toileting issues
4. Conservative management or care practices (defined as "any therapy that does not involve pharmacological or surgical intervention"[143] (p.1020) including catheterisation.

Of the 1348 citations retrieved, after title and abstract screening 114 remained. After standard screening processes by two reviewers, 87 were included: 40 studies (across 48 publications), discussion/opinion papers (n=17), reviews (13 reviews across 17 publications), audits (n=2), guidelines (n=2) and a documentary analysis (n=1). Studies or reviews published multiple times were treated as one, hence the final number of included papers was 75.

In keeping with the EPPI-Centre approach, findings were presented to stakeholders to ascertain their views on the priority areas for the second phase of searching. All stakeholders (Appendix 2) as part of this process were asked to complete a priority setting exercise, facilitated by answering the question, "What do you think are five of the most important ways that continence could be managed for PLWD when they are in hospital?" Responses were collated, coded and grouped together to generate a list of methods for managing continence in the hospital setting.

Descriptive maps of the findings from the scoping exercise and a summary of the consultation with the stakeholders were presented to the collaborative research/project team of co-applicants. Across both groups, the top two priority areas identified as most salient to informing and improving continence care within the acute setting were "communication" and "individualised care planning". This exercise informed the research question taken forward to the mixed methods systematic review: "What is known about the management and practices of continence care in relation to communication and individualised care planning for people living with dementia in acute, long-term community healthcare, and home settings?"

Mixed methods systematic review

Objectives

- To explore carers', family members and HCPs perceptions and experiences of communication and individualised care planning caring for people living with dementia with regard to toileting and continence.
- To identify the communication strategies and the use of individualised care planning employed by carers, family members, and HCPs to manage toileting and continence for PLWD.

Eligibility criteria

We used PICOS/PICo framework to guide the inclusion criteria on participants (P), intervention /phenomena of interest (I), comparators (C), outcome (O), study design (S) and context (Co) (see Appendix 3)

Searching

Eight databases were searched from inception to June 2018 (updated August 2020) and included Medline; PsycINFO; EMBASE, CINAHL; ERIC, ASSIA, BNI and Open Grey (Appendix 4). Relevant organizational websites were searched for UK policy and guidance and key journals hand-searched (Appendix 5). Reference lists of included studies were scanned, experts contacted, and forward citation tracking performed using Web of Science.

Screening

All citations retrieved were imported into EndNote, where duplicate references were removed. Two reviewers conducted all screening processes, with disagreements resolved through discussion with a third reviewer. Multiple articles by the same authors reporting the same study were linked to help inform decisions on which studies to include.

Quality appraisal

Quality appraisal of the research material was conducted by two reviewers, with disagreements resolved through discussion with a third reviewer using the Mixed Methods Appraisal Tool (MMAT-Version 2011).[144–146] Each study was assigned a score based on the number of criteria met (25%—one criterion met; 100%—all criteria met). Studies were excluded if they scored under 50% for quality, (a maximum score of two of four criteria).[144] Non-research evidence (e.g. policies, reports) were not subjected to quality appraisal.

Data extraction

Demographic data from the included primary research studies were extracted and entered into a series of electronic tables (tables 4-6 in Appendix 6 and tables 7-8 in Appendix 7). Study findings for the primary research studies for the purposes of this review were considered to be all text labelled as results or findings. All such results were extracted and entered verbatim into Microsoft WORD. Data for non-research material were extracted and entered directly into an electronic table (see Appendix 8). All non-research material was available as electronic documents, searched using keywords relevant to the priority areas (for example "communication", "tailored", "individual"). This data was then considered to be findings, extracted and entered verbatim into Microsoft WORD. Data extraction was independently checked for accuracy and completeness by a second researcher, with any disagreements noted and resolved by consensus.

Data synthesis

Thematic synthesis was employed to bring together data from both qualitative and quantitative primary research studies and non-research material.[149]

Assessing the certainty and confidence of the evidence

The confidence of the overarching synthesised findings derived from descriptive quantitative (that had under gone qualitisation) and qualitative research were assessed using the Confidence in the Evidence from Reviews of Qualitative research (CERQual) approach[147] and the findings from quantitative experimental research were assessed using the Grading of Recommendations Assessment, Development, and Evaluation (GRADE) approach.[148]

Flow of studies through the review

The database searches yielded a total of 5029 citations after removing duplicates (PRISMA flow diagram):[149] see Figure 1.

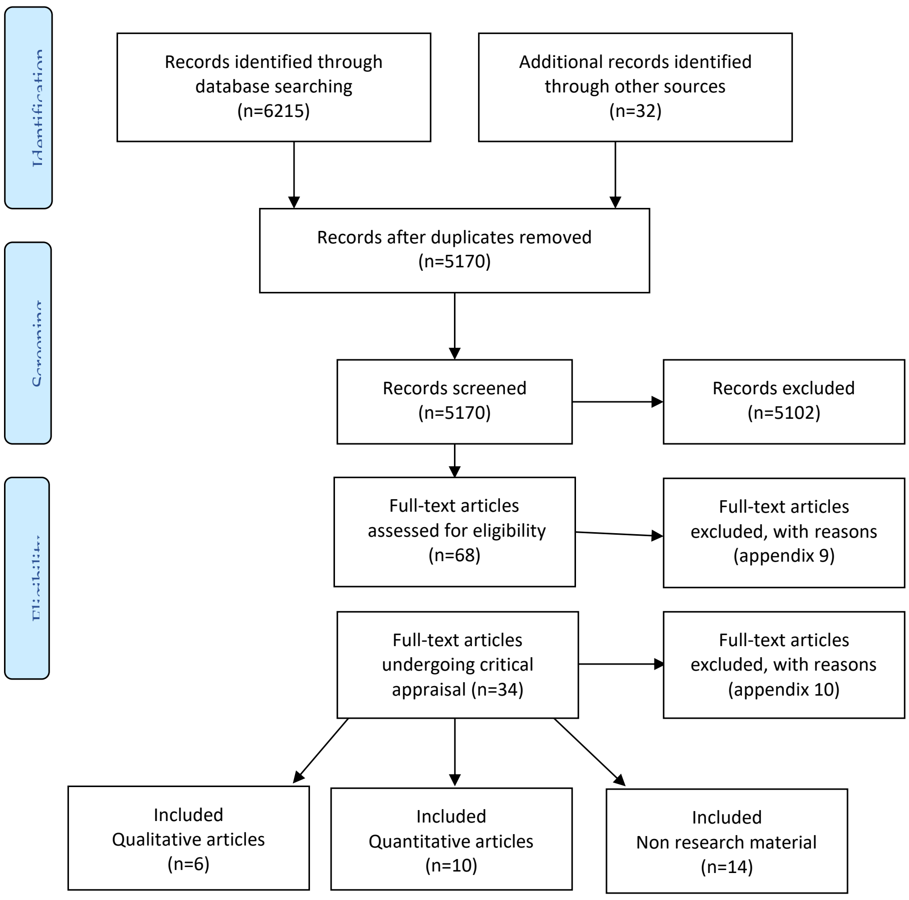

Figure 1: Flow of citations through the systematic review

Characteristics of the included studies

The 30 included publications included quantitative research studies, qualitative research studies and non-research material studies and non-research material (see table 1)

Table 1: Design of included material

Study design	**Number of studies and citation**
Case series with non-concurrent multiple baselines	n=2[150,151]
Randomised controlled trial	n=1[152]
Pre-test/post-test	n=1[153]
Prospective cohort	n=1[154]
Post intervention descriptive surveys	n=2[155,156]
Cross sectional survey	n=2[157,158]
An adapted three-stage Delphi consultation study	n=1[159]
Qualitative	n=5 (across 6 publications)[160–165]
Web pages/web booklets	n=5[166–170]
Guidelines	n=2[1,87]
Reports	n=2[171,172]
Guidelines/guidance	n=2[173,174]
Framework	n=1[175]
Model	n=1[176]
Information sheets	n=1[177]

The 15 research studies were conducted in seven different countries (see table 2). Only four of the non-research material were published outside of the UK with one European guideline,[87] one international guideline[173] and the framework and the model published by the same author from Australia.[175,176]

Table 2: Country where research studies conducted

Country	Number of studies and citation
USA	n=8 (across nine publications)[150,151,155,156,160,162,164,178,179]
Australia	n=2[157,163]
UK	n=1[159]
Japan	n=1[153]
Taiwan	n=1[158]
Sweden	n=1[154]
Malta	n=1[165]

The research studies were conducted across a variety of settings (see table 3)

Table 3: Setting where research studies conducted

Setting	Number of studies and citations
Home care/community setting	n=5[152,155,156,159,160]
Nursing homes	n=2[153,163]
Residential care facility	n=1[154]
Alzheimer's disease rehabilitation centres	n=2[150,151]
Secondary care settings	n=3[158,164,165]
Alzheimer's disease specific day centre and home care setting	n=1[178]
Hostel care for ambulant people with dementia, aged care complex with hostel and nursing home facilities and an acute hospital ward	n=1[157]
Day centre and long term care facility	n=1[158]

Methodological quality

The methodology quality is reported in Appendix 11.

Thematic synthesis

The findings from the quantitative and qualitative research, and from the included policy and guidance materials, were synthesised separately for each objective

Objective one

The first objective was to explore carers', family members', and HCP perceptions and experiences of communication, and the use of individualised care planning for PLWD with regard to toileting and continence, and consisted of eight sub-themes.

Communicating in a dignified way

The importance of protecting personal and social dignity[161,163,164] during continence care was significant and HCPs reported a belief that PLWD and their caregivers prefer not to talk about incontinence because it is a highly embarrassing[163,164] and distressing issue.[176] Health care professionals believed that the provision of quality continence care for people living with dementia includes measures and approaches that conceal incontinence by creating situations that allowed PLWD to go to the toilet in private and avoided communication which revealed their issues around incontinence or care dependence that could cause them to feel embarrassed, ashamed or humiliated.[163]

The importance of respecting PLWDs' right to privacy was also considered important.[161,163,176] In order to relieve PLWDs' perceived embarrassment of accepting assistance,[161,163] HCPs stressed the importance of building rapport and trust, using humour[176] and "acting natural"[161] when supporting continence needs. Health care professionals also felt that in order to communicate with PLWD in ways that would minimise any emotional impact that HCPs should have the appropriate knowledge and skills.[163] Other strategies to enhance privacy included whispering to the client about toileting issues[163] and keeping these issues secret.[161] However, HCPs acknowledged that PLWD may have difficulties in recognising and communicating their continence needs and that not being verbally being able to request toileting assistance was viewed a barrier to protecting dignity.[163] Closely overlapping with this theme of communication is the issue of HCPs' attitudes towards continence care.

The attitudes of HCPs towards continence and continence care

The language used within a care environment is important regarding continence care[171,175] and is not always respectful,[171] but where staff had good knowledge of the people they cared for, they were respectful and built good relationships with PLWD.[171] Ostaszkiewicz et al.,[175] discussing coercive continence care practices, described them as including "the use of verbal or physical force to wash a person, to accept wearing continence pads or other forms of incontinence containment and to accept continence checks".[175 p.2] The authors also suggest that chastising a person for being incontinent could be said to be a form of verbal abuse. Although some ward staff promote continence, this does not appear to happen consistently within acute settings.[165] Relatives expressed concern that PLWD would be happy to go to the toilet if assistance was provided, but that staff encouraged them to "do it in the nappy".[165.] Other times, it was found that in some cases, routine toileting was avoided and cues ignored when staff members were busy, or appeared uncomfortable with or disinterested in providing support.[161,165] Ostaszkiewicz[175] recognised that "*Communicating therapeutically about incontinence with any person, including people with dementia, involves the demonstration of warmth, compassion and humanity*".[175 p.523] This is a skill that requires both clinical knowledge and interpersonal and communication skills, which should all be included within education programs.[176] Both formal caregivers and family carers would benefit from such programs, which would also enable the development of "empathetic understanding"[175(p.8)] to the emotions that a PLWD has in response to incontinence and its care.[175]

Presence of PLWD during outpatient consultations

There is no consensus as to whether PLWD should be present with their caregivers during outpatient consultations.[160,162,164] Health care providers believed that care recipients should be present when discussing continence problems during consultations;[164] however, caregivers expressed mixed opinions.[160,162] Caregivers who favour this approach, view the HCP as an authority in this subject, with the result that they believe the PLWD would be more likely to cooperate with management strategies because they had been involved in the discussion.[160] In contrast those who opposed this reported that they did not want to upset or make their care recipient anxious by discussing a problem that the PLWD might not fully understand or be able to control.[160] Caregivers who were daughters felt the need to be sensitive to their parent's privacy and feelings, preferring to discuss incontinence in greater depth with their HCPs, but this finding was not found for spouses. However, time constraints or inability to meet alone with the HCPs prevented in-depth discussions from taking place.[162] Some caregivers suggested that HCPs could explain the problem and management options in simple terms when the care recipient was present in outpatients and then speak separately to the caregiver, providing more details.[160]

Initiating conversations during outpatient consultations

There was a lack of consensus with regard to whom caregivers thought should be responsible for initiating conversations about incontinence during dementia-related consultations within outpatient settings.[160,162,164] Caregivers believed that it is the responsibility of HCPs to initiate conversations about incontinence during both initial consultations and follow-up appointments [160]. However, there were differences depending on whether the care recipient was a parent or a spouse. Caregivers who were daughters or daughters-in-law would only discuss incontinence with HCPs when it became problematic to manage at home, whereas husbands tended to communicate their wives' problems much sooner. [162] In contrast, HCPs thought that conversation about incontinence should be initiated by the caregiver. [160] However, when HCPs did initiate conversations about incontinence, they reported that this was appreciated by the caregiver who was receptive and engaging in discussion around the topic.[164] However, within secondary care, not all HCPs saw addressing incontinence as a priority and many thought that the topic should be dealt with by the patient's primary care providers rather during a specialist secondary care referral.[164] Extended family and friends who were caregivers reported that HCPs don't always ask about incontinence during consultations.[162] A lack of awareness of available resources or concerns about frightening patients/caregivers about potential problems before they occurred, was suggested as possible explanations as to why HCPs do not routinely discuss incontinence and fail to initiate conversations about incontinence.[164] Time was found to be the most common barrier reported by HCPs to discussing incontinence, because they believed that considerable information needed to be covered during appointments and discussing incontinence issues needed more time than was typically allocated.[164] Possible solutions suggested by HCPs were for the patient/caregiver to have a follow-up appointment to discuss incontinence or to offer referrals to a nurse in continence care.[164]

The language of incontinence during outpatient consultations

Caregivers desired "straight talk" from HCPs about incontinence and its management in relation to PLWD.[160] Hispanic caregivers stressed that it was essential for providers to discuss incontinence using language that those with English as a second language can understand. They strongly supported having written materials about incontinence in PLWD and treatment plans available in Spanish.[162] During outpatient consultations caregivers rarely used the term incontinence, instead use terms such as having accidents, leaking, losing control, wetting or messing their pants, having a urine/bowel problem, urgency, diarrhoea, loose bowels, being unable to hold it, and not getting there in time, difficulty in getting to the bathroom, leaking, soiling themselves.[160,164] Health care providers also tend to adopt these terms when discussing incontinence with family caregivers or patients.[164] Caregivers when questioned said that they did not know the right terms and didn't want to be disrespectful to their care recipients. However, once they were made aware of the term incontinence they were happy to use it.[160]

There were a number of suggestions presented by both caregivers and HCPs in terms of different types of written information resources that could be provided for the caregivers attending outpatient consultations,[160,162,164] for example:

A guide for caregivers was developed that covered talking to a health care provider about these problems; with definitions of common clinical terms.[160]

A pre-visit checklist or written materials of some type so that patients/caregivers could indicate whether incontinence was present, this could then prompt the HCP to start a discussion during the consultation.[164]

Readily available handouts that would offer more detailed explanations of what had been covered during the appointment.[164]

Short, focused handouts that could stand alone and address a single concern.[164]

The importance of non-verbal cues

People living with dementia are not always able to recognise and communicate that they need to go to the toilet or indicate that they need assistance.[87,150,151,155–157,160,161,163,164,169–171] It is therefore important to recognise the non-verbal signals, body language, facial expressions, behaviours and any signs that the PLWD uses to communicate in such instances[161,169–171] so that their wishes can be acknowledged.[171] Listening carefully to the words or phrases that PLWD use for describing the toilet[1,157,168,170,171] as well as being able to recognise familiar gestures[1,157,171] is seen as important. New staff should be trained to recognize the importance of toileting and to how to understand individual behaviours and non-verbal cues in relation to toileting.[161]

A range of different non-verbal cues had been observed or reported and include: someone pulling/taking off their clothing when they need to go to the toilet;[87,158,169] making particular sounds such as moaning or grunting;[158,161,169] assuming a different posture;[87] someone looking around;[161] fidgeting;[87,161,168,177] getting up and walking around or pacing[161,167,168,177] or restlessness; [87,158] holding their crotch or their stomach;[87,161,168] different facial expressions such as worry[87] or sorrow;[158] going to the corner of the room[168] and pulling at their clothes.[87,177]

Hutchinson et al.[161] also reported a number of affective cues which included anger, profanity and acting frustrated and irritable. One study investigating common behaviours when PLWD experience either bowel movement or urination needs, found that anxiety, restlessness, and taking off/putting on clothes inappropriately occurred in more than 30% of patients.[158]

Finding the appropriate words and symbols to describe the toilet

Wilkinson et al.[157] sought to evaluate the comparative suitability of a range of words or symbols to label a toilet for people living with dementia. As part of an institutional survey (n=24) the words that were used to label the toilet were "toilet "(67%), "Male/Female" (11%) and there was no labelling in four institutions (22%). Only four institutions used symbols, and these included the international symbol (n=1), toilet symbol (n=1), yellow wrapping over door (n=1) and ceramic plaque upon which was written the word "Toilet". A further survey was conducted with participants living with dementia and the preferred word and symbol for toilet varied significantly ($p<0.05$) according to mental status (which had been assessed using the Folstein mental state examination and classified as normal, mild, moderate and advanced). "Ladies" or "Gents" was preferred by those with no cognitive impairment and "toilet" by those with moderate dementia. The international symbol was preferred by people with no cognitive impairment or mild dementia whilst the toilet symbol was preferred by those with more advanced dementia.[157]

The importance of individualised continence care

Targeted and individualised/person centred continence care[87,166,170,172,173,176] that is established after a thorough clinical assessment has taken place[87,173,175,177] is seen as being important, including the use of a bladder diary.[87] Individualised continence care is described as about what is best for the PLWD[87,170] avoiding harm[87] and about promoting autonomy and independent living.[87]

Objective two

The second objective was to identify the communication strategies and the use of individualised care planning that carers, family members and HCPs have employed to manage toileting and continence for PLWD and consisted of five sub-themes.

Strategies for improving communication

A number of general communication strategies have been suggested:

- To reduce anxiety/fear / embarrassment it is important to check HCPs' awareness of good communication techniques when working with PLWD[159]
- Prompting[1,87,169,171]
- Get to know the PLWD[169] and how they communicate[170]
- Health care providers introducing themselves and seeking PLWD approval before performing tasks[163]
- Ask the PLWD how you can help them manage their continence[168]
- Communicate with the family to determine usual behaviour patterns[178]
- Get to know the PLWD such as previous routines, habits and lifestyle[168,170]
- Don't make assumptions and see the person as an individual[170]

Caregivers reported that they sought additional information about incontinence from the internet but were concerned about the accuracy of information retrieved, whether they could understand it, with concerns about their searching skills.[162] They wanted support and reassurance that they were providing the care that was required and they wanted information before any problems such as incontinence occurred so that they could feel prepared.[160]

One further study described how nursing staff communicated with residents' families about methods to manage incontinence when taking the PLWD "*on an outing*".[163(p.2432)] The advice included information about how to check and change continence pads, how to assist the resident to the toilet, and how long continence pads could potentially last between changes.[163]

Using technology to present instructions

Two pilot studies[150,151] conducted by the same authors explored the effectiveness of verbal instructions, presented automatically through simple technology, in helping persons with mild-to-moderate Alzheimer's disease recapture basic daily activities. Data from both studies showed that the use of verbal instructions and basic technology to control their presentation has the potential to be effective in helping people with mild or moderate AD recapture relevant daily activities, including toileting.[150,151]

Components of individualised care plans

A number of different components that may be considered as part of individualised care plans have been identified which include being theory based,[173] being concerned with the practical issues,[166] and involving multi-components exploring both day and night time care of incontinence.[173] There was a general consensus that the needs of both PLWD and their caregivers need to be considered.[87,172–175] The advice given by the Alzheimer's Society was that continence care plans should be tailored to the individual. This should aim "*to cure toilet problems or incontinence wherever possible*".[166] Other components to consider include changing medication,[166] changes to lifestyle, [166] exercise,[166] skin care,[173,175] manipulating the type, quantity and timing of food and drink,[166] describe support available from HCPs[166] or follow-up advice.[166]

Ostaszkiewicz et al.[175] comments that nurses and care workers need support in order to develop individualized strategies to *"optimize the care-dependent person's rest/sleep in the context of the person's concurrent need for continence and skin care."*[175 p524/5] Three studies described individualised care plans as part of their interventions.[153,155,156] One was conducted within a nursing home and one member of staff from each was selected to take part in a training program. This person was then responsible for educating other staff members. The intervention here was individualized and comprehensive care that focused on providing adequate fluids and meals, encouraging patients to use toilets, and reducing the size of their "diaper" pads. This approach differed significantly from the usual urinary incontinence (UI) care in which "diapers" would be changed only at scheduled times. Improvements across the different methods of urination were observed ("diapers", chair, commode, urinary chamber pot) with only 11% of residents making improvements but this finding did not reach levels of statistical significance, whereas 19% of residents showed improvement during the night, changing from using "diapers" to using the toilet, which was shown to be significant, although a large number of residents' continence status remained static.[153]

Two studies[155,156] evaluated an environmental skill-building program, a home environment individualised intervention delivered by occupational therapists, including toileting and incontinence. The intervention was designed to enhance the caregiver's ability to problem-solve and to develop effective solutions to problematic situations. One was a pilot study[156] where 17 effective caregiver-initiated environmental solutions for incontinence were observed. Of these, nine solutions (53%) were accepted by the caregivers and integrated into their management routine by visit five of the intervention. For the later study,[155] 29% of caregivers identified continence as a problem area. Twenty-six attempted strategies that involved assistive devices were identified and of these, 21 (81%) were used. Fifty-one attempted strategies to manipulate the type, quantity and timing of food and drink and 46 (90%) were used.

One further study implemented a person-centred approach that focused on incontinence for residents with cognitive decline in residential treatment facilities.[154] The health workers were provided with training; however, only 20 out of 100 participated although the process outcomes were measured among all residents who agreed to participate in the study. There were no statistically significant mean differences in QoL scores before and after the intervention or between control and intervention participants. However, the quality of care improved for the intervention participants in that fewer aids were needed to manage incontinence and an increased number of UI assessments were conducted.

Health care professionals and caregivers working in partnership

The importance of HCPs and caregivers working together to deliver individualized/person centred continence care was a feature of three intervention studies[152,155,156] and was encouraged within four pieces of non-research material.[166,170,172,174] Within one intervention study[152] nurse practitioners worked with the carer to plan the schedule for the PLWD, followed up with monthly phone calls and bi-monthly visits. Occupational therapists worked with the caregivers in a further two intervention studies[155,156] to deliver solutions to toileting and incontinence problems, consisting of five visits over three months[156] or five 90 minute visits over two months.[155] Other HCPs that can work with PLWD and their caregivers include continence advisors[166] or other HCPs specialising in continence care.[170] Working in partnership with caregivers and PLWD is important[166,170,174] and enables HCPs to gather their personal story[172] to work out the best solutions and to ensure that specialist help can be accessed when needed so recommendations are achievable.[166]

Establishing a toileting routine within the home environment

The importance of developing a regular toileting schedule was discussed briefly within one study[156] and one piece of non-research material[87] and was the focus of one intervention study.[152] The intervention group for the individualized scheduled toileting program in the study by Jirovec and Templin[152] were taught an individualized scheduled toileting procedure, which compensated for cognitive impairment by providing "memory-impaired patients" with toileting reminders. Initially, assignment was to one of two intervention groups: one group of participants was visited every 2 months, and the other group after a 6-month interval. There was also a control group. At the 6-month follow-up the two intervention groups did not differ with respect to UI so the original two intervention groups were combined, leaving a single intervention group and a control group. The authors conducted a completer's only analysis and reported that incontinence decreased in the experimental group (28 of the 44 participants still in the study at 6 months) with almost no change in the control group. Further analysis of this data using the non-parametric sign test was conducted and a significant decrease was reported in the experimental group ($Z=-1.83$, $p<.05$). The participants were coded according to any decrease in percentage of incontinent episodes versus staying the same or showing no improvement. However, two previous reviews that reported on this study conducted a re-analysis of the data and although the results favoured the experimental groups, they were not statistically significant.[180,181]

Synthesis summary statements

Twenty-six summary statements were produced with associated levels of confidence using the CERQual and GRADE approaches (see Appendix 12). As the design of all the experimental quantitative research were poorly designed observational studies, the ratings for evidence from each outcome generated using material from these were downgraded from "low quality" to "very low quality".[182]

Chapter 7: Findings from the ethnographic observations

This chapter explores the findings from the ethnographic observations in relation to continence care for people living with dementia during an acute hospital admission and sections of this chapter have been reproduced from Featherstone et al.[124] under licence CC-BY-ND-4.0 (https://creativecommons.org/licenses/by/4.0/).

Our detailed analysis provides understandings of the complex social relations that occurred within these wards, the ways in which the organisation and delivery of continence care at the bedside connected closely with and was informed by wider institutional expectations, policies, and priorities, which in turn shaped the personal impacts of continence care for both patients living with dementia and ward staff. Given the scope of our data set, within this report, we focus on presenting the five major themes that emerged within our analysis: 1) Continence as significant, visible, and public phenomenon, 2) Continence communication, 3) Rationales of safety, 4) Pad cultures and 5) Impacts of continence care.

Theme 1. Continence as significant visible and public phenomenon:

Each of these wards and units possesses its own distinct and competing patterns and rhythms, the timetables of the wards. Despite organisational and environmental variants in tasks, across these wards the timetable dominates. This includes, but is by no means limited to, medication, diabetes checks ('BMs'), personal care, changing sheets, toileting rounds, observation rounds, mealtimes, refreshing water jugs, the hot drinks round, and the almost always handwritten recording practices that precede and follow each and every task.

Each team, the care assistants, the nurses, the ward doctors, plus all the specialist and auxiliary teams external to the ward but temporarily present upon them, have their own, often conflicting, timetables. This, in turn, powerfully shapes the timetables of the other groups within the ward, setting expectations and targets. Personal care and bed-making must happen before the arrival of the breakfast trolley, meals must be cleared away before the medical rounds, care packages in place before the discharge team clock off.

These timetables always dominated the ward and overrode individual patterns of daily life. This has a huge impact on continence care. Thus, for example, there was no room or opportunity for individual continence plans,[140] known to be crucial to high quality continence care within other care settings. These timetables reduced opportunities for individual ward staff to recognise the needs of the individual patient. Individual agency concerning waking up, getting dressed, and, central to this study, going to the toilet, were instead timetabled, reduced and limited to "toileting rounds" and "pad rounds".

Continence care was essential, and very visible care, within these acute wards. We found it was a significant feature of the everyday routines of care, representing a considerable workload, reflected in the pace of care work, and in the soundscape and odours pervading each of these wards. The "privacy curtain", the partition to protect dignity and to allow a modicum of privacy between bedsides in these semi-public settings, did little to disguise the sounds and smells of "toileting", as the everyday organisation and fast paced delivery of other everyday ward routines continued and overlapped at close quarters (as in these cases, afternoon tea, and the bedside deliveries from the hot drinks trolley and the lunchtime delivery of hot meals).

> The mealtime assistant has a tray to take into side room 1. She sees the door is closed and looks through the privacy window. It has a switch to change from opaque to clear and she decides to go in. She opens the door and reels back physically at the stench and exclaims. She then quickly composes herself and staying well away from the door looking in, cheerily shouts though the door to the person (recorded in notes as living with dementia) 'Dinner! Beef curry!'
>
> The medical team are cleaning their hands in the sink so she cannot get into the room yet. They leave and she goes in and puts it down in front of him on the bedside trolley [...] The medical team leave side room 1 and a nurse heads to the room with deodorising spray and sprays it liberally at the door and

> adds some more to the air around them as they walk away. The team of 3 medics and 2 nurses talking together at the nurses' station, and all laugh as this nurse (with the room spray) says to [sister in charge] 'Did [side room 1] open his bowels?' They all snigger. 'Oh my ***, let's say yes he certainly did! Don't give him any more [laxative]!' They all smile and laugh together as they head down the corridor together to the nurses' station. [Site F Ward 12 Day 2]

These acute wards all had a distinct institutional smell, a cocktail of disinfectant mixed with cooked food slowly congealing on plates at the bedside. There was a general odour of bodies, mingled with something less pleasant, smells of infection, the whiff of acetone mixed with an underlying cloying sweetness with hints of compost, the odour of concentrated urine, faeces, and diarrhoea coming in waves from behind curtains, through closed doors and lingering at the entrances of vacated toilets. These toilets, often designed so that doors remain wide open when not in use, and the (typically) closed sluice room, produce strong smells of bodily waste mingled with disinfectant that filled these overheated wards in regular and often overpowering waves throughout shifts. Beyond these smells were the near constant sounds of urgent care needs, the personal bedside alarms, unspecified cries, and calls of "help" for urgent care. While one may assume in a hospital setting these calls would relate to clinical or medical need, within these acute wards we found they overwhelmingly indicated the need for urgent continence support. Similarly, although we expected the practice of drawing privacy screens and curtains would be primarily for medical consultations, examinations, and procedures, for people living with dementia the practice of screening beds was predominantly for intimate care and continence care. While continence care may be concealed, the audio and visual cues of its practice are constant.

> Bay A has a metal trolley parked outside of it. The bottom layer is stacked with folded clean hospital robes and pyjamas in pink and blue, the middle with towels and bed sheets, while the third holds a grey plastic box containing adult continence sheets and pads. A patient (Bed 6) on bay A is

> taken a commode by a nurse, she is curtained for this, and the nurse talks to her behind the curtain. A healthcare assistant (HCA) walks purposefully down the busy corridor past both stations, with a full bedpan in each hand, literally full to the brim with urine, and walks around and sweeps past several staff on the way to the sluice room for disposal. An auxiliary returns to the ward carrying a very large cardboard box full of flat topped bedpans, which he takes past bays A-C to the store room. [Site F Ward 12 Day 3]

Continence care is an ever-present aspect of the routine activities undertaken by ward staff. It is a particular focus in the everyday care work of HCAs, but is also significant within the routines of nursing within these observed wards. In contrast, it was notably absent from the routines of the medical teams, even when it was associated with a patient's admitting condition. While small specialist continence teams worked at each of the sites observed, their caseloads included both inpatient and outpatient referrals within these hospital settings, thus their presence on these wards was unusual.

Healthcare assistants and nurses moved between bedsides, bays, and sluice rooms, often crossing considerable distances within these wards, balancing full "pans" containing urine and faecal matter to the sluice room for disposal (each ward has a sluice room or "dirty utility" dedicated to the disposal of human waste and the disposal or disinfection of associated equipment. This includes used disposables such as incontinence pads and reusable products such as bed pans which are cleaned and disinfected). Attempts to conceal bedside continence work behind privacy curtains and closed (and partly closed) doors were matched by the ritual practices of attempting to hide waste by covering bed pans and commodes for this journey to disposal. This was always a makeshift affair (typically covered with paper towels or with re-purposed disposable plastic aprons) because concealment of waste on the journey to the sluice was not built into the design of the continence products used within these wards. Visible in the covering practices and in the everyday ordinary nature of this care work:

> An HCA walks by me in the corridor on the way to the sluice room with a very full bed pan (it is clearly heavy, and she is focussed on keeping it steady

> without spilling), the contents barely covered over by toilet roll, 'Afternoon!' she says, stopping to greet me. We chat briefly about the shift. [Site F Ward 12 Day 17]

The activity of these wards was punctuated with the coming and going of staff with distinct and recognisable continence equipment (bedpans ("pans"), "bottles", wipes, and pads to larger equipment such as commodes, "Stedys", and hoists) to be used at the bedside, or to support and/or transport patients to and from the toilets. The toilet doors are equally visible, labelled with brightly coloured signage and symbols, situated within the bays, the rooms, and along the corridors of these wards. Nurses and HCAs (and sometimes the nurse in charge of these wards, particularly at the start of the day shifts) dragged bulky bags out of the bays and along the corridors for disposal and collection by other hospital services. These contained wet and soiled sheets and institutional clothing (gowns and pyjamas), stuffed into the semi-opaque coloured bags (an NHS colour coding scheme indicates location of contents and their disposal). These activities were a key feature of the routine and repetitive care work of these wards. Although this was typically viewed and described by ward staff as "heavy" work carried out early in the morning or at specific points in the timetable of care work, in reality, this continued throughout shifts.

> On C bay the senior nurse is working as a "double" with an HCA and they are with the woman in bed two. 'Can you turn over to me?' the nurse asks. The HCA adds 'You are too fast for us you are, at my age you need to take things easier, there we are, that's better'. A groan can be heard from the patient as they do this, 'It's ok, it's ok, we are going to sit you back up now'. They have changed her pad and this has included changing her gown and bed sheets. Throughout, they describe what they are doing and provide lots of reassurance. The HCA comes out from behind the curtain with a semi-opaque red plastic sack full of dirty linen, returning a minute later with arms full of clean linen, asking her, 'Do you want a blanket as well?' [Site F Ward 12 Day 16]

The everyday and mundane aspects of this ongoing work within these wards could also be observed in the public nature of the often loud discussions surrounding it between individual staff and patient and within and across these bay teams. Staff often used a raised and slower "institutional" tone of voice to talk to people living with dementia, and shouted for help or with instructions to colleagues across bays:

> In side room 23 the Nurse in Charge is talking to her patient, the conversation audible down the corridor: 'DID YOU GO FOR A POO? Oh, you've got a pad on, did you do it on the bed? Lift your bum up for me'. RN2 passes the room, so the nurse shouts for her to come in and help. As RN2 goes in she is instructed 'Whole change, everything, pyjamas, pads, sheets', suggesting the pad, or the failure of it, has created a lot of work (2 nurses for approximately 10 minutes). [Site H Ward 16 Day 22]

Importantly, here we can see the Nurse in Charge of the ward shapes the continence care culture within this ward. In this instance the nurse leads this ward by example and is actively supporting her team and contributing to bedside continence care; however she is also demonstrating to staff within the ward the status of continence care (potentially as a form of interruption), how to talk to patients living with dementia (in a loud institutional tone of voice), and how continence care can be (re)prioritised when undertaken by a senior member of the ward team.

Visibility of continence care in the ward

The visibility and centrality of continence care can also be seen in the large number of toilets, signage, and the volume of everyday equipment, artefacts, and continence products within these wards. The visible signs could be found everywhere across these wards, forming part of the detritus of medical records, bedside files, documents, and forms, across observation stations, and at patient bedsides on the mobile tray tables, often next to water jugs and trays of food. For example, the urine "bottle" could be seen everywhere (particularly within assessment units across these sites), typically left on tray tables or stacked on bedside cabinets waiting for personal usage (male patients frequently use bottles openly on the bay, under bed sheets or sitting or standing at the bedside).

> I notice some male patients on bay B have cardboard “bottles” next to the water bottles on their tray tables. They are clean and unused, but are striking next to food and drink. Most of the tray tables are stationed at the foot of the bed, so only accessible by the patient leaving the bed or by requesting it. [Site F Ward 11 day 2]

The sheer volume of continence products required within each ward made their visibility to some extent inevitable, but also meant they became ubiquitous and taken-for-granted. Boxes of disposable continence products, labelled with both generic and recognised brand names, were evident in store and supply rooms, but also stacked in corridors, at each nursing station (the main station, but also the satellite small desks stationed at each bay), and the mobile equipment trolleys attached to each of the bays.

> There are two cupboards opposite bay C, one labelled as a store room, the other just with a number. Both are stacked full with continence products, including pads of all sizes, flat sheets, packs of wipes and catheter tubes, all sealed in white plastic packaging. Along this corridor there are also numerous toilets and bathrooms, some a single toilet or a disabled access toilet, with other doors propped open to multiple cubicles including showers, baths, sinks, and more toilets. Each toilet is clearly labelled, but there is no consistency to the signage used. [Site F Ward 11 Day 2]

Commodes and hoists stand in alcoves in the brief intervals between their frequent usage. There were usually a number of commodes (typically two or three, which had to be shared across all of the bays and single rooms) and one hoist per ward, although there was some variation in numbers of beds and the admissions, and the expected dependency of admitted patients. Hence equipment was typically in high demand, particularly at busy points in the shift such as the morning, afternoon, and evening routines of personal care and toileting, when continence care was part of bedside care timetabled across these wards, and where urgent continence needs were high for patients. Of note, during the periods of observation, there were shifts when all these wards were described as close to “running out” of “pads”, reflecting the high usage of continence disposables and equipment in the care of people living with dementia within these wards:

> 17:10 Beep! (personal bedside alarm) coming from somewhere in bay 3. The person in bed 18 is back in bed again. 17 is still behind curtains, a mobile phone is ringing, possibly one of 15's visitors. Senior member of the medical team, pharmacist, and the nurse in charge of the ward, are discussing the patient in bed 17. They are standing apart with the nurses' station and a computer trolley between them. The doctor states that the person in bed 17 have got through 3 pads and filled 2 colostomy bags, the Sister is recording all this at the computer. [Site H Ward 16 Day 28]

There is, of course, some variation across the male and female bays. Continence technologies, in the form of urine "bottles", a cardboard (sometimes plastic) curved tube, were highly visible and accessible within men's bays. Within female bays, the artefacts of continence care were less immediately visible at the bedside. Here, "pans" to be used in bed, or commodes (a portable toilet on wheels, this looks like a wheelchair and has a lid that can be removed to reveal a removable pan which needs to be emptied after each use) for use at the bedside, were the most common form of continence technology. Both had to be requested (or prompted), brought onto the bay, and taken to the bedside by staff to be used behind the curtain. The commode was also used as a mobility aid to transport the person to the nearest toilet. These methods all required support from and dependence on ward staff to obtain, use, and for disposal.

Continence must be observed and recorded

Continence is tacitly acknowledged as a bodily process that happens out of sight of others, an expectation in line with the emphasis placed on dignity and privacy of patients found within the institutional policies governing these wards. However, this was rarely possible for people living with dementia (and older people) within these semi-public hospital spaces. Privacy was also overridden by the recording practices and required documentation of the wards: what, when, how often, and what, individuals have or have not "passed", which must be viewed, assessed, described, and recorded within patient notes. As a result, continence discussions and its assessment occurred openly in these wards and bays by ward teams across the semi-public ward spaces. We found that these assessments and the associated documentation appeared to be routinely applied during the care of people living with dementia (and older patients), compared to other patient groups (the very small number of working age people within some of these wards). It was not uncommon for staff to discuss publicly a patient's continence or the organisation of their continence care in hearing range of others, at the foot of beds, in the middle of bays or in the corridors that line each ward.

> The handover sheet states the man in bed 19 has dementia, although there are no specifications of what type of dementia; the man in bed 22 has Alzheimer's and "confusion". It's interesting that they have both been to the toilet today independently, while there was nobody on the bay to observe them doing it: it feels like together they are cheating the system, working in silent collaboration. The HCA is now helping the man in bed 22 to walk to the toilet. She seems very worried he will fall, so she gets him a walking frame to use and guides him in with an arm on his back and stays inside the toilet with him (even though he can walk there by himself when the nurse is not there). The man in bed 19 is now asleep on his bed. The HCA then comes off the bay and has a loud conversation with the nurse about his toilet trip: 'Did he pass urine?' 'No, but he opened his bowels a little bit, at least I think that was his.' They discuss that they don't know if anyone went to the toilet before him, so it could have been left in the toilet by someone else. I tell him that this man (bed 22) had walked to the toilet recently, assisted by the man in bed 19 who went after him. They were completely unaware of this and seem genuinely surprised that these patients, or indeed any patient in this bay, would go to the toilet without them. [Site H Ward 15 Day 23]

The visible, public, and recorded nature of continence care was observable in other aspects of everyday hospital practices. As we can see from the example above, privacy was typically not considered by staff to be possible for people living with dementia, with their use of the toilets closely monitored. It was common practice for staff to stay within the bathroom or behind the curtain while a person living with dementia was using a toilet (or commode at the bedside). Toilet doors were commonly kept ajar or closed but unlocked and staff would stay present either inside with the person or just outside the door. This was also associated with managing risk and the fear amongst staff of falls, as this HCA explains to me, ”They fall when you are not watching”.

> The woman in bed 7 gets up and out of bed and tidies round her bedside picking up bits of paper from the floor. She is wearing a hospital gown and her large wrap-around pad is very visible. She suddenly holds onto her crotch, heads into the bathroom, and locks the door. The HCA comments to me, ‘She is very secretive she doesn’t like anyone looking at her bits and pieces.’ She then tells me about another patient she has cared for, ‘A lovely lady, very independent, she wouldn’t let anyone look at her downstairs at all. I will leave her in there for a bit and then use the scissors to turn the lock (from the outside) and just check on her. I will just have a quick look.’ The HCA uses scissors to open the lock and opens the door, the woman is standing at the door and she closes it and locks it, leaving the HCA outside. The HCA turns to me, ‘It’s not nice, but they fall when you are not watching!’ [Site H Ward 16 Day 14]

This could lead to close monitoring and control of the person living with dementia. Here, the nurse supporting this man not only goes into the bathroom but also repeatedly gives him instructions on how to use the bathroom, to sit rather than stand to urinate.

> When the man in bed 19 wakes up, she brings him a frame so he can walk to the toilet. When she gets the frame to his bed, he immediately demands a cup of tea. ‘Okay,’ she says, ‘You were asleep till a minute ago!’ He responds, ‘Now what, I was getting up’. He seems quite irritated. He walks to the toilet using the frame, mentioning that his trousers are loose (hospital issue pyjamas which are far too big for him). He complains that the toilet light

> keeps getting left on but should be turned off when not in use. The nurse goes in with him and asks him to sit down to go to the toilet. This irritates him - 'I'M STANDING UP TO DO A JIMMY RIDDLE!' he shouts, refusing to sit down. She explains that he keeps getting his trousers wet when he stands up, repeating this three or four times, standing in the doorway to the toilet, holding the door open. He refuses to sit down, so eventually she leaves and lets him do it as he wants. [Site H Ward 16 Day 17]

Here, the close shadowing and instructions to wash her hands by this one-to-one carer clearly irritates this person living with dementia

> The one-to-one carer follows the woman in bed 4 into the bathroom, she is standing very close behind her, but they are very friendly and relaxed and both smiling as they walk through the bay. This woman has a diagnosis of dementia and the team tell me she also "has a touch of delirium". She says firmly, 'Don't come in, I want to pee in peace!' The one-to-one carer stops and they laugh together as she waits outside. As she comes out the one-to-one carer says, 'Have you washed your hands?'
> 'Yes! I am not stupid!' [Site G Ward 14 Day 29]

Shouting instructions through doors and into bathrooms were established practices, occurring frequently during shifts within these wards. That they would draw public attention to a patient's private continence and capabilities was neither recognised nor considered. Here the team support this woman into the bathroom and check on her progress. Note that although she is capable of reaching the bathroom using a walking frame (and this was a regular occurrence during this shift), the team use a wheelchair to return her to the bedside. This has consequences (which we will discuss later) for the person; although using the frame was viewed as quicker and more efficient by the team (increasing the speed of continence care was often an explicit priority within staff discussions informing the organisation of continence care, and the rationales for their use of Stedys and wheelchairs to transfer people living with dementia to or from the bathroom), this could deny patients opportunities for independence and lead to deconditioning.

> 17:00: The registered nurse from bay A is helping the patient from bed 5 walk to the toilet. She is wearing a pink dressing gown over her nightie, with blue slippers on her feet, and walking with support from a walking frame. She has two visitors (her sons) who move to the corridor to give her some privacy, where they stand talking to each other. She is walking very slowly with the frame, with the nurse now supporting her, leaning forward, and appears to be in danger of going over the frame without support. The HCA joins them, walking along with her, then helping her into the toilet once they reach it. 'I got you', prompts the HCA. Both the nurse and the HCA go into the toilet with her, before leaving with the frame. Opposite the toilet the nurse from Bay B is helping a patient from Bay C to the shower, pushing this patient's IV drip along with her. After five minutes pass, the HCA knocks on the toilet door 'Have we finished?' then goes back into the toilet (the door was closed but not locked), taking a wheelchair in for her, wheeling her back rather than using the frame again. Getting 5 back to her bed is much quicker in the wheelchair. She smiles when she sees her visitors standing in the corridor.
> [Site F Ward 12 Day 9]

This was a common feature of continence care within these wards: patient privacy was overridden by the expectation of close observation and instructions, recording, and often loud public discussion. Discussing a patient's continence was an everyday assessment made by ward staff. However, although we were not able to follow family discussions with the ward and medical teams elsewhere, we very rarely observed individual patients living with dementia involved in discussions about their continence care or preferences.

Theme 2. Continence communication: silence, codes, and the contracted language of continence care

Despite its apparent centrality within the everyday work of these wards, a fundamental way in which continence care for people living with dementia (and older patients) remained silenced, appearing almost unmentionable within these acute wards, was via the strategies of communication and language used. The naming of, or failure to name, body parts, in particular genitalia, bodily functions, urine and faecal matter; the naming and description of continence technology; and the language and etiquette of communicating continence needs during personal care for people living with dementia (and older patients more widely) were all notable. Some aspects of continence care were never discussed, or only by using humour, while others were talked around, or euphemisms used. At the other extreme, particularly in discussions of clinical processes and technologies, coded institutional language was used, with the assumption made that everyone within these wards shared these understandings.

Although this was most notable during care at the bedside, this extended to include staff discussions of continence, for example within clinical meetings and team handovers, where body parts and genitalia were rarely named and euphemisms and infantile and informal language to describe continence predominated. The routine addition of humour and laughter that supplemented or emerged around discussions of continence also highlighted the discomfort of this topic, particularly during clinical discussions and team meetings. Descriptions of continence care often emphasized the impacts on staff and their intractable workloads:

> Handover meeting in the small cramped nursing office:
> Night shift handover nurse: 'I've dressed that (worried about the potential for a pressure ulcer and prevention), it's intact [good] I put a convi [a urinary sheath] on as well.'
> 'Last night he was soaking as well,' - the nurse demonstrates by putting her hands to her crotch, 'So yes a convi is great.'
> They discuss the woman living with dementia in the side room (SR7): she dressed herself and washed herself – 'Can [discharge coordinator] confirm where she is going? We thought she was awaiting a package of care but she says she is going to live with her son, so she doesn't need it.'
> 'She does have a supportive son.'

> They move on to discuss the man living with dementia in the next side room.
> (SR8): ‘Doubly incontinent, he was in a mess.’
> The day shift discuss that they are doing discharge planning with him
> [...]
> They get to the man living with dementia in bay C (C2): ‘Loads better.’
> A nurse on the day shift, ‘YESSS!’ She punches the air.
> Night shift handover nurse: ‘He is piddling every hour in the night.’
> They all chime in: ‘Lush man’.......’Beautiful’........’I know I love him’
> [..]
> They then move on to the man a few beds along (C4)
> Night shift handover nurse: ‘He is 60 but looks 40.’
> Nurse: ‘I know!’
> Nurse in Charge of the day shift: ‘He’s fine. He had a recent diagnosis of UTI, he’s a bit pussy around his catheter.’ Then to the nurse in charge of that bay: ‘Take a sample - he can do it, you don’t need to go down there!’
> They all laugh.
> [Site F Ward 12 Day 7]

Of note is how descriptions of continence between staff across these sites typically focused on describing the levels of matter (“mess”) and wetness (”she’s wringing wet” “you are all wet”) of the person. In this discussion, there is celebration of a patient’s improved condition, and reticence of carrying out intimate care and contact with a man (without a diagnosis of dementia but potential cognitive impairment diagnosis) who appears to the team to be much younger than his chronological age.

Silence at the bedside

It is important to note that continence care at the bedside was also often carried out in complete silence. This approach was routinely observed during the care of patients living with dementia, particularly those who had difficulties in communicating verbally. Hence, although staff would routinely announce what care was going to happen when they arrived at the bedside, the many procedures involved in carrying out intimate continence care on the body of the person often continued without explanations of what was happening to them, and seemed to assume tacit understandings and consent. Here, the team carry out intimate continence care in silence:

> The patient in bed 18, who is living with dementia, is beginning to moan louder than previously. The team with her are giving no instructions, and are not talking through step by step what they are doing, in contrast to the other patients in this bay (they have been going round the bay in order from bed 13). They are just acting on her body, completing necessary tasks without talking to the patient. Her moans get louder and longer, but the work continues, with everything done in five minutes. The curtains are opened, and she is now lying flat on her bed, as if asleep. Her head is resting on the pillow. I think she is still awake, but her eyes are tightly closed, as if hiding. Her tray table is no longer over the bed and has been moved to the side, now out of her reach. [Site H Ward 16 Day 23]

This above exchange is additionally complicated for this patient because the absence of communication from the team also signalled a requirement, a taken-for-granted expectation that this work must continue and involved the delivery of essential care. However, this approach was also problematic for people living with dementia and as we can see in the tightly closed eyes of this person following this care, could lead to significant distress (discussed in more detail below).

The language of continence care

The language used by ward staff to describe body parts, particularly during the delivery of intimate and personal care, was striking. The anatomical terms for genitalia appeared unmentionable and were rarely if ever used within these wards in discussion with patients, especially with people living with dementia (although this extended to other older people) and family visitors. Euphemisms would commonly be used for male genitalia in the discussions between staff and with patients during bedside continence care, and these were always juvenile (and included “todgers”, “Johnsons”, and “willies”) in nature, with expletive forms never used. Female genitalia was never named anatomically, always talked around, and only euphemistically referred to (for example, as “your bits”, “bottom parts”, “lady parts” and “bits and pieces”) or simply not referred to. The word “vagina” was heard spoken by ward staff to a patient living with dementia once during continence care over 180 days of observations (which we present later in the analysis). More widely within these wards, ”down below” (or versions of this such as “downstairs”) was the phrase most commonly used during the care of both women and men to describe and communicate intimate continence or personal care that was about to or was happening to the person. During timetabled personal care (which often included continence care) it was common for staff to describe (to each other and to patients) the routine of “give them a good wash down below”, or “we need to look downstairs to check if you are wet” with the goal of such personal care explained as getting the person “nice and fresh” and of “freshening up” the person.

Continence care was often part of the wider personal and intimate care routines of washing the person, with a restricted range of language used to explain to people living with dementia what this entailed. Here the team carrying out continence care as part of personal care, describe to the person their goal of a “little freshen up”, with their notification to him that intimate care was about to take place described as “a little wash down below”. In addition, although the team talk about his continence, they do not involve him in these discussions and ignore his clear “NO”, in response to being asked if he is “enjoying” this.

> The man in the side room (SR3) is a tiny extremely thin man with very thinning grey hair, he appears quite frail and has no front teeth, which makes him seem even more fragile (I wonder where his false teeth are as these can often go missing in the wards). The team (two HCAs) are working as a “double” carrying out routine personal care at the bedsides and have now reached his side room. One HCA does all the talking although they are clearly doing all the work together:
> ‘Morning [they use his first name], did you sleep ok? You in a bit of a shape there!’ (he has been lying in what looks like a very uncomfortable angle in the bed with the sheets fairly tangled) ‘Sore?’

> He replies: ‘Yes.’
> HCA: ‘You came in for a PEG’ [Percutaneous endoscopic gastrostomy is an endoscopic medical procedure in which a tube is passed into a patient's stomach through the abdominal wall, usually to provide nutrition when oral intake is not possible or adequate], ‘can I see your tummy? You’re in a right little shape there! Can I have this arm my sweetheart? Work with us.’
> They laugh together as they are taking his pyjama top off: ‘Ready one, two, three. Yes, there we go [they use his first name], getting somewhere... It’s warm in here! Watch your arm.’
> ‘It’s ok [they use his first name], relax my sweetheart I am going to give you a little freshen up.’ She uses a wipe to wipe his face, ‘A bit cold and wet! Alright?’
> As they work, the other HCA asks, ‘Had he got a catheter?
> The first HCA responds: ‘No but he is doubly incontinent.’ (She says this in a low tone) and then asks the patient, ‘Your wife coming in today?’
> Patient: ‘I don’t know.’
> ‘I bet she is!’
> [I can hear that they are pulling the side fasteners on his pad] and they say ‘You are determined to flash us! Are you helping?’
> Patient: ‘Yes.’
> ‘Let’s have a little look at this butt. Lovely job.’
> They are now drying him: ‘Are you ticklish on your feet! Are you enjoying that?’
> Patient: ‘NO.’ [he says this very firmly and clearly]
> ‘What did I do with that pad?’ She gets it from the chair. ‘Now a little wash down below.’ [Site F Ward 12 Day 7]

It is important to note that during the removal and replacement of clothes and pads, this man who is living with dementia is also described as “determined” to “flash” them, suggesting these ward staff are experiencing significant discomfort during this process, with this signalling that some intimate care was being viewed or experienced as potentially transgressive.

The language used by ward staff to describe continence care was often highly coded, with a taken-for-granted expectation that patients (and their families) already had a working understanding of and familiarity with ward practices and the everyday clinical jargon used within it. This was particularly problematic for patients living with dementia (and older people), who often did not appear to recognize these terms, what the technologies, such as the "bottles" and "pans" they were offered, or what the "pads" (and catheters) attached to their bodies, were, or why they were wearing them.

Here, an everyday example of an HCA talking around continence technologies and care, broadly referred to a continence pad as "it", with the nurse using both highly contracted and coded language with this patient. The team become increasingly frustrated when this patient does not appear to recognize or respond to these requests, as they try to find language to communicate, which included "change(s)" and in response, they use repetition ("leave it"), and from "dirty" to eventually the more medicalized language of "opened your bowels", rather than further explanation of what this care entailed.

> The nurse walks down the corridor and comes back minutes later with an armful of packets of wipes. The HCA remains talking to the patient in bed 15. 'Leave it alone now darling… leave it alone… leave it alone… leave it [pad] alone …. We are going to change it… it's dirty … leave it!' She keeps repeating this until the nurse returns again, this time with a big yellow bowl full of soapy water. Throughout this, the only communication with this woman is to tell her to 'leave it' although not referring directly to her pad, and to warn her that 'it' is 'dirty'. No introductions or explanations. It seems reasonable for this woman to want to remove the pad if it is wet or soiled. The nurse arrives and speaks to her more directly, saying her name five times until she has her attention, 'We need to change you, you have opened your bowels, let me wash you.' Two minutes later I hear an exaggerated intake of

> breath and hushed giggles from the team behind the curtain. [Site H Ward 15 Day 17]

A key feature of the communication used by ward staff to rationalize with the person living with dementia to allow them to continue with intimate continence care (cleaning the body and changing pads, clothes, and sheets) was the emphasis of managing and containing "dirty" (and "wet" as we have seen earlier) bodies, beds, and surfaces. The contracted phrase "it's dirty" was often used by staff and repeated to the person living with dementia during care, particularly when staff appeared anxious to speed up and complete continence care. The anxiety within this team (above) appeared to increase when this woman tried to remove the continence pad herself, suggesting fear of not containing waste during continence care and the potential for contamination (and the additional personal care required) as an unsettling prospect. When patients appeared to resist this care, the team emphasized the institutional expectations and that there was no choice for either the person or the team, with the phrase, "we need to change you" as seen here, commonly used.

Although clinical terms were also used to discuss continence care and bodily processes, such as "bowel movements" and "stools", they are often highly coded particularly during routine bedside personal and continence care. These terms were often beyond the comprehension of many patients. These forms of coded language were commonly used when directed towards the technologies of continence care, and in particular, towards the continence "pads". Staff would typically announce to the person living with dementia "we're just going to change your pad" [Site F Ward 12 Day 1] before actively beginning to do so, often without context as to what the pad was, its purpose, or location on the body. The routines of bedside continence care were typically abbreviated by ward staff to the point of jargon. Staff across these wards would routinely refer to "opening", "passing" or "voiding", a shortening of "voiding his/her/your bowels", or "passing [urine]" in descriptions and instructions during often fast paced bedside continence care. This could be especially problematic for patients living with dementia. Here, two patients living with dementia do not respond when staff repeat these terms at the bedside; however, the team appear to assume repetition will ensure their recognition and comprehension (or that this is not possible for the person) and move on.

> The HCA has taken two bottle bedpans to the man in bed 3. The female member of the medical team asks the HCA for 'a sample to measure', and then explains to the patient he is dehydrated so they want to 'monitor intake' and 'how much he passes', and explains that the consultant will be coming to see him later. [Site F Ward 11 Day 17]

> HCA(A) and (B) are with the person in bed A1, who has a dementia diagnosis. They are doing the timetabled observations at each bedside in turn. 'Any pain [name]?' 'When you went to the toilet [name] did you open your bowels by any chance?' She repeats this question three times without rephrasing: 'Did you open your bowels? Did you open your bowels? Did you open your bowels?' A1 doesn't answer. [Site F Ward 11 Day 18]

Importantly, as we can see in the example above, verbal responses to this coded language were also often required by ward staff to confirm a patient's health status (and in turn could inform informal assessments of the person's cognitive capacity). Ward staff typically used contracted speech and repetition of these key phrases to talk around continence. A key feature of communication more widely to people living with dementia at the bedside was repetition, and these approaches also indicated (to us, to people living with dementia, and the wider ward) staff understanding of the condition, that the compulsive repetition or slow annunciation of single words and phrases would aid comprehension. In contrast, our observations indicated that such loud repetition of contracted phrases appeared often only to increase distress in the person living with dementia.

Ward staff regularly using this coded language to the patients living with dementia who were expected to understand this language, and to comply with instructions. Such institutional lingo, as characterised by Goffman,[75] could be heard along with the host of wider acronyms, job titles, medical jargon, and familiar words given new meaning, that all patients, including those living with dementia and their families, were expected to understand without explanation within these wards. More widely, names of areas of the hospital, the processes and procedures that take place within them and the brand and common names of the equipment and technology used were spoken of without introduction or clear explanation.[124] For people living with dementia this language could be particularly problematic as assessment of their independence and mental acuity was based on their ability to appropriately recognise, respond and reply to unfamiliar jargon around unfamiliar processes.

Communication of continence needs: seeking permission, institutional, and embodied forms of communication

A key aspect of the cultures informing continence care within these wards was the explicit requirement that people living with dementia must communicate and request continence care at the bedside or obtain permission to walk to a toilet, even if they were able to do so independently. However, for this patient group, the communication of an urgent continence care need was often not verbalized (either through difficulties in communication or embarrassment), but rather was embodied, and could only be identified both in their body language and via changes in their behaviour. It was unusual for staff to recognise or respond to these non-verbal forms of communicating an underlying continence care need.

During everyday care at the bedside, staff repeatedly emphasised to people living with dementia that they must communicate their care needs, including continence needs, using institutionally mandated forms of communication, through verbal requests and using the personal call button or "buzzer" to seek help. Staff typically emphasised to all patients living with dementia (and other older people within these wards) the risks of "falls" and "falling", the importance of waiting for assistance and of and seeking permission to leave the bedside, even for those who were able to independently walk to and from the bathroom.

The requirement of "permissions"

The requirement of permissions was associated with the impacts of the built environment of these wards. Patients within each bay (usually with four to six beds) typically shared a bathroom cubicle (attached to the bay or close by). There were always a number of toilets and bathrooms along the main corridor and throughout the wider ward, which is notable because although in principle they were accessible to all, they were designated for use by the patients within the geographically closest bay (and in some cases the nearby side rooms). In addition, visitors and staff were prohibited from using these bathrooms (signs directed visitors towards public toilets outside the wards). This meant some of these facilities were rarely, if ever, used.

People living with dementia were restricted by ward staff to the use of the specific toilet designated to their bay. These restrictions were typically tacit, although also sometimes clearly expressed by ward staff, who would not routinely support or permit the use of other toilets and bathrooms within these wards. Thus if the allocated bay toilet was in use, people living with dementia would be expected to wait, or were unsupported in leaving the bedside, until their allocated toilet was vacated, regardless of the other many alternatives typically available within the ward. This routine practice was associated with the typically fast pace of work carried out by the bay teams and the observable pressures ward staff experienced to keep within their designated bays (to monitor vulnerable patients). However, this could have a significant impact on people living with dementia, who often had to wait their turn to use the toilet allocated to their bay.

> With clouds low outside and lights dimmed down, it feels much later in the day than it is. The woman in bed 15 gets up to go to the toilet opposite the foot of her bed. She is younger than the other patients on the bay, but notes record her as having a non-specified cognitive impairment. All of the women on this bay have a record of cognitive impairment, dementia or queried dementia in the handover notes today. A large nappy-style continence pad is clearly visible under her backless hospital gown, despite her now demonstrated ability to get up and move to the toilet as required. The nurse tells her somebody is in the toilet and she responds by rattling the door, but the woman in bed 16 is in there. The nurse leads her off the bay, holding her hand. Rather than returning the patient to her bed the nurse and the patient go for a walk, giving the person in the bathroom time to finish. They go for a

> short loop of the unit, but do not go into any of the many vacant patient-only toilets they pass on this loop. [Site H Ward 15 Day 17]

This was also associated with an observable reluctance amongst people living with dementia to enter bathrooms independently, acting as if doing so was prohibited. People living with dementia within these wards appeared to quickly recognise that they were not permitted to act independently without seeking approval, particularly actions that involved leaving the bedside or the use of the bathrooms and toilets outside of the immediate area of their bay.

> One of the men from bay C is walking to the toilet. He is barefoot and has a small cut above his left eye. He looks in the toilet, but the housekeeper is in there cleaning, so he keeps going, walking towards the showers. The HCA and the housekeeper call him back and tell him it is OK to go in the toilet, which seems to confuse and startle him a bit, and so they again explain to him he is OK to go in. He doesn't want to go in while the housekeeper is in there, but once she comes out, he is fine. After a few minutes HCA(B) knocks on the door to check that he is alright and reminds him to wash his hands when he is done. A different HCA working on the bay then comes and helps him to walk back to his bedside. [Site F Ward 12 Day 13]

This culture of permissions was clearly an expectation held by ward teams, who assumed this to be an understanding shared with their patients, and reacted in surprise when they found patients living with dementia had independently walked to the toilet without them, had not used their designated toilet, or had used the "wrong" toilet elsewhere in the ward. So engrained was this culture of permissions that unflushed toilets could lead to ward staff calling estates to report a "code brown" (a blocked toilet), rather than consider whether a patient had walked to the toilet without support, or had used the "wrong" toilet.

The permissions and privileges granted to people living with dementia around continence care and independence were closely associated with the cultures and understandings of risk and safety within these wards. A key concern in the care of people living with dementia was a risk of “falls” during their care and managing and reducing this risk. If witnessed by ward staff, walking within the ward and looking for a bathroom or toilet would often be recognised as a potential risk, so it was common for ward staff to interrupt a person living with dementia attempting to leave their bedside, ask them to return to the bedside, and offer alternatives.

> 8:30am On bay 3 a female patient with a catheter tube visibly hanging between her legs is assisted by a nurse as she walks to the toilet. Minutes later another patient walks back from the toilet. She is walking using a frame, her hospital gown is open at the back, revealing a large nappy-style pad. When this patient is back at her bedside the nurse reminds her to tell her when she needs the toilet, and not to get up, emphasizing that if she does, she will fall. She then repeats this instruction to the neighbouring patient, showing her where the bedside buzzer (personal alarm) is so that she can call her if she is not there. This emphasis seems odd given that this nurse and I have observed both of these women independently get up and go to the toilet and show a clear awareness of their own continence needs. [Site H Ward 15 Day 16]

Theme 3. Rationales of safety, reducing risk, and deconditioning

The importance for ward staff of ensuring safety and reducing risk (particularly risk of “falls”), is significant. Minimizing the risk of “falls” often featured within discussions of continence care for people living with dementia. In contrast, we observed little discussion with people living with dementia of the importance of maintaining and increasing their mobility (an HCA within ward G was a notable exception to this) or recognition that keeping a person from leaving the bedside risked rapid deconditioning.

Here the lead nurse from the night staff reports during the handover to the day team that during the previous night shift a patient was “incontinent in bed”, “confused” and has “very loose” stools and needed support washing and helping to the bathroom, the result was “she went down”. A key emphasis in this description is that this fall was unavoidable.

> AE [room 22, bed 3] Yesterday she was incontinent in bed, told [ward team] to monitor, very loose again and again had to shower her during the nights, she is confused. The nurse leading the handover whispers the continence episodes. ‘We helped her to the bathroom in the night, [the HCA] was behind her and I was next to her and she spotted another Zimmer so left hold of her own Zimmer and went to grab that one. And she went down, although she didn’t hit her head or anything. The doctor came up and asked why were we pushing fluids (via an IV), and just to drink, so we pushed fluids that way.’ [Site F Ward 12 Day 13]

Night shifts, with fewer members of staff, were often a point where a person could become more distressed or become assessed as “confused”, and although there may be long periods of “quiet”, there was often a point where staff had to respond a number of simultaneous calls for urgent and competing patient continence care needs.

There were other times when it could be precarious for people living with dementia (or indeed any patient with an acute condition) who often walked at a slower and less confident pace within the corridors of these wards on their way to and from bathrooms, since at the same time, as many as thirty staff members may be working within and striding through these wards. This reflected the impacts of the wider institutional cultures that valued speed and efficiency that were felt powerfully by staff within these wards. These values could be observed in the pace of staff who rarely paused as they moved within it, striding past those walking at a slower pace, the typically older and unsteady patients, avoiding eye contact, suggesting they are viewed as potential obstacles to their work.

> The woman in bed 4/5 is living with dementia and delirium and is walking along the corridor with a one-to-one carer who says ‘This way!’ and guides her back to her bedside. As she walks down the corridor a nurse and the Senior Registrar stride past her. They do not appear to register her or speak to her as they pass by almost touching, but both seem practiced in avoiding contact, both physical and eye contact with patients in the corridors and they both walk at the same fast pace. She (4/5) walks past me down the corridor to

> the end of the ward and reaches the doctors' office and peers in without entering. She had urinated on the floor in this office yesterday and I wonder if she is considering doing this again; she is looking thoughtful. The one-to-one carer is still shadowing her at a distance as she walks slowly back and says to me as she passes, 'I am going back to bed'. The one-to-one carer has to take a sharps box 4/5 has picked up from a medication trolley on her on the way back to the bedside. [Site G Ward 14 Day 4]

However, there were some notable exceptions, for example, an HCA within ward G regularly encouraged mobility and had discussions with people living with dementia of the importance of maintaining and increasing their mobility. Within one ward (Fa), a locked general medical ward, staff were generally encouraging and supportive of people living with dementia (and older patients) walking independently within it. The everyday nature of walking independently within this ward can be seen within this afternoon observation of activity in a corridor, with older people including those who are also living with dementia moving freely within the ward to the bathroom and back. It was also notable for the encouragement and prioritisation of older patients walking at their own pace, with staff slowing their pace to support and encourage these older patients:

> A woman (90 years old) wearing a long pink dressing gown is using a walking frame to go to the bathroom across the corridor and back. She does this slowly but steadily. As she walks, she is crossing a really busy part of the ward with lots of staff, opposite the nurses' station. As a couple of staff pass her by, they do not rush past her, but slow down and give her plenty of space. Then one stops, smiles at her, and says 'After you, my dear, are you ok?'
>
> A man walks briskly from the bedside and across the corridor to the bathroom. He is a grey-haired older man in navy and red polka dots silk pyjamas using a walking frame in front of him with arms stiffly outstretched and locked. He marches swiftly across to the bathroom, his head down, a little later he marches back from the bathroom with the same stiff gait.

> The woman from bed 23 walks slowly to the bathroom and back. She is wearing a large and extremely fluffy dressing gown with a patterns of large cartoon flowers all over it.
>
> The woman from the next bay (22/3) is using her frame to walk to the bathroom. It is a very smart one that has been brought from home, with large wheels and brakes. She has short grey hair and is wearing a jumper and smart stay-pressed trousers and slippers. One of the nurses working in a different part of the ward goes over to her and reassures her, 'You are doing really well'. I have not seen staff stop to recognise and encourage an older person walking in these wards before. [Site F Ward 12 Day 26]

The recognition of the person living with dementia (who was not "their" patient) and the encouragement and support of this person's steps in regaining independence was unusual and so notable that it is recorded in the fieldnotes as the first time this had been observed (after many months of observations across other wards and sites for this and other observational studies within wards this team member, KF, has been involved in) and informed a follow-up discussion with the nurse in charge of this ward. She believed this was a recent change, only possible once they became a locked ward, which they had to "fight" for, describing that previously they had been constantly worried about "falls" and patients "absconding". With the locked door (keypad access with the code 1-1-1-1) described as changing the atmosphere to a more relaxed approach to PLWD walking within this ward. This was not the only locked ward in the study; however, of note was the different pace of work and bedside care within this ward, generally far slower with a more relaxed tempo than the other wards.

Institutional forms of communication prioritised

We found that in order for people living with dementia successfully to communicate an immediate and urgent continence care need that resulted in staff interrupting their timetabled care routines to attend to them, they needed to articulate clearly their request verbally, or use the bedside personal call button. In the example below, this patient was able to verbally communicate their continence needs clearly, and in response the HCA immediately interrupts timetabled care at another bedside to support her. Of note is that this woman is continent and independently mobile, but it still helped to the bathroom and placed in a continence pad as routine. It is the removal and replacement of the continence pad that this woman needs support with; she is able to walk to and from the bathroom independently.

> For the first time in some time, I hear a clear request of 'Help me', coming from one of the side rooms. An HCA goes straight to this and assists the woman in question to walk to the disabled toilet opposite bay B. She goes in with her and closes the door, although their discussion is clearly audible from the corridor: 'I'll get you a clean pad, you just sit down there.' She returns to the corridor, gets a pad from the store room, and returns to the toilet with a pad, 'Let's get you up, let's get this pulled up… ready now, let's go back and have a wash'. The woman does not audibly respond but appears to follow the HCA's instructions. They come out of the toilet and walk back down the corridor holding hands. The patient's hospital gown is tied tightly all along the back hiding the continence pad from view. [Site F Ward 11 Day 12]

Many people living with dementia admitted to these wards, as with the woman above, could clearly articulate their urgent continence needs. However, for others, verbal communication was not easy, restricted by their condition or by the quick responses of staff which overrode the person's ability or opportunity to communicate themselves. In addition, although staff quickly responded to bedside alarms or "buzzers", many people living with dementia found these difficult to access and use.

> The woman in bed 15 is sitting up in her bedside chair aided by the physiotherapist who stops to explain the personal bedside alarm. The physiotherapist explains how it works then tests her comprehension. However, this woman appears to have no recollection when questioned about this button's purpose or how to use it. The physiotherapist then puts it on the tray table in front of her and explains again, but when she repeats the test, this patient seems to become more confused. The physiotherapist then changes the subject, asking her if she wants to stay in the chair or get into bed.

> She responds that she would like to stay in the chair, then lifts up the button from her tray table to examine and asks the physiotherapist what it is for. After the physiotherapist leaves, this patient asks the HCA what the button in her hand is for. [Site H Ward 16 Day 25]

We found that as researchers who were visible within these wards and typically in the corridor outside of these bays, we (KF & AN) were regularly called over by people living with dementia (and older patients) to their bedside and for the person to ask for continence care and support. This was typically saying to us, “I want to wee”, that they needed support at the bedside (“Can you bring me a commode?”), or help to walk to the bathroom (“Can you help me get to the bathroom?”). These requests were typically made using more informal language (“wee” and “tinkle”) in hushed tones, but also contained a clear sense of urgency for the person. Here two women on a ward for care of the elderly with cognitive impairment, ask the ward team to call the researcher (KF) over to their bedsides. They have been admitted for a number of days and so we have spent quite a bit of time talking together during periods of observations over this period. Of note is that they bypass the ward team and ask the researcher (although viewed quite reasonably as a “nurse”, despite being dressed in civilian clothing) for support.

> 5pm The HCA comes over, ‘The ladies are asking for you!’
> It is the ladies in beds 2 and 3 in this 6-bedded bay and I head over and they both start talking to me at once. The woman in bed 2 is sitting up in bed. Her grey hair looks dishevelled and she has a cut on her lip (from her “fall”) and is wearing a pink hospital gown. She looks quite neatly tucked in the bed. The trolley next to her is very tidy and has a sip cup and water jug, a portion of cake and a packet of custard creams sealed in their wrappers laid out on it. The woman in bed 3 is sitting in the chair, a tiny figure in a pink hospital gown and red hospital socks, a blue hospital blanket around her shoulders and an IV port in one arm leading to a mobile drip. The trolley is placed low in front of her and she has a glass of water and a water jug in front of her. They both talk quickly and at once.

> The woman in bed 2 tells me 'I'm not supposed to be here.' She giggles and shrugs nervously, 'Something happened, I am not supposed to be there, I feel awful, embarrassed! I'm taking up space, taking up a bed meant for someone else, my husband is in [a small market town, south of the city], he won't know where I am. I just came here as a visitor, I am not supposed to be here, something happened but I don't know what.'
>
> I listen to her and reassure her as best I can and tell her I will let the team know that she needs to contact her husband (I do that later).
>
> At the same time the woman in bed 3 asks me, 'Can you help me please, I want to wee, where is the commode can you help me nurse, I want the commode, where is it?' I go to the team and they go to fetch the commode and wheel it to her bedside and close the curtain. I feel a certain discomfort that I seem to be the person these ladies feel they can speak to, bypassing the team. [Site G Ward 14 Day 25]

> The woman in bay D (D1) opposite the nurses' station, is a tiny woman with a silver-grey bob and had been described as 'lush' by the team in the morning handover. She is wearing blood-stained hospital issue pyjamas and is using a walking frame to leave the bedside and slowly making her way across the bay. In one of her hands she is clasping the walking frame, but also an extremely large wrap-around continence pad. She reaches the doorway and looks around. I smile at her and she beckons me over. She explains that she needs a pad and shows me what she has in her hand and explains that it is far too big. 'Are you a doctor? Sorry?'
>
> I explain who I am and that I will go and find someone who can help. I find the HCA in the corridor and explain, and we head to the store room together. [Site F Ward 12 Day 5]

We had many such enquiries for continence support, requested in hushed and urgent tones by people living with dementia and older patients, throughout data collection. This patient group were not always able to recognize or use the call button, or use it as instructed, but also faced the difficulties of publicly talking about or requesting continence care. In addition, in the fast pace of work of the wards these difficulties and their attempts at communicating urgent care needs were often not recognized.

Bodily expressions of continence need

For people living with dementia, their urgent care needs were often not easy to communicate either verbally or via personal alarms. Instead, the communication or awareness of an urgent and pressing care need was often embodied. These embodied signs could be identified in the person's body and changes in behaviour, which were typically subtle at first, but if unrecognized, often became overt, repetitive, and increasingly urgent.

We identified several common patterns of embodied communication, which included: touching, adjusting, or trying to remove pads and catheters; displaying pads; looking increasingly uncomfortable in bed or in the bedside chair, repetitive drumming of hands or tapping of feet; and repeated attempts to get out of bed or the bedside chair, and walking across the bay or into the wider ward. In addition, this could take the form of unarticulated moaning, calling, or crying out, that was often prolonged and repetitive. These embodied expressions of underlying care needs were observable in almost every person living with dementia at some stage during their admission. Because we could follow ward teams and their patients living with dementia over time, we observed that the embodied expressions of continence needs could be missed or, if recognised, the ward staff did not understand the urgency of these needs communicated, or they were interpreted as something that the ward staff felt unable to respond to within the expected pace of timetabled care.

Without early and prompt recognition and support, these underlying care needs, often related to pressing and urgent continence needs (needing the toilet, having a soiled or wet pad or bed) could quickly become more entrenched experiences and overt, audible and visible communication of distress; yet even these could remain unrecognized, and instead be understood by ward staff as a feature of the person's dementia and as such, considered a behaviour without purpose, and unremarkable within this setting; hence continence needs remained overlooked.

In the example below, this person's embodied communication is neither subtle nor difficult for staff to interpret. The person living with dementia highlights their urgent continence needs by attempting to urinate on the floor in the ward day room. What is of note is that the response to this is not to assist the patient directly to the toilet, but instead focusses on preventing the transgressive behaviour and exposure that appears to violate the expectations of decorum within these wards and the dignity of the person. As we have discussed in an earlier section, there was a powerful sense within all of these wards that continence care should remain hidden on the person and unseen by others within the wider ward. The immediate response of the ward team was to cover up the patient and return her to the bedside; neglecting this person's clearly expressed urgent continence need and distress communicated by her actions:

> The patients in Bay 7 to 10 all seem to be awake, handover is under way (this started at 7.30 am) following the safety meeting in the seminar room. One person living with dementia (bed 20) is in the day room, accompanied by a nurse, who is now wearing a brown cardigan over her nursing scrubs, ready to go home after the night shift. The patient suddenly hitches up her pink hospital gown and squats to urinate. The nurse reacts by talking her out of what she is doing. The nurse is able to talk her out of going to the toilet on the day room floor, but then walks her directly back to her bed, passing the bay toilet. [Site H Ward 16 Day 2]

It is important to note that although this was a less common example, this powerfully demonstrates the ways in which the organisation and delivery of care within these wards meant that staff could often not recognise or respond to the continence needs of their patients, even when they reflected an obvious physical and urgent need. It also reflects "pad cultures" (see the following section) where patients are expected to use the pads they have been placed in.

More commonly, people living with dementia attempting to leave the bed or bedside would be viewed as at risk of a “fall”, “wandering” or “absconding” and would be instructed to remain at the beside. They would also typically be reminded of the risks of leaving the bedside. However, leaving the bed was often an unverbalised attempt to reach the bathroom. Here this woman receiving one-to-one care, typically used for patients seen as “at risk” or a “disturbance” to the working of the ward, is restricted to the bed.

> The one-to-one carer with the woman in bed 2/1 sitting opposite her. She is in the bed with the side rails up on the sides and she is slowly trying to place her legs over the rails.
> In response the one-to-one carer says, ‘Where are you going? Stay inside please.’ Putting her leg back in the bed the one-to-one carer hands her a little triangle of sandwich from the tray table. This woman takes it and throws it at the one-to-one carer, but she doesn’t have much strength and it reaches the end of the bed. She has also now pulled the sheets off. The HCA joins them and tells the one-to-one carer, ‘We have run out of sheets, we need to use the blankets.’ They get a blanket and tuck her into the bed.
> A little later the woman cries out, ‘I have wet the bed! I forgot!’ She sounds distressed.
> The one-to-one carer responds, ‘Do you want to go for a number 2?’
> She draws the curtains around the bed. [Site G Ward 14 Day 29]

Here, as this man walks unsteadily from the bedside, the team unsurprisingly focus on his immediate risk of falling, however this means they do not recognise his need for independence and his underlying continence need. In addition, this is not easy for him to articulate and it takes him significant effort to walk independently and to express that he needs “a wee”.

> A man (bed 15) comes into the corridor wearing hospital pyjamas and red socks, there is orange liquid smeared all over his face and top [orange juice or

> soup?] and he is walking very unsteadily in the corridor. The senior nurse is following him, ‘Do you want a wash?’ And the HCA with her pulls the visitor seat out into the hall in front of him [they are clearly worried he will fall] and he pushes it away.
>
> He response: ‘I don’t want any of your help!’
>
> The team try to guide him back to the bay, but he looks at me though the glass and I say ‘Hello’. He walks towards me and the team. She tries to hold him and guide him back. He repeats, ‘I don’t want none of your help!’
>
> I say ‘Hello,’ and he is very unsteady and clinging onto the door frame to the day room and says to me, ‘I want to walk by myself.’
>
> I say, ‘Of course, please join me.’ He unsteadily and slowly sits down in one of the chairs opposite and I ask him how he is.
>
> He tells me, ‘I would love it if they had asked me!’ He leans over and holds my hand and says, ‘I need a wee.’
>
> I say, ‘I will get the team to help you.’ I inform the nurse at the mobile workstation and ask her. She joins him and directs him to the bathroom in the corridor. She tries to hold him, but he pushes her away and gets quite frustrated when the team tries to hold his arm. She asks if he wants his frame. He says no to the frame. As he walks unsteadily, he gets halfway to the bathroom and stops, ‘I am doing it I am weeing.’ He stands still. He doesn’t move but looks very alarmed.
>
> He has a large pad on [wrap around nappy style] which can be seen underneath his pyjamas. She waits, then leads him back to the bed and gets a plastic apron and closes the curtains. [Site H Ward 16 Day 1]

However, there were also examples of an embodied communication of need being recognised by ward staff. Here a one-to-one agency HCA is walking with a person living with dementia. As they walk along the ward corridor, she holds her sides and fiddles with her waistband, and in response this, the agency HCA asks whether she has a continence need, and instead she reports pain. In the second example below, the HCA responds to the person becoming increasing uncomfortable within the bed.

> The woman living with dementia (in bed 4/5) is walking along the corridor with a one-to-one carer by her side who says to her ‘This way!’ and guides her back to her bedside. As she moves, she holds onto the sides of her stomach and tells me she is in pain. She fiddles with the waistband and the one-to-one carer asks her if she wants to go to the bathroom, ‘Do you need the toilet?’
> ‘NO!’ she is clearly irritated at being followed by the HCA.
> A little later she stands at the medication trolley with the nurse as she does the medication round and says she is in a lot of pain holding her stomach, she does an extremely loud fart which reverberates across the bay. She turns and points at me and exclaims to the room ‘SHE DID IT!’ We look at each other at each other across the bay and laugh together. [Site G Ward 14 Day 4]

> The woman in bed 2/6 is in bed, the side rails up.
> She is a tiny figure with very white hair wearing glasses. She is also wearing a cotton nightie covered in pretty blue sprigs of flowers. As she lies there, she starts to look increasingly uncomfortable. The HCA working in the bay sees this and heads over, ‘Are you ok?’
> She replies: ‘I need a bed pan.’
> The HCA immediately goes off the bay and gets one for her. [Site G Ward 14 Day 19]

A person living with dementia leaving the bed or bedside was always interpreted by ward staff as a risk to be managed. It was rare for staff to consider or investigate potential underlying reasons why a patient was repeatedly trying to climb over the side bars of the bed, was repeatedly trying to get out of the bed or the bedside chair, or was repeatedly pulling off their bed sheets. Instead, the ward team typically focussed on the immediate behaviour with the goal typically to contain and reposition the patient within the bed or bedside chair. That these movements could (and often did) communicate urgent continence needs was often only recognised following a contracted pattern of staff repeatedly covering and repositioning in the bed, or returning a patient to the bedside, and once the person had become incontinent.

Over time, we observed these patterns repeated within and across these wards. A person living with dementia attempting to get up and stand was often eventually found to be expressing an underlying and eventually an urgent continence need. If unrecognised, this could be transformed into more entrenched patterns of conflict between a person and the ward team. The patient becomes distressed as they are constantly prevented from going to the toilet, while staff become frustrated by the management of what they perceive as behavioural features of the person's dementia (we will discuss this later below).

Theme 4. "Pad cultures": Conflicting urgencies, and continence containment

Within these wards, "pads" were by far the most common and ubiquitous continence product, widely used in the everyday bedside care of people living with dementia. We focus on "pads" within this report, because they played a key role in continence care, but were also of significance in informing wider ward cultures of care. These cultures were produced and reproduced in the organisation and delivery of everyday continence practices, expectations, and language of continence care, which had wider impacts, particularly for the recognition and understandings of dementia, the needs of people living with dementia, and their opportunities for independence within these wards.

What was most notable when first entering these wards was how visible "pads" were, given their invisibility outside of the wards and the ways these products are publicly marketed to consumers. While the term "pad" brings to mind the sanitary towel style pads promoted as "discreet" and "invisible" within advertising, the "pads" used within these wards were far larger. These came in a range of sizes, from those that resembled extremely large sanitary pads (available in S, M, L and X+ sizes), to large padded absorbent flat square sheets, which were all used to produce a bulky "wrap around nappy" style on the person. None resembled the "pull on" style of continence pants available to purchase outside of the hospital, or with self-sealable strips to aid fitting within underwear, and instead were typically held in place with thin net or mesh pants.

These “pads” were normal, mundane artefacts to be observed everywhere, in boxes and bags, on the many trolleys within these wards. Mobile trolleys were typically parked in the corridor outside each bay (or just inside if this is a newer build, which typically had larger bays), standing ready for personal care. These were always kept stacked with piles of neatly folded laundered linen, sheets, towels, and institutional gowns and pyjamas. Amongst this, there were always multiple packets of disposable wipes (for use on the body), sachets of cleanser or soap, barrier cream (also sometimes built into the disposable wipes), and disposable water bowls. However, the key item that typically dominated these trolleys were the often precariously stacked piles of boxes and packs of continence pads. These were made ready for the pace of use at the bedside; typically ripped open and spilling out of their packaging, or loose, balanced on top of the linen and in plain view to all. These “pads” were also often unpackaged, sitting loose on tabletops, at nurses’ stations and on top of files. Given their significance within continence care practices within these wards, the presence and visibility of these products may appear unremarkable and to be expected. However, they were so ubiquitous that they had to some extent lost their meaning as a medical device or technology and were viewed as everyday mundane and familiar objects to be found unpacked and loose not only on clinical and personal care stations but left across workstations and bedsides.

> The nurse sits at the small nurses’ station at the entrance to bay 3. There is a large pile of plastic folders with the bedside records for the 6 patients in the bay stacked up in a pile. On top of the pile in a large continence pad (unused) loose and out of its packaging. The nurse lifts it off, takes the first folder and replaced the pad on the files almost as a paper weight. She starts to update the first file. [Site G Ward 14 Day 27]

Pads could also be viewed being carried around by ward staff as they moved between beds and bays for everyone to see. In some instances, this appeared to be a signal to others within the wards that continence care was being carried out, particularly when this was being carried out by senior nursing staff within these wards.

> The sister in charge of the ward is wheeling a large shiny metal trolley outside of the row of three single occupancy rooms. On the trolley there are large piles of sheets, blankets, hospital gowns, disposable bowls, large bags of continence pads, rolls of red and orange waste bags, and a large pack of continence pads open and spilling out ready for use. At each door in turn, she takes into the room a large pile of sheets and gowns, with a friendly, 'Good morning, let me show you what we are doing this morning. Are you ready for a wash?' She then goes back to the corridor, gets a disposable gown and gloves from the dispensers in the corridor and takes a large folded pad from the packet on the trolley and unfurls it at the doorway. It becomes a large square sheet as she shakes it out, like a large white flag unfurling in the corridor and then heads back into the room. [Site H Ward 16 Day 7 and 19]

Other continence technologies were of course visible (such as the visibility of catheter bags when hung from bedsides, or from the back of chairs as patients were transported around the hospital) and in constant use (such as commodes, "Stedys", and hoists which take up considerable space along ward corridors). However, the sheer volume and visibly of pads was far more prominent. Their consistent use in the care of people living with dementia within these wards was a stable and unchanging feature of ward life. This suggests that although pads are typically viewed as an ordinary, unremarkable, and ubiquitous feature of both the landscape of these wards and the everyday bedside care work carried out by nurses and HCAs, their use is also of significance for patients living with dementia, for ward staff, and the cultures of care within these wards.

Pads as standard practice for people living with dementia

Disposable continence products were universally referred to by ward staff as "pads" and discussed with and described to patients in this way. For example, explanations at the beside were typically limited to "We just need to check your pad", "We need to change your pad", and "Don't worry, you've got a pad on". However, what a pad is, what a pad does, how a pad works, or if the person had ever worn a pad previously, was never explained nor discussed with patients living with dementia during our observations.

The standardised strategies of care at the bedside were typically accompanied by standardised and restricted language, which often took the form of incongruous or contracted phrases to describe continence products, care routines, and practices. There was an assumption that these phrases would be immediately understood by all within these wards. Here we can see that these explanations were typically made using contracted language which did not fully describe what was happening or about to happen to the person, and was delivered in a slow, enunciated, and loud institutional tone of voice.

> A member of staff is walking through the ward waving a continence pad and says out loud to the patient at the bedside, 'WE ARE JUST GOING TO PUT YOU IN A PAD.' [Site F Ward 12 Day 1]

The taken-for-granted language within these routine statements as above, or there wear a small number variants such as "I'm just going to check your pad", followed by an (often swift) intimate examination (there were routine and regular checks to see if continence pads were "wet" or "dirty" and needed changing using touch to evaluate this, which will be discussed later in this analysis) was assumed to be easily recognised and understood by people living with dementia within these wards.

> In side room 5, a patient is lying on their bed. They are quiet but have been awake the entire shift just looking out into the corridor. Two nurses (including the nurse in charge of the ward) put on latex gloves and go into the room. As they do this one says to the other 'I'll get a fresh pad [points to a pile on the nearby trolley], there's some over there.' Having already walked into the room, the nurse in charge announces, 'Can I come in? Hello, can we change your pad?' They close the door behind them. [Site H Ward 16 Day 23]

This limited repertoire of phrases and descriptions were used across all these sites, with repetition, increased volume, and slow enunciation of the same phrase a response to a person's apparent failure to recognise this routine care. We explore later how this could mean people living with dementia may not expect the intimate care this involved, which could lead to significant distress for many patients.

"Pads" a routine precautionary strategy

This widespread and everyday use of pads in the care of people living with dementia was often explained and rationalised by ward staff (in discussion with patients, to families, to us, and to each other when organising care) as a precautionary strategy, used "just in case", as a "safeguard" for all, including those recognized as continent, "mobile", and "self-caring". Of course, many people living with dementia within these wards did have continence and mobility issues. However, we found the widespread use of pads was not limited to those with identified continence issues associated with their dementia or their admitting condition. Rather, there was an expectation that the wider timetabled routines of care would mean that continence urgency could not be prioritised by ward staff, thus these technologies were viewed as providing essential safeguards, to ensure containment, prevent "accidents" or incontinent episodes during a shift, and to support the smooth running of the work of these wards. This precautionary "just in case" approach to continence care for people living with dementia was deeply embedded and pervasive in all of the wards observed within this study.

Here the bay team discuss one of their patients living with dementia, who is routinely "dressed" in continence "pads" by the team even though she can walk to and from the bathroom independently (we observed her doing this), describing this practice as a "safeguard".

> I speak to RN and HCA about continence amongst the patients living with dementia. A6 is continent but the HCA says she is still placed in pads. The RN interjects and says she isn't, and the HCA says she just now changed her pad in the toilet, and has put it on as 'a safeguard'. RN criticizes this, asking the HCA, 'what's the point', and describes how it is not encouraging independence. [Site F Ward 11 Day 20]

This example also demonstrates that ward staff recognised that this precautionary approach had wider implications for this person, could impact on opportunities for rehabilitation, and lead to deconditioning and reduced independence. Ward staff (nurses and HCAs) often reflected (across the sites) this viewpoint in our discussions about continence care; however, they also described feeling powerless in having any influence to change these approaches, viewing it as a direct consequence of wider institutional pressures (this is examined in more detail later in the analysis).

Justifying the use of "pads" as a safeguard for people living with dementia who were otherwise continent, was a common rationale used by ward staff to support their routine use. Here, this example also demonstrates that this reflects wider expectations and understandings within these wards of poor QoL and dependency as inevitable in the context of a diagnosis of dementia.

> The woman in bed 2 is eating chocolate from a large box on her tray table. I speak to the HCA about her, who tells me that she has put a pad on 'just in case', but confirms she is continent. Have conversation with RN and HCA about this patient and the RN says she wouldn't want to live that long, and the HCA talks about how lovely she is for her age, 'she does seem with it', despite her admission and dementia, and 'she knows where she is'. [Site F Ward 11 Day 25]

The use of pads in the care of people living with dementia was so embedded within these wards that they were used even when multiple other continence technologies were already in place to support the person. In many ways, "pad cultures" were the most visible sign of the containment approach to continence care within these wards.

Cultures of containment: wearing a "pad" informed expectations they could and should be used

This use of "pads" as a precautionary strategy had real and significant consequences for people living with dementia. Once adopted as a "just in case" strategy, the routine use of pads in the care of people living with dementia resulted in the maintenance of continence being deprioritised, and the precautionary strategy became an expectation that patients living with dementia not only wear pads, but that they could and should use the pad. We found this expectation was a feature of all these ward cultures, regardless of an individual's continence, independence, or preference.

> 11:35 - Inside side room 6 the visitor is explaining to the one-to-one carer that her father doesn't like the continence pads. He finds them uncomfortable and they are too tight. No action is taken. [Site H Ward 15 Day 7]

Of course, many people living with dementia (and older people) did have episodes of incontinence or were incontinent, and indeed, we observed many people called for assistance too late, after they had used their continence pad. However, we found that the use of pads as standard care for people living with dementia contributed to ward cultures and expectations of patients (we also saw some slippage in the assessment of the person and their capabilities and this could lead to a recognition of the person as "bedbound"). This was not just because pads were associated with incontinence, but that once this patient group were placed in them, this, together with the associated visibility of the "pad" on the person "wearing" them, established a widespread culture that expected and instructed people living with dementia to actively use these pads.

The communication of a continence need and a request to go to the toilet by a person living with dementia was often answered by ward staff with the commonly used phrases "You've got a pad on", a signal for the patient to remain in bed and to use the "pad". Here a nurse (who is covering the bay and tells me she does not know these patients) supports a woman living with dementia to the bathroom. It is clear that this woman is both mobile and continent, although she is lacking confidence in walking without support to the bathroom. We can also see that she appears not to have been to this bathroom before and, in her repeated thanks to the HCA, her relief in being able to reach and use it. However, as this example shows, supporting a patient to the bathroom was unusual and can be questioned.

> After being told to stay in her chair, the woman in bed 17 asks the nurse from bay B, who is covering for the regular nurse's break, if she can go to the toilet. 17 is really appreciative of the nurse for helping her with this, 'Thank you. Oh, you have a little room.' They open the toilet door and it is as if she has not seen this toilet before, even though it is located within the bay. 'Is there a light?' The nurse turns the lights on for her, 'Oh, thank you. Thank you so

> much'. The nurse explains to her that 'When you are finished, pull the red one and I'll come back,' pointing out the buzzer. 17 doesn't seem to understand this. She responds, 'Will you stay here and help me back, I'm almost finished.' 'Okay,' says the nurse and stays in the toilet with her. 17 finishes and they walk back to her bedside. As the nurse turns to leave, the other nurse returns from her break, so she lets her know 17 has just been to the toilet. The returning nurse responds questioning this, 'Why? She's got a pad on'. [Site H Ward 16 Day 11]

Within all these wards, in response to a person living with dementia asking for continence care, we identified staff reminding the person that they were wearing a pad and to explicitly instruct them to use the pad. Later in the day, the same patient (as above) clearly states "I need the toilet" and in response was reminded that she was wearing a pad and directed to use it, "You have a pad on, you can just go there". This is extremely confusing for this woman who appears to interpret this as removing her pad and to use the bedside chair as a commode, which leads to high levels of distress for both the person and the team caring for her.

> The woman in bed 17 gets up and moves to her bedside chair but remains standing up. She announces, "I need the toilet', to which the response of the one-to-one HCA (who is closely monitoring this patient and the person in the bed next to it, bed 16) is to remind her that she has a pad on. This woman (bed 17) responds to this by reaching down and beginning to take the pad off. The one-to-one HCA tells her to pull it back up and again reminds her, 'You have a pad on, you can just go there'. She (the woman in bed 17) appears to be confused by this and she again tries to take the pad off and sits on the bedside chair. The other team member in the bay suddenly shouts across the bay, 'Wait a minute, that's not the toilet! Wait a minute!' She (the woman in bed 17) looks confused and says, 'I can't wait I need to go… I'm going to do it here'. The member of staff now keeps asking her to 'sit down'. [Site H Ward 15 Day 11]

The routine use of “pads” appeared to be informed by a number of institutional expectations and pressures powerfully felt by ward staff, particularly the expected pace of the organisation and delivery of bedside care for this patient group. As we can see here, ward staff emphasise to this person living with dementia that she must use the pad or “wait” (her urgency must fit the timetables of wider care delivery the team are working to), and they repeatedly instruct her to “sit down” further emphasising the potential risks to the person of independently leaving the bed or bedside to reach the bathroom. It also appears to reflect a belief that it is possible to “use” a pad, particularly for people living with dementia.

The families we spoke to often described their family member living with dementia experiencing these strategies of continence care during their admission. Here two daughters join me in the day room and share their concerns about their parent’s continence care and the effects of the reliance on “pads”, the strategies of containment, and the impacts for the person.

> Dad [patient in bed 16 who is living with vascular dementia] gets agitated if he wants to go to the toilet or if his pad needs changing. I got here, there was a puddle in the bed so it hadn’t been changed in a while. I asked both nurses who said they were busy so I changed the sheets, stripped the bed, and put clean clothes on. When he gets sundowners he starts to swear. He was trying to get up and saying, ‘I am bursting for a piss, bursting for a piss.’ I said to the nurse he wants to go to the toilet and she said, ‘He’s got a pad on!’ He doesn’t, it’s just for accidents, he has accidents, but he can walk to the bathroom! And we took him out to the bathroom the nurse said, ‘He can walk?’ Yes! They had been leaving him in bed and we got him up, it’s not good to be in bed and we walk him to the toilet. The nurse says, take him in a wheelchair, but no, he can walk. They think because they are in pads, they are toddlers and babies not adults. My brother does more, I am more squeamish, and he takes him to the toilet and changes his pad. But the nurse said, no, she will do it, but she was annoyed with him for doing it. She said to my dad ‘I

> am just going to change your nappy I am going to change your nappy.’ That’s basic, that took all his dignity.
> Daughter of 20 nods in agreement and tells us about her mum, ‘I could smell it, my mum can’t tell someone she needs changing. Oh my ***, if I wasn’t here it could have been all day and until the night shift. I could smell it!’
> [Site H Ward 16 Day 16]

These ward cultures emphasising the organisation and delivery of timetabled bedside care and the strategies of ensuring patient safety and reducing risk also appeared to constrain the power of staff to respond legitimately to urgent continence care needs, particularly if they involved supporting the person to leave the bedside, or promoting independence and continence.

These ward cultures emphasized pace, efficiency, and busyness (as seen within many examples above), with the need to maintain the daily organizational timetables of bedside care powerfully felt, creating a palpable source of tension amongst nursing and care staff. And feared underlying anxiety of “falling behind” during shifts was frequently discussed. Conversely the sense of meeting or being ahead of the timetables, of having time for a break was notable, and a sign of a “quiet” day (although to vocalize this was to “jinx” it).

Continence care that supported the independence of people living with dementia was recognized by staff across these wards as requiring skilled interactional work, but also as a form of care that requires significant time, and in some cases many members of staff. When unscheduled, driven by a person’s urgent needs, continence care was often perceived as taking “too long”, a source of delay that could impact other routinized timetabled aspects of bedside care. This shaped the dominant culture of continence care we observed across all wards and sites, the “pad cultures”. While pads would be rationalized as being used “just in case” (as we have discussed earlier), our observations revealed that the use of pads was an embedded practice within these wards, not only in response to incontinence in the person or as an (in)continence tool, but to support the wider organization, management, and delivery of the ward timetables of care that were institutionally mandated. These strategies were also reflected in the explanations and rationalizations staff provided to patients living with dementia at the bedside and to their families. The standard use of pads removed the urgency of continence care, shifting the delivery of this care from one that interrupts these timetables, to one that can fit within it. The use of pads transforms the continence care of people living with dementia into what was perceived by staff as requiring a relatively quick and efficient set of care tasks contained at the bedside, preventing ward teams from "falling behind" with the wider timetabled care perceived as more critical, or more closely monitored by the institution.

The pace of care at the bedside (expected and perceived) meant that the independence and autonomy of patients living with dementia could become a reduced priority. Where staff perceived that they were "short" (understaffed) or were "falling behind" with the wider timetables of bedside care, the use of pads became prioritised over patient independence. At these junctures in shifts (we found that this typically occurred at some point during almost every shift), patterns of prompting and the procedures of assisting a person living with dementia to use a bathroom could become viewed as taking too long and perceived as clashing with and potentially delaying other institutionally mandated timetabled tasks of care (this included the timetables of other teams, for example the arrival of medical teams or mealtime deliveries). Hence, while staff within these wards discussed and recognised the importance of prompting patients to go to the toilet, particularly before or after a meal, in practice these pad cultures dominated.

These pad cultures also created their own new routines and rituals within the wards, such as regular "pad rounds" and "pad checks", where ward staff (typically HCAs) "checked" on and prompted continence at points during the shift. These involved ward staff asking people at each bedside in turn about their continence needs. If a person was unable to respond verbally (we have discussed the importance of verbal communication earlier), this could involve staff relying on detecting the smell of urine or faeces on the person, and by carrying out a physical examination at the bedside by swiftly lifting sheets, hospital gowns, robes, and clothes, using touch to check if a person's pad had been used. These pad checks would be carried out in turn for each person within a bay or carried out as part of other task-based bedside care throughout shifts, although this could also be less systematic and varied depending on the individual staff and team approaches to bedside care and the pace, space, and pressures on the timetables. In this way continence care could become transformed and reduced to containment practices and the "checking" and replacing of soiled or wet pads as part of other scheduled activities during a shift.

Conflicting urgencies and fear of falling behind

Within these wards supporting independence and continence for people living with dementia was recognised as requiring expertise but also considerable time and resources (as with the person living with dementia in the example above). As we have described, the nurses and healthcare assistants who supported a patient living with dementia to the toilet almost always stayed within or near the toilet, or within the bay, until that patient needed to be supported to return back to the bedside, where personal care may be needed and clothing and/or bed sheets may also need replacing before a patient was assisted back into the bed or chair. Supporting a person living with dementia from a bed or bedside chair onto a commode also involved a similar intensity of care work, carried out behind the curtain. Supporting independent or assisted continence typically took between 5 to 10 minutes, steps which often required additional support from the bay or wider ward team (sometimes requiring a "double" of two members of staff within the team or requiring a "floating" member of staff working across the ward (or "on the floor"), or more commonly, taking them away from their own bays and patients), but could frequently take far longer. When this was a timetabled aspect of ward care, such as at the start of the morning handover, as part of the pre-breakfast personal care routines, such supportive care was observable throughout the shifts within these wards:

> The HCA on bay 3 puts on a plastic disposable apron to go into the toilet to help the patient in there. It's the woman from bed 16. 'Why do you want to hit me?' says the HCA loudly. She comes out and asks other staff for help, 'She's so aggressive'. As she does this, 16 dashes out of the toilet. She has a

> stumbling lurching walk. Her hospital gown is pulled up high and she is holding up her large continence pad. The team try to talk her into going back into the toilet and tell her she is 'showing herself' to the unit and that men are going to walk past and 'will see her'. It is only then that she turns around, before locking her legs and insisting that she wants to go back to her bed. They tell her that she needs to clean up, and manage to walk her back to into the toilet. The nurse comes out of the toilet and sighs, she is clearly tired at the end of the night shift, but goes immediately to support another patient who is calling out for help. Suddenly, the instructions change - previously the staff just wanted to get this woman (16) to go back into the toilet and now they are struggling to get her out of it. The HCA tries to reason with her and offer incentives, 'Your breakfast is getting cold', 'Come and have your breakfast'. 'Come out of there. Please come out of there.' At the same time the senior nurse helps the woman (bed 12) who is using a frame to walk from the bedside, he is directing her towards the toilet, she is very slow and he is being very patient. She is really struggling to use the frame, and looks terrified, and this senior nurse is supporting, holding the frame in front of her, but she starts to look distressed and the nurse calls out for a chair. The clerk at the nursing station tries to bring one but can't get the chair brakes off and there is no one free to help and the clerk eventually forces the chair against brakes onto the bay, making a huge screeching sound. But she (12) then refuses to get on the chair, and continues to shuffle with the frame towards the toilet. She is very slow and shaky, but at the same time desperate to get there, and vocal about her worry and fear of 'going' before she gets there. The rear heel of her walking frame gets caught on the open toilet door, it takes a few minutes and I am convinced she is going to fall as they edge the frame around the door. She (12) turns to the nurse and says, 'It's difficult when you don't know your way around!' The nurse stays with her throughout and this takes around 10 minutes from bed to bowl. [Site H Ward 15 Day 25]

Continence care was also an important opportunity for staff to provide wider supportive care and comfort to the person, which could require more time than expected to see the person and to support their wider needs. Here, the HCA prompts support to reach the bathroom, despite this patient's hesitancy, and at the same time she also responds to her wider needs, with a focus on her painful skin.

> The woman in bed 8 asks the HCA, 'Can I get out of bed a bit more today?'
> The HCA replies, 'Yes of course. Toilet first?'
> 'We can try!'
> The HCA takes the commode to her and drops the bed, puts fresh red hospital socks on her feet and helps her to sit and to move across to the commode. She is wearing a white gown [here they have the institutional logo printed across them] and has a large wrap around pad on. They discuss how to swing her legs around from the bed because there are lots of skin breaks on her legs and she complains about her back being sore. The nurse gets some cream and rubs it across her back, working it into her skin.
> This woman looks relieved: 'Thank you nurse that's much better.'
> The HCA helps her onto the commode and takes her in to the bathroom, leaves her and returns to the bedside to make the bed and puts pillows on the bedside chair. She then heads back to the bathroom and wheels this woman out on the commode, locks it in place at the bedside and helps her out. 'Have you got me? '
> 'Yes.'
> 'Ok lovely.'
> Once she is in the bedside chair, the HCA puts pillows behind her back for support, arranges her gown straight and over her knees, and moves the bedside trolley next to her and in reach. [Site H Ward 16 Day 7]

However, outside of these points in the organization of the acute ward where continence was prioritized, the time required to support a person living with dementia from the bedside to the bathroom and back was often seen as significant, as taking too long, and as interrupting the other timetabled demands. Continence care could then become deprioritised, overshadowed by pad cultures that enabled staff to focus on fulfilling the timetabled work of the ward, and the recordable and quantifiable aspects of their work. We had many discussions with ward staff about how they managed the timetabled routines of bedside care and the urgency of continence care needs for their patients living with dementia. This HCA describes these constant judgements on what to prioritise during a shift, highlighting the centrality of the observation routines:

> There are 6 people in this bay, that's a lot of attention, everyone needs the toilet so observation [timetabled rounds at each bedside that must be recorded at set points in each shift] or the toilet – or observation and wipe it up afterwards. I can only do what I can do. If I can do it I do it, but you can't do it all on your own. Some days I have 10 patients on my own. [Site G Ward 15 Day 10]

For ward staff, as we see in the example above, the organisational pressures emphasizing speed and pace meant concerns about "falling behind" with the timetables of routine bedside care (for example observations, medications, and mealtimes, but includes many other routines of care that must be completed and recorded to meet internal and external institutional timetables and the associated recording practices) were deeply felt. Here an HCA from a different site describes the recording of the timetabled observations (blood pressure, heart rate, temperature), as the institutional priorities, and as such more pressing than other aspects of bedside care. Note how these institutional priorities trump urgent patient continence care needs.

> We discuss continence care in the ward and the HCA tells me, 'It's important to stay in the zone, do the routine stuff and have tunnel vision, no interruptions to the routine observations, observations are more important, the priority, more important than someone sitting in poop. The happiest most productive nurses are the ones who stay in the zone. If anything happens to that patient then they will ask why weren't the observations done, so the person sitting in poop has to wait, but at the same time if they sit in it for too long then they have skin issues and that comes up, but you only have two hands.' [Site H Ward 16 Day 14]

This could lead to staff carrying out these timetabled observations during continence care, and overriding concerns about the impacts (and potential immediate distress) to the individual person living with dementia.

> 2/5 is crying out. I thought the team were with her but no, she is by herself behind the curtain drawn around her bedside. The HCA goes over to her and asks her, ‘Do you want to wee?’
> Another HCA joins them and repeats this: ‘Do you want to wee?’
> The first HCA comes back with gloves on and a bed pan in her hands (it looks like a very large plastic shovel with a cardboard disposable insert fitted within it) and goes behind the curtain. This HCA tells her, ‘See if you can go, see if you can do a wee. I will just do your blood pressure while you are here.’
> She wheels the mobile BP monitor in: ‘Which arm did you hurt?’
> When they are finished this woman is lying flat in the bed, tucked into the bed, and looks calmer. The side rails are also up on the bed. [Site G Ward 14 Day 7]

These organizational pressures could inform cultures of continence care, which would mean prompting and supporting independence and use of the bathrooms become limited and withdrawn as non-essential, while continence pads (and bedside continence care) come to be relied upon to ensure containment. Hence we regularly observed a team carry out fast paced bedside care within a bay for two to five hours without seeing a single patient living with dementia leave the bedside and go to the toilet, including before and after mealtimes and drink rounds.

> On bay A the man in bed 10 is up walking from the toilet to his bedside chair. Only the patients on this bay (younger, no dementia) have been up to go to the toilet during today’s observations. [Site H Ward 15 Day 21]

> I stand between the nurses’ station and the toilet in the corridor and throughout the time I am here (9.30-11.30) no-one has used this toilet. It is the only one for the 8 women in bays 3 and 4 opposite. This seems like a long time with no visits to the bathroom. [Site G Ward 13 Day 1]

This was associated with approaches where prompting patients living with dementia to walk to the bathroom was viewed by staff as only possible during “quiet” moments in the ward schedule. However, these quiet moments were rarely identified and acted on; pad cultures allowed patients to be left while ward staff used these times to focus on the next timetabled task (or the required updating of patient records).

Containment, prompting, and the prioritization of urgent and visible continence care

Ward teams employed a range of strategies to manage their workloads and to try to keep pace with the expected timetables of care, including, prominently, continence care. If a ward team believed they were falling behind schedule, prompting independence was reduced, calls for the toilet were difficult for staff to respond to and were replaced with reminders to patients both of the competing demands of their workload and of the continence technology. Continence care that supported independence was replaced with containment.

Strategies of prompting

Toileting was regularly prompted at points across shifts, with prompting typically timed (informally) to support the wider organisation and delivery of routine bedside care and external institutional schedules entering the wards, such as meal delivery or medical rounds, to continue uninterrupted. Prompting and encouraging toileting independence was, in practice, often sporadic rather than routine, readily stalled once staff perceived they might “fall behind”. This would also reduce opportunities to respond to urgent continence care needs. Here the team reassure a visitor that the person “has been seen”, however, this means they find it difficult to recognise as legitimate his continence care needs outside of these points in the timetable.

> A visitor on the bay goes over to the clerk at the main nurses’ station and says one of the patients has been calling out for a nurse for a while. In response, the clerk says a nurse ‘has seen him’, but the visitor challenges this, saying the patient is uncomfortable and nobody has seen him. An argument of sorts starts, with the visitor adamant no nurse has been and that a nurse is needed, and the clerk saying the nurse has already been and will be back again soon. There hasn’t been a nurse on this bay for some time. ‘He’s not comfortable’

> says the visitor, with an emphasis on urgency missing from staff interpretations of the situation. A nurse passing by says she will 'come and see him next.' [Site H Ward 15 Day 24]

In discussions about continence care, ward staff typically talked about these strategies of prompting and continence promotion, but also the competing realities of the expected pace of care, the urgent needs of their patients, and their fear of falling behind. Here this nurse exemplifies this everyday challenge:

> We go to all patients every 2-3 hours and if continent we will ask them if they want to go to the toilet, if incontinent we will check that pad, we promote continence. [...] but we can't always do it, we have acutely ill patients here, so we don't always have the time to take them, the best time is when washing and dressing. [Site F Ward 11 Day 21]

Prompting was also typically timed to support the smooth delivery of the wider institutional systems and routines. This included organisational demands such as staff clinical meetings and Board rounds, and the schedules of specialisms, services and teams external to these wards, which were typically prioritised over the individual person living with dementia and their continence needs. Here, the competing timetable of the external audiology service is explicitly prioritised over the personal care and continence care needs of this person.

> The man from C bay (C1) passes in the hall, he wears a hospital gown and is using a frame to walk to the bathroom and we smile to each other as he passes by. He later returns and looks a bit uncertain and I ask him if he is okay. He tells me, 'I need a pad and a wash.' His pad is falling off him. It looks uncomfortably large and he is exposed because the hospital gown doesn't cover his back. I go and find the nurse for this bay and tell her and she tells me he can't [? wash?] yet because he needs to go to audiology. She goes over to him. He is now back in the bay sitting in the chair next to his bed. 'I will get you a pad but you are going to audiology first.' [Site F Ward 12 Day 5]

The external timetabled order of food delivery could conflict with the urgency of the person's continence care needs. However, the prioritisation of the mealtime and the hot lunch (and the schedule of the audiology department above) means that ward staff appear unable to recognise the urgency of the person's need or the unpleasantness of this for the person.

> A man in pale checked pyjamas walks gingerly and slowly down the corridor and he asks me where the bathroom is. I point him in the right direction. He is directly at the entrance to the bathroom so as I show him, he turns and goes in. When he comes out and heads down the corridor to the bay, I can see his pyjama bottoms are quite stained at the back. He does seem to be walking quite uncomfortably back to the ward. The nurse joins him and guides him back. She notices the stain but does not say anything [...]
> Later he goes to the bathroom and back the stain on his pyjama bottoms is big. It's definitely a large patch of faeces.
> The same nurse sees the patch and leads him to the bedside: 'Your food is here.'
> [Later after lunch I can see the curtain is drawn and she is helping him change.] [Site F Ward 12 Day 27]

When ward staff attempted to fit the urgent continence needs of a person living with dementia into the timetabled order of bedside care, for whatever reason, this could lead to significant patient distress. Here this distressed patient becomes viewed as requiring high levels of support that cannot be met by this ward, even when this shift is described by the nurse in charge as "well-staffed". Ward staff were constantly managing a number of conflicting organisational demands and patient care needs. In this case compliance with the institutionally mandated recording practices is prioritised with this person's continence care needs managed through a strategy of "hourly checks", with the nurse in charge also reassuring this patient. However, this does not recognise the distress this approach and the associated delays causes to the person.

As I enter the ward the woman (in bed 2/1) calls me over to her bedside. She seems very distressed as she holds her arms out to me: 'Help me.' I go over to her and she tells me, 'I want to wee, I am desperate, ooh, I am going to wee now, it is too late!' She is wide eyed and looks extremely distressed as though she has been desperately holding on for a long time. I say I will find the nurse who is looking after her. She replies, 'Please! I need the commode.'

I go over to the nurses' station. The nurse who is writing updates in the medical notes, her head down, focussed on completing the patient records, is her nurse, and I tell her about her patient, emphasising the urgency. She remains sitting at the desk and tells me, 'She is very, very confused, we have dipped her urine, she came in with a fall so completely confused. We keep trying her on the commode but she won't sit, she says it's uncomfortable and she can't go, so we are checking on her hourly. We are trying to satisfy her with something, but it's constant, you can't reply all the time to everything. You need to find a strategy for all the patients, we tried her on the bedpan but she won't stay, you have to find a strategy that will help.'

As we talk, the nurse in charge of the ward passes and this woman also calls out to her, 'Help me!' She still sounds very distressed. The nurse in charge goes over to her and the nurse from that bay joins her. The nurse in charge tells this patient, 'We are looking after you, I am going off shift now, you will soon feel better. She also tells her her name and reassures her she is ok - she has an incredibly gentle manner.

However, when she leaves, this woman continues to call out her distress, 'Please help me, please help me ....'

I follow the nurse in charge into the staff room as she leaves to ask her about this patient and the strategy. She tells me, 'We are well staffed, so it's easier to not get behind, but that's going to change, I am going off I am on an early only (she gets her bag and coat) and they are moving (another very experienced nurse to cover another ward) now, so it's going to get more chaotic from now on.'

> I return to the ward and the woman is still distressed, it is affecting both me and also the other ladies in this bay, we are all starting to feel anxious for her. [Site G Ward 14 Day 21]

Importantly, once the continence needs of this person do not fit the routines of the wider ward, her behaviour and her high levels of distress become viewed as a feature of her dementia and of being "confused". We will explore the impacts of continence care on understandings of "behaviour" and dementia later.

Prompted continence care as a "disturbance" to the older person/patient

Within these wards, the widespread cultures of using pads as a precautionary strategy (as discussed earlier) was associated with reduced prompting to support independent continence care for this patient group. Acute wards are typically fast-paced spaces, with an expectation of a sustained tempo of speed (as a demonstration of efficiency) in the organisation and delivery of care within them. In contrast, inpatient wards are unstimulating places, particularly for people living with dementia, who did not typically have access to newspapers, books, television, or radio. Although some had communal screens (often fixed to a wall, tuned to one channel) or pay-per-view screens at the bedside, these were often inaccessible (bedside screens typically complex to use), and few had them available for personal use within these wards. Thus, people living with dementia were often sitting in the bedside chair or within their bed for extended periods with no stimulation. This produced a pervading sense of ennui, of patients left to wait, sitting in "pads".

> It is so quiet, but even when there are empty beds and little to do, the patients admitted with dementia are dressed in continence pads and just left to sit unsupported in their beds. I have seen no prompting to go to the toilet. Fewer patients and fewer tasks do not seem translate to more engagement or more care, just to a quieter day. The team are either writing up notes at the nurses, station or are not visible. [Site H Ward 16 Day 24]

This lack of stimulation meant that people living with dementia often appeared sleepy, drowsy, and moved less, which in turn meant individuals may not be as connected to their immediate bodily needs, including their continence (also extending to include a wider range of care needs, for example hydration). At the same time, their immobility (which could be viewed as a feature of dementia) meant these individuals were often conceptualized by the ward team as not needing prompted continence care, particularly in the context of the wider pace of care work on these wards. Combined with the precautionary strategy of pad use, this meant that prompting toileting and independence was often judged non-essential or as something that could be delayed for this patient group. This could inform other aspects of personal care where within the fast pace of timetabled care work, people living with dementia who were “quiet” could often be judged by ward staff (and other teams and services entering these wards) as not having obvious urgent support or care needs.

> The patients in beds 19, 21 and 22 have all been on the unit for over a week. They seem to be bored, almost institutionalized, and are just sitting on their beds, propped up by pillows, staring forward blankly. 19 and 22 are just waiting for social workers to arrange discharge and safeguarding placements. This seems to take forever, both cleared to go home but seemingly no urgency for this. [Site H Ward 15 Day 16]

This could extend to recognition of intense faecal smells. While this was a familiar and everyday odour within these wards, it was also masked by and mingled with the overpowering and familiar disinfectant smell of the institution, to become a usual and everyday smell that ward staff were habituated to. It was customary for staff to comment and note particularly intense and powerful odours, and although this could alert staff to prioritise a patient and their continence needs, the source was not always identified until bed covers were disturbed for other routine care.

> On Bay 2 the patient in bed 14 is hidden behind the curtains. The nurse is at the bedside for what appears to be personal care, including washing and changing clothes and sheets. She admonishes this woman ‘Less of that’, who

> grumbles as the nurse continues, ‘We need to change you… your bed smells of urine… it doesn’t look good…’ [Site H Ward 15 Day 5]

Thus, the needs of people living with dementia could appear less visible to staff and in turn, ward and other external and auxiliary staff also appeared less comfortable approaching immobile older patients, with prompting potentially viewed as inappropriately “disturbing” individuals appearing less alert. This in turn could further distance the person living with dementia from social stimulation and care.

Strategies of containment

The “pad cultures” we observed could create new additional and unplanned work of their own. Because continence “pads” are designed to contain urine and faecal matter, there were widely held assumptions amongst staff that “pads” worked as a containment technology and that people living with dementia could remain in soiled or wet pads, until staff judged there was sufficient space in the timetables of care and the competing needs of other patients, when they felt able and permitted to attend the bedside and deliver continence care. However, when continence was not contained and became visible or noticeable on the body or at the bedside, this was recognized by all as requiring urgent and prompt care.

Our observations suggested that despite their intended design, “pads” rarely functioned as a containment technology for long, creating problems and work of their own. “Waste” from continence “pads” (and other technologies and equipment) that became visible within these wards was typically prioritised as urgent, especially if it was left the bedside and out of place within the wider ward. Visible waste or “accidents” were not tolerated within these wards, viewed as highly disturbing by staff within and entering these wards. Timetables would be interrupted and the cleaning of patients, surfaces, and floors, would be prioritised.

> Bay 1 smells really strongly of faeces. I look in and there is a trail of faeces leading from the corridor along the floor back to bed 8. The NIC sees me looking at it and apologises about the mess. 2 HCAs are crouched on the floor

> wiping it up with anti bac wipes. They tell me nobody had noticed until the ward sister slipped over in it. [Site H Ward 15 Day 2]

Such incidents often showed the failings of retroactive pad culture, as changing a full bed and the patient and their clothing was typically required which could be more resource intensive and distressing (both immediately and in longer term impacts for the person) than proactively supporting patient continence and independence. These impacts were, however, unrecognized (or unattributed) by ward teams, with little recognition of the urgency or distress for the person wearing the soiled pad and their immediate needs or the practical considerations that once a person had "used" their pad, then this typically meant they required urgent support with personal care.

The emphasis placed on the use of pads as a precautionary strategy of containment meant that within these wards, optimum organizational efficiency was believed to be achieved when people living with dementia (and this extended to older people within these wards), were wearing pads and contained in bed and at the bedside. Here the ward team were caring for a group of patients living with dementia who are all wearing "pads", the key focus of their work during this shift involved a strategy of containing these patients within their beds. In comparison to many shifts observed, this is an average team (1 nurse to 9 patients, 1 HCA to 13 patients); however, the demands of timetabled routine care (perceived and expected) and the support needs of this patient cohort meant there appeared to be no potential for the team to prioritise care strategies that supported continence or independence more widely.

> The nurse from bay 3 goes into bay 4, talking in whispers to the one-to-one agency HCA before shutting the door behind quietly. Two doctors in the corridor are preparing to go into the bay to see the patient in bed 21. They also repeat these actions quietly closing the doors behind them. The nurse from bay 3 now seems primarily occupied with picking Elvis songs from YouTube to make sure the man in bed 15, (who is wearing a pad and had an additional large continence mat underneath him) stays in bed. The job of the one-to-one carer on bay 4 seems to simply keep the patients in bed and asleep, while the nurse is away from the bay. Another nurse is just trying to keep

> patient 14 at her bedside. Each staff member is on differing bays to the ones they were assigned at handover, covering for other staff, and concerned chiefly with containing individual patients at the bedside. There is little visible medical or personal care happening. [Site H Ward 15 Day 17]

The use of “pads” in the care of people living with dementia, and the expectation of their use, would typically result in the person needing support to ensure hygiene and cleanliness. These containment technologies regularly failed in their primary purpose; pads leak, smell, and can damage skin, requiring significant personal care including support with undressing, washing and changing, and a change of sheets. For staff, this also involved repeated trips to linen stores and sluice rooms, often located far from the patient’s room or bay. This required care that was far more personally invasive and distressing than supporting the patient to the toilet.

> The woman in bed 12 calls out, telling the team her pad needs changing, and the nurse and HCA go to her bedside and together decide that ‘the whole bed needs doing’. I wonder, are the pads ever effective? It is still tough to observe the bays today, everything is blocked by curtains. This woman’s (bed 12) visitor first reported she needed the toilet a long time ago. The visitor is still in the day room waiting. [Site H Ward 15 Day 28]

Prioritising the management of “dirty” and “wet” bodies

Judgements about the relative urgency of continence care typically emphasized to patients and the wider ward, the importance of cleanliness and of managing “dirty” and “wet” bodies, beds, and surfaces within the timetables of care. This organisational focus on responding to “dirty” or “wet” bodies (as with the urgency of responses to visible waste or “accidents” described earlier), meant that other aspects of continence needs of importance to patients living with dementia were hard for ward staff to recognise and respond to. Here, this patient clearly and repeatedly tells the team and the wider ward that she is “sore” and needs barrier cream applying. However, because she has repeatedly been assessed as “dry”, it takes time for the ward team to recognise, understand and respond:

The woman in bed (4/6) calls me over with a movement of her hand and tells me, ‘Sore bottom, no cream, sore bottom, no cream...’ repeating this.

I tell her the team are behind the curtain with another patient and I will let them know as soon as they come out. When they do I tell them, and the HCA draws the curtains around her and reports, ‘You are dry.’ This is directed at this woman but also at me and the rest of the team. She comes out from the curtains and goes over to the nurse to discuss her: ‘I think she is clean but this is a constant issue, but I don’t have anyone to help me - she would need rolling, I’m new to this and it’s difficult.’

A bit later they meet again at this woman’s bedside and discuss the cream. They believe she has enough cream because it’s part of the cleansing wipes. They discuss whether this is the right type of cream for her or if it is enough.

Meanwhile this woman continues to plead with them: ‘Please nurse, nappy please....’

The nurse tells her, ‘Don’t worry we will definitely do it.’

[...]

Later during the medication round that day, she repeats her request, her body is now shaking: ‘Bottom sore.’

A nurse who can translate (this patient is of south Asian origin, although throughout she is clearly stating her needs in English) says, ‘She is happy for you to do it (give her the injection required during the medication round) but she wants cream on.’ The nurse and HCA discuss and decide she needs extra cream: ‘I think she is used to having the cream on at home and we use the wipes so she is not used to it.’

The nurse goes to get the cream and returns: ‘Here we go!’

The nurse turns to me: ‘The moisture cream is in the wipes, they are great, but she won’t be happy until we use this cream as well.’ The nurse is very gently and sympathetic, and they both now have gloves

> and pinnies on and close the curtains. and as they do this they tell her again they have the cream. [Site G Ward 14 Day 4]

The distress of visible waste or "wet" and "dirty" bodies was also unsurprisingly a cause of great distress for families.

> A couple come out of a side room (9) and see the nurse and they report, 'She's all wet.'
> Nurse: 'How did that happen?'
> They add, 'She's just woken up and she's wringing wet.'
> Nurse: 'Ok we'll be over to sort her out.' She asks other people in the team for help.
> The family wait outside and the team head in and shut the door.
> After a while the HCA is at the door, gloves on and brings out a red bag full of soiled linen, she talks to the family and they chat for a long time. She is lovely and friendly with the family.
> [Site F Ward 12 Day 27]

> In bay 5-8 the one-to-one carer has been sitting in the bay watching the room, the four women in the bay are all lying in bed and no one has moved all morning. The daughter of 8 arrives, she comes every day to care for her mum who is living with dementia. She comes out of the bay towards me looking incredibly distressed and she says to me in a low voice, 'She is all wet.' The one-to-one carer and I join her at the bedside behind the curtain the sheets that were covering her have been pulled back and the entire sheet and bed is completely soaking. The smell is overwhelming.
> The one-to-one carer asks me to 'watch the bay' as she takes sheets in behind the curtain and offers to help the daughter who looks very unimpressed but says yes. They are behind the screens together for a long time. When they are finished the one-to-one carer drags a number of large heavy orange waste bags and linen bags out of the bay. The daughter washes the plastic wash

> bowl inside and out and then washes her hands, she looks very upset. [Site H Ward 16 Day 20]

The failure of containment strategies could also cause distress to ward staff. Here a student nurse seeks support from a more experienced HCA:

> An HCA heads over to the other more senior HCA in the team: 'We need your help with [side room 3]'
> 'Why? Who is with them?'
> She tells her, 'It's [the student nurse]. Diarrhoea it's gone everywhere all over the floor and we need more pads.'
> The student nurse joins them, she is looking very stressed, 'We need more pads! Diarrhoea everywhere!'
> The senior HCA: 'Do we need to wash her?'
> 'Yes.'
> 'Get a bowl and towels and let's start from scratch.'
> The student nurse gets a bowl and towels and they head into the room, the HCA ahead. The student nurse looks scared, but able to face it with the HCA. [Site G Ward 14 Day 11]

The isolation and impacts of being responsible for continence care

A key feature of discussions with ward staff about continence care was their experience of it as a "heavy" burden, described by all of these ward teams as "heavy" work," "heavy nursing" and a "heavy load", to express the perceived dependency of the patients and the physically demanding nature of this care. Continence care for people living with dementia was also typically described by ward staff as "demanding" and requiring "doubles", two members of staff at the bedside.

> 'It's lack of nursing care, lack of bedside care. Filling in forms rather than nursing, that's the biggest change in the profession. They [patients] are very disabled, very demented, incontinent, it takes time and it's heavy nursing, if you add all these together, it's all about time.' [Site H Ward 16 Day 6]

In our discussions with these teams, nurses typically focussed on prioritising the timetabled care they were responsible for, particularly the completion of the medication rounds, viewing continence care as primarily the role of the HCAs. Here I ask a nurse about the previous day shift where I observed her interrupting the medication round (in many sites nurses wear "do not disturb" red tabards during the medication round, although disturbances may happen in practice) to respond to urgent care requests and to support her team to complete what she describes as "heavy" highly dependent patients and the unremitting "heavy load" of providing continence care at the bedside:

> 'Yes, the drug round there are the 6 rules you have to go through and, yes yesterday I wanted to change my name, there were too many calls! It's so busy and the patients here are heavy so you need help. If there are not enough HCAs, we have to step up and wash and toilet on the ward but sometimes it doesn't allow the nursing role to the gold standard. Toileting - it's a heavy load.' [Site G Ward 14 Day 25]

The HCAs often described feeling abandoned and left on their own with the "heavy load" responsibility of caring for bays of people living with dementia, who needed highly supportive continence care.

> HCA: 'Staffing for the past few days with [HCA colleague] has not been bad. But nurses are bad. We find we are on our own. We struggle with the heavy load. Everyone in Bay 1 is very needy. They are calling for the toilets every five minutes. With commodes and pans I have just done five washes on my own with no help.' [Site G Ward 13 Day 13]

I discuss the shift with a small group of HCAs during their short break and this HCA who looks exhausted (not yet half-way through this 12 hour shift) as she describes her cohort of 10 patients (the majority living with dementia) as including four "doubles" and three who need support at mealtimes.

> We discuss the shift in the little break room.

> HCA1: 'I've done one double and 3 more doubles to do, I have done the rest on my own but then it will be lunchtime and I have 3 to feed'. She sounds exhausted. It is the lunch break and while everyone else eats she doesn't eat or drink anything. She continues 'I have 10 patients, 6 and 3 and a side room. 7 patients - 6 in the bay and 1 side too, it's enough and it means the other 3 (in the next door six bedded bay) get forgotten. 1 into 10 patients does not go! You need 2.'
> HCA2: 'Yes that's why they lose people, they don't want to do it - but we old fogies we just crack on! Sometimes you get held up because there is no one to help you - I have two doubles to do but no one to help. I had one shift where I did the last wash at 7pm, I told the lady she was really patient.' [Site G Ward 14 Day 26]

This also reflects the perceived status of continence care within these wards and within these teams. Within the teams, higher status is defined by those whose role does not involve intimate continence care. Here a ward clerk became agitated when she is required to leave her computer desk at the nurses' station and visit a bedside, while the Dementia Specialist team also delegate this care to the HCA within the bay:

> The ward Clerk is now vigorously washing her hands at the sink next to me. She tells me, 'I'm keeping my head down. I have to engage. But I'm not wiping no one's bum. You know what I mean? I have to engage with families. But I'm not here to wipe bums.'
> [....]
> The [dementia specialist team] has been with a patient in this bay and as she leaves, she tells the HCA, 'She now needs to go to the bathroom.'
> The HCA takes a walking frame and heads to the bedside. [Site G Ward 14 Day 13]

Those outside of the team entering the ward could identify and report when continence care or cleaning was required, but would not consider carrying this out themselves. Here, a member of a medical team enters the ward to examine a patient:

> It has been silent during this night shift, the lighting is dimmed, and no one is around as I stand by the nurses' station. Screaming has started to come from one of the bays. The locked door bangs open and some light enters from the hallway and a Medic in scrubs strides in. We acknowledge each other and she says, 'Interesting night here!'
>
> As she heads into the bay to see the patient [bed 9] we both suddenly see there is faeces smeared all over the floor in the middle of the bay. It is unclear whose it is. After stepping around it to examine the patient she steps gingerly around it and says firmly to me, 'There is faeces on the floor someone needs to clean it up.' She marches off. There are no other members of staff around or in view and she leaves the ward.
>
> A little later the nurse in charge and an HCA are in and out, and both carefully step around it to reach the bedsides. It feels like we are all pretending it is not there. Eventually they identify some more near the sink and the HCA clears it all up. [Site H Ward 16 Day 21 - night shift]

The isolation of decision-making around continence care, assessing who and what to prioritise against the demands of everyday timetabled care, meant that for staff exhaustion and burnout developed over shifts and rotations.

> I chat to the nurse. She is sitting at the small nurses' station by bay 3. There are two huge piles of folders on the desk. On the top of one is a further pile of fresh (but unpacked) continence pads. She is going through the folders and filling the bedside records within the files for both bays 3 and 4 and tells me, 'I am trying to do everything but most of these patients need 2 [members of staff] so I have to go and find an HCA and then someone needs me and needs something and I just can't do it all! It's also so hot!' (The heat in this ward is oppressive and a nurse fainted on the previous day shift). She goes to side room 4 and returns with a disposable bowl covered with a paper towel and heads to the sluice.

> The HCA tells me, 'I have the pad round to do, I have a loose routine in my head and when it goes like this you re-enter yourself (in the routine) at the next person you see ... it's like the patients don't lose out too much because we run around like idiots, so in the long run we pay the price.'
>
> As we talk, we look over to the nurse at the nurses' station who is about to start the medication round and is adjusting some IV equipment. She doesn't look well and the HCA calls over, 'Are you ok?'
>
> She says she needs to sit down: 'But I don't have time!
>
> HCA: 'I will get you some water,' and heads to the kitchen and gets her some water.
>
> When she returns, she then decides between answering the phone and continence pads, looking from one to the other she chooses continence pads. She tells the student nurse to have a drink of water as well.
>
> She opens the bedside curtains and wheels out a commode, the lid is balanced on the seat and there is tissue poking out. As she wheels it to the sluice room, she turns to me, 'People don't understand, but there is not enough of me, I haven't stopped, I think it's an alright day when everyone is ok, but not if someone is poorly.'
>
> The nurse adds: 'When you are doing the drug round and have three people who want to go to the toilet then what do you prioritise!' [Site G Ward 14 Day 16]

Theme 5. Impacts of continence care and pad cultures on recognition of the person and understandings of dementia

In the previous sections our observations revealed that continence care for people living with dementia was viewed as a source of unscheduled, conflicting, and "heavy" care work within these acute wards. Staff must find ways to incorporate continence care within the wider institutional timetables of care delivery, without creating risk (the fear of falls) and without impacting on the pace and schedule of care during each shift and "falling behind". In response, "pad cultures" dominated these acute wards, with a focus on containing continence care to fit the wider schedules governing the organization and delivery of bedside care. In many ways this reduced the act of continence to the biological, the patient producing waste that required containment, removal, and disposal. By conceptualizing continence in this way, the personal impacts of continence care on people living with dementia can remain unrecognized. The expected pace of work could mean ward staff did not always have opportunities to recognise patients' unarticulated and embodied care needs or consider the impacts of routine continence care practices on the person. The impacts on ward staff responsible for delivering this care also appeared unrecognized within these wards and by the wider institutions.

This characterization of the dependency of people living with dementia within these acute wards had wider and significant impacts on the person. These impacts were intrinsically linked to "pad cultures". Placing a person into "pads" and institutional gowns and containing them at the bedside could lead to the reclassification of these individuals and people (living with dementia and older people) grouped together within a given bay or ward area. This could also extend to recognition and understandings of behaviour. Walking to the bathroom could become understood by staff as "wandering", no longer a sign of continence, capacity and capability but a potential risk of "falls" or "absconding" and recognised by staff as a sign of confusion or resistance to ward care. Distress at experiencing intimate continence care from strangers, often carried out in silence or without adequate warning, could become quickly perceived as "aggression". Forms of embodied communication of continence care needs could be viewed as transgressive or as a form of behaviour constituting a feature of their dementia, rather than an expression of underlying need.

Clothing, contagion, and the recognition of "high dependency"

While there was some variation, it was common practice for people living with dementia who were wearing pads (and this often extended to older patients) to also be dressed in hospital-issued institutional gowns (with ties at the back) and pyjamas within these acute wards. These were typically ill-fitting and loose, they were also easily removed and replaced, which aided the use, checking, and changing of "pads" at the bedside.

Institutional gowns were preferred by staff over personal day clothes to improve access to continence technologies. They are another way in which (in)continence is highly visible within these wards, othering older patients, and particularly those living with dementia, from the general patient population. The everyday use of gowns was also a response to the routine failure of pads as a containment technology, which soiled clothing (people quickly run out of clean clothes brought in by family). Thus, the requirements and failures of the pad technology itself, are expected, normalized and prioritized. These practices could become applied to a wider group of older patients within a bay or a ward as they become viewed as equally high dependency.

> Posters in the hall state – '[Hospital] is working to end PJ paralysis- get dressed, get up, get better, get moving.' All the patients in the ward are wearing hospital issue gowns and pyjamas and I have yet to see anyone wearing their own clothes other than a cardigan or jumper over the top of a gown. Only one person has left the bedside today and I have seen him get up and walk to the bathroom, the HCA tells me: 'The only patient who is continent is 22, he is continent.' [Site H Ward 16 Day 25]

This institutional clothing also exposed the body, which meant these "pads" were highly visible as these typically bulky continence could be viewed by all within these wards. Together, the wearing of "pads" and institutional clothing were markers that staff recognised as representing high dependency patients. This could overshadow individuals and their capabilities.

> I note that on the semi-public admissions board 11 of the 23 patients have a flower symbol (representing dementia) attached to them. The Nurse in charge of the ward tells me: '95% of people on here all wear pads, it's just an age thing, this is really a dementia ward, it's general medicine, but it's mainly people who have falls and dementia. Thursday we had 4 one-to-one carers because they were confused, frightened, want to leave, need to be watched. We wanted 4 but only got 3.'
> The HCA adds, 'We have a new lady really poorly and scoring 8, she's ever so confused, she had an accident all over the floor because she's confused, but all

> of them are incontinent, every single one of them and we only have two nurses on so you can't do a lot, because as soon as I have done the washes it's time to turn them and do their pads.'
> The woman in bay 3 (4) has been sitting in the bedside chair all morning. She is wearing a pink hospital gown with a white cardigan over the top and red hospital socks on her feet. She gets the walking frame by her bed and walks steadily across the bay to the bathroom opposite. [Site G Ward 14 Day 5]

Institutional clothing within hospital wards affects both the male and female body, is a significant feature of the presentation of the aging body within these wards, and had a powerful role in reinforcing understandings of people living with dementia.
This further reinforced to all within it that the use of pads was usual practice in the care of people living with dementia, the "ways things are done" within these wards.

These "pad" practices had significant consequences within these wards and at the bedside. We identified processes of contagion and spread in their use in the care of people living with dementia, the recognition and application of continence care, and the category of who was believed to be "incontinent", of "reduced mobility", or "high dependency" patients within these wards. The established routine care practices believed to be appropriate for one group – patients who had a formal classification or diagnosis of incontinence - could quickly become attached to a wider group of people living with dementia and older people within these wards.

This could be exacerbated by common practices of "zoning" or "corralling" patients who share specific attributes (for example by assessments of dependency, condition, age) being placed together within these wards and bays. This often resulted in older people living with and without dementia being cohorted side by side within bays and areas of these wards. Thus, the routine organisational practices and delivery of bedside care believed to be appropriate for one group, could quickly become recognised and applied as standard care for a larger and heterogeneous group of patients living with dementia and older patients aged 65 years and over, but who were understood to be a homogeneous population with similar care needs within these wards.

We found that within these "high dependency" bays, all patients could become placed in continence pads, regardless of their continence status prior to and during their admission. Here discussing continence assessments of patients within what is categorised as a "high dependency" bay, this nurse discusses continence only in the context of the wider capabilities and dependencies of her patients. The mobility of her patients, not being "mobile" or "reduced mobility" is central to her assessments and is associated with the expectation that wearing "pads" was an essential feature of their bedside care.

> Speak to the RN on Bay A. Reading from her handwritten handover notes she tells me about the patients (only asked about 3 and 4) on this bay. She tells me: '3 is usually mobile with assistance from a frame, but vastly reduced at the minute. 4 is really not well, has dementia but also blind, not mobile. 5 has reduced mobility and cognitive function, but the other patients are fine.' She is reluctant to discuss continence, talking around this with mobility. She did not confirm but suggests that 3, 4 and 5 are all wearing pads (I know that 3 is for certain as it has been visible). [Site F Ward 11 Day 16]

Importantly, continence cultures on the wards explicitly extended to the routine and standard practice of using "pads" in the care of people living with dementia, even if they were continent. Here a woman living with dementia was able (with some support) to use a frame to walk the short distance (a distance of approximately three meters) from her bedside to the toilet opposite the bay and back. However, she is still expected by the ward team to continue to wear a continence "pad" at all times. This was observable and highly visible to the wider ward through the open backed hospital gown that she, and the other patients within this bay, were wearing.

> On bay 3 the woman in bed 17 is up and out of bed. As she goes to the toilet, 18 is still on the phone, and 16 is awake, looking across the bay towards bed 18. The nurses' buzzer red light is on above the door of bay 3. The nurses

> have not seen this as they are talking in the corridor besides the nurses' base and the huddle of computer trolleys. 17 opens the toilet door and calls for help. The HCA goes over to her and 17 tells her, 'I got giddy when I stood up'. With the door open, the HCA helps her up from the toilet to her frame. 17 is then able to support herself walking back to her bedside chair. Through the back of her open hospital gown a large clean pad is visible, despite what seems obvious continence and mobility. [Site H Ward 15 Day 16]

It was also a widespread practice for a wider group of older patients to be placed in continence pads, reflecting their routine use within these wards, staff also recognised this did not reflect best practice. Here, this senior ward nurse reflects a widely held view amongst staff within these wards (as we have seen earlier) that "we shouldn't use them" and describes this standard use of pads as something that she recognises, but feels unable to change.

> The nurse in charge arrives. She is very friendly and welcoming. We discuss and tell her about the study. She picks up on continence products: 'I do the order but I tend to under-order the full continence pads because I hate them being used. We use them with the confused patients, the wrap-around nappies, but they shouldn't use them. One woman came in confused and she woke up and found herself in a wrap-around nappy and she was very upset to find she had been put in this. It's one of my bugbears.' [Site F Ward 11 Day 1]

Continence technologies also restrict the person in more subtle ways. They appeared difficult to walk in, given their size and bulkiness, impacting on the person's ability to move. This could mean that patients who were previously independently mobile now needed to request assistance to leave the bedside, and to walk short distances, and support in their application and removal, creating a new level of dependence. These impacts were recognised by staff.

> In the break room discussing continence pads with the HCAs on a break. We talk about the large wrap-around ones and one of the HCAs says, 'They are

> the last resort, they take away their liberty, it's a choice you are taking away.' [Site F Ward 12 Day 17]

Understandings of behaviour – "wandering"

Attempts by people living with dementia to leave the bedside and walk could also be quickly understood by ward staff not as a trip to or a search for the toilet, but as "wandering", a behaviour without purpose, and potentially a feature of their dementia diagnosis. Although as we have described earlier (Site F medical ward above) that there was some variation across wards, leaving the bedside was typically discouraged for this patient group. In contrast, the small number of working age people within these wards were typically able to walk around unrestricted, to use the bathrooms, and to leave the wards unchallenged by staff.

We identified that ward staff would regularly return people living with dementia to the bedside, but rarely considered that this person could be leaving the bedside because they had urgent continence needs. This could sometimes result in patterns of the person being returned to their bedside (or reminded to remain in their bed or at the bedside) multiple times during a shift, which could cause anxiety and frustration for ward teams and increasing distress in the person who was not able to communicate their needs in the way staff recognised or understood.

> Handover is finishing. As staff come out into corridors, I notice the woman from bed 20 quite far down the corridor, walking with the frame. She is 97 and has delirium with suspected (but undiagnosed) dementia and is wearing a large nappy-style pad, which is visible through the material of her hospital gown. A one-to-one carer stands in front of her, saying loudly 'NO, THIS WAY', pointing with her arm back to the bay, her arm thrust out and pointing straight ahead. She calls the patient 'mama', 'no mama, this way'. She does not explain to this patient, just repeats this command. The patient mutters under her breath throughout, turns slightly and walks in the other direction, the one-to-one carer stops her, so she turns and walks to the nurses' station, leaving her frame. She sits down on one of the chairs, then stands and repeatedly tries to climb up on to the desk to sit, while the HCA admonishes

> her, warning that she will fall. The phlebotomist approaches, and takes this woman's bloods at the nurses' station, the one-to-one carer continuing to call her 'mama' as she talks through the process and reassures her. The patient whimpers as bloods are taken, but she does not resist the process. Afterwards she says, 'Oh my *** before muttering incoherently again. The one-to-one carer says, 'Come on, back to your bed' and this time she gets up and goes with her. [...] The one-to-one is still with her, still addressing her as mama, and insisting she stays in her bed. The one-to-one sits with her back to her, updating the bedside records on a computer on a mobile stand at the foot of her bed. [Site H Ward 15 Day 2]

In the instance above the act of leaving the bedside, and "wandering" eventually leads to the patient's needs being recognised and being permitted to walk to the toilet. We observed how these cultures of recognition and responses to "wandering" were deeply engrained. As well as the bodily assertion of leading a person back to the bedside, it was also accompanied with set phrases and commands. This included repeated and contracted commands to "sit down", to "leave things alone", to "stay" in bed or to "turn around". This also demonstrates the restricted understandings of the needs of people living with dementia, rather than a recognition that these patterns could reflect underlying discomfort, urgency or distress for the person or simply a desire to walk.

Reactions to intimate care perceived as "challenging behaviour"

Distress at experiencing intimate continence care from strangers, often carried out in silence, could become quickly perceived as "aggression". These responses could be understood by staff as the impacts of dementia, but also as a wilful disregard for the routines of continence care and essential care more widely within these wards.

Here the team are carrying out routine pad checks in turn at each bedside of this bay and when they reach the second person, they inform her they are going to "check" her "bottom". As they do this, they switch between providing reassurance and instructions to her, to talking about the person, their continence, and decisions about what care is required to each other as though she is not there. This involved intimate care, which, although discussed between these two staff members, is not explained to the patient who is clearly unhappy with this procedure.

> The team discuss (3/2) as they head to her bedside.
> [They use her first name] ‘Shall we stand you? We came to check and make sure you are clean.’ They draw the curtains. ‘Stand up for us [first name], we are going to check your bottom.’ They discuss her as they get gloves and a fresh pad: ‘Will she be wet?’ And they head back behind the screen, saying to her, ‘Sorry darling you don’t like it.’
> ‘She was soiled yesterday, I think they are giving her laxatives, we will probably have to change her.’
> ‘Sit down for us now, well don’t, there you go.’
> ‘It’s definitely from the laxatives.’
> ‘Can you sit back in the chair for me?’
> ‘AAAh don’t put your hand in it.’
> ‘Get more wipes...’
> The HCA heads out taking a large folded pad out to the sluice.
> [Site F Ward 12 Day 21]

Although staff were often very reassuring during continence care, they were also limited by the restricted language used in the care of people living with dementia within these wards. Here, as the nurse in charge meets this person living with dementia to deliver continence care, she focusses on repeatedly reminding her that she is “in hospital” as a way to prepare her for this intimate care.

> The nurse has been incredibly busy. She is the nurse in change and also leads care within this bay. She has been reassuring the woman in 2/1 intermittently all day as she passes her bed, talking to other families, bagging and lugging large bags of dirty laundry through the ward. She gets a plastic pinny and a pad and closes the curtains around 2/1. She is very reassuring and gentle in her tone as she approached the bedside: ‘You are in hospital, you are in hospital, we are not going anywhere.’

> In the background the radio is playing, ‘Now I've had the time of my life, No, I never felt like this before, Yes I swear it's the truth, And I owe it all to you…’ I realise this is Dirty Dancing. As this plays, care continues behind the curtains, everyone is silent in the wider bay apart from a regular sound of snoring from the bedsides.
> [Site G Ward 14 Day 12]

Patterns of distress were notable during the routine bedside rounds of personal care, in particular if the person living with dementia required staff to support personal and intimate continence care. As we have discussed earlier, staff would typically focus on and describe this as checking and changing the “pad”, which was often carried out using restricted language or in silence. However, this did not prepare the (most often female) patients for this intimate contact. This could result in responses to care by people living with dementia which ward staff could interpret as “aggression” or “refusal”, but which could be defensive reactions to unexpected or unprompted intimate contact.

In the example below a patient in her 90s, admitted with a diagnosis of dementia, was observed on a cohorted bay of older women, many of whom also had a diagnosis of dementia and/or delirium. She had been admitted to this bay for several days, receiving one-to-one supervision, imposed due to her “wandering” (the patient was able to walk independently but was considered a fall risk) and her “aggression”, which included punching and scratching at staff. We repeatedly observed staff describing her as “aggressive” during the timetabled rounds of continence and personal care. The example below describes an incident where this does not happen, where in contrast to other observed personal care she had received, the communication used by the nurse throughout clearly lets this woman know step-by-step what is going to happen and what is happening to her:

> With the woman in bed 16 the nurse continues to talk the patient through every step. She is being really clear and focusing on each individual part of the process. There is a real focus on keeping the patient calm and informed.

> ‘I'm going to wash your face’. ‘I'm going to wash your legs’. ‘No, no, you don't want that. It's rubbish’. ‘I'm going to have to change your sheets, we will have to wash your pyjamas.’ ‘Lie down. I have to wash your vagina’. She repeats this three times. ‘Is it Okay? Can you lift yourself up? I'll have to wash your bottom as well. Yes, it's very wet. I'll get it dried off.’ The talking trails off as the wash continues. I'm surprised to hear talking so directly about washing her genitals. Normally this is not described by staff. But in explaining what she is going to do, there's no shock and this patient who is usually quite distressed during personal care, doesn't cry. With the wash finished the nurse goes through the same process to get the patient dressed and back into bed. ‘Just going to put your new pad on. Let's get your pyjamas on’. When this is finished the curtain is drawn back and the patient looks comfortable and appears to be falling asleep. [Site H Ward 15 Day 12]

The language of staff within these wards to describe body parts was so significant (see above), that when anatomical terms were used it was striking. In this example, it is notable that when the body part was explicitly named, a patient previously identified by ward staff as highly “aggressive” during personal care appeared able to recognise what the nurse was doing and why, and fully cooperated with intimate care that had resulted in distress and resistance on prior occasions. However, more commonly the challenges of communicating continence needs and the resulting distress, could be observed amongst both people living with dementia and ward staff.

Chapter 8: Discussion

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This study aimed to deliver detailed understandings of the everyday practices and impacts of continence care for PLWD following an unscheduled admission within the acute hospital ward setting. Utilizing ethnography permitted examination of those details of everyday life within acute wards previously unexamined within the literature, and the seemingly hidden and undiscussed activities and phenomena of the hospital ward, while placing them within the wider context of everyday care. We were able to examine the "hidden mechanisms"[119(p377)], the organizational infrastructures, and rationales embedded within the technical and procedural work of continence care, as it was delivered within these wards, and how ward staff account for and make sense of the continence needs of PLWD, how staff respond to and rationalise these needs, and the consequences of their actions over time. We have presented findings which provide an original, detailed understanding of the social and institutional forces that shape and influence everyday organisation and delivery of continence care within these acute wards for this significant patient population.

The use of ethnographic "thick description" in presenting our detailed empirical findings permits the reader to develop a strong connection to the social worlds of these wards. We shine a light on the multiple nuanced, complex, and skilled, everyday interactions involved in the practices of continence care carried out by ward staff, predominantly nurses and HCAs, within them. Our detailed analysis provides understandings of the complex social relations occuring within these wards, and the ways in which the organisation and delivery of continence care at the bedside connects closely with and is informed by wider institutional expectations, policies and priorities,[122] which, in turn, shape the personal impacts of continence care for both PLWD and ward staff.

Our analytic goal was not that of “representation” or “comparison”, but rather one of “identification”: to reveal the social processes underpinning and informing the everyday practices of continence care for PLWD within these acute ward settings. This allowed us to identify the significance of continence “pads” in shaping the cultures of care for PLWD.

Within this report we have focussed on presenting our analysis on continence “pads”, the most common and ubiquitous continence product within these wards, widely used in the everyday bedside care of people living with dementia, with significance in informing wider cultures of care for PLWD within this setting. These products both produce and reproduce cultures of care in the organisation and delivery of everyday continence practices. They also have wider impacts, particularly for shaping staff understandings of dementia as a condition, the recognition of the needs of PLWD within these wards, and their status within the organisational and wider institutional priorities.

The “pad cultures” identified within these wards emphasised the routine use of continence “pads” as a precautionary “just in case” strategy, a “safeguard” preventing but also containing “accidents” or incontinent episodes at the bedside for PLWD admitted to these wards. Their use was often regardless of independence, mobility, capacity, and functionality. Importantly, we identified processes of contagion and spread in the recognition and application of this category of patient, which meant that this practice typically informed care for a wider group, including not only those living with dementia recognized as continent, “mobile”, and “self-caring” but also the large numbers of older people also within these wards.

This strategy was recognised as routine across these wards, legitimising care practices with real and significant consequences for the dignity, rights, and outcomes for PLWD, and their status in the wider cultures of care within these wards. “Pads” were transformed beyond a precautionary strategy into a routine feature of continence care. In turn, this allowed the practices to support maintaining continence (particularly mobility, walking to, and support to the toilets within these wards) to become deprioritised, no longer expected or required of the PLWD. Instead, there was an expectation (often explicitly stated by ward staff, but also embedded within other routine timetabled care practices at the bedside) that the person not only wear the pad, but that they could and should use the pad. This strategy was a feature of continence care across all of these wards, and could become a feature of care regardless of an individual's continence, independence, or preference.

The timetables of the ward and bedside care are critical here. Expectations of maintaining the daily organizational timetables of bedside care were powerfully felt, a palpable source of tension amongst nursing and healthcare staff. An underlying anxiety of "falling behind" during shifts was frequently discussed and universally feared. The development of these "pad cultures" does not represent a malicious act or poor care on the part of ward staff; rather a solution or "workaround" to complete the (both perceived and expected) pace of work, the institutionally mandated timetabled "rounds" of routine and essential care, and the associated recording and monitoring practices at the bedside. The use of pads as a precautionary and containment strategy was not only in response to a person's incontinence or their inability to independently walk to a toilet within these wards, but was believed to be necessitated by organisational constraints. The timetabled organisation and delivery of care during shifts appeared not to allow for urgency of continence care needs to be prioritised by staff over other routine care or the associated recording practices. In turn, this organisational strategy acted to create urgency by discouraging people living with dementia from leaving the bedside and walking to the bathroom. Similarly, the use of pads as containment mean that incontinence or "accidents" could remain undiscovered or concealed on the person and at the bedside until the timetable allowed.

Ward staff described these approaches as being the only way they could function; to complete the timetabled routines of care and its recording practices, there were reduced opportunities to respond or to prioritise urgency and the unpredictable and significant care involved in supporting the continence needs of the large numbers of PLWD within these wards. This informed understandings, expressed by staff across these wards, that this approach to the continence care for people living with dementia was both legitimate and institutionally mandated. Many ward staff did recognise the significance of these approaches and the potential for the rapid deconditioning of PLWD, but did not see as possible other ways of working that supported continence and independence. This rationale was expressed to the research team, and also by staff in their justifications to each other, in their explanations and rationalisations to PLWD, and to their families at the bedside.

Here other institutionally mandated priorities arise. The reduction of risk, particularly, for this patient population, of “falls”, was deeply embedded within the rationales supporting pad cultures. This risk is legitimate for many PLWD; however, staff were not simply motivated to reduce this risk for its own sake, but were universally fearful of the sanctions (for the ward and for themselves) of a person living with dementia falling whilst in their care. Thus, containment at the bedside, through the use of continence “pads”, saw continence care transformed into a form of restrictive practice within these wards, lessening perceived risk by reducing or eliminating the requirement to leave the bedside, at the expense of, or despite of, the preferences and needs of the person. Within these wards (although we identified notable exceptions to this) a PLWD independently trying to get out of bed or walking to the bathroom (including using a walking frame) could provoke high levels of anxiety in ward staff and was a form of independence that was generally discouraged and often forbidden.

This ethnographic study has revealed that continence care represented a significant and central aspect of care work for staff within these wards. A key feature of discussions with ward staff about continence care was their experience of it as “heavy nursing”. As a “heavy” burden, and a “heavy load”, they expressed the physically demanding nature of this care, but also the experience of feeling abandoned and of being isolated with the responsibility of caring for large numbers of people living with dementia, who required highly supportive care. They were further isolated by the perceived status of this care work. Much has been written about continence care and its status within nursing.[66] Within these wards, continence care was typically invisible to teams and services entering these wards, viewed as low status work to be delegated to others, and of little consequence to the experiences and outcomes of their patients. As we have already stated, ward staff were aware that the continence care strategies of these wards did not reflect the care they wanted to provide to their patients. However, more widely, there were no indications within these wards and their cultures that continence care was recognised by these institutions as critical for care quality and with significant implications for the individual PLWD in their care.

Time is of significance here. Continence care that supported the independence of people living with dementia was often viewed as taking "too long", a source of delay that could impact other routinized timetabled aspects of bedside care. Our synthesis[140] identified the difficulties of communicating continence needs and the importance of healthcare staff having the time to recognise and respond to the non-verbal and affective cues people living with dementia may use to convey their need; however, these "pad" cultures included the requirement of "permissions". Strategies of containment, and the requirement for continence care to be carried out at the bedside, in turn, also generated significant care needs and care work. As we have described, the large wrap-around continence pads typically used within these wards regularly failed in their primary purpose; pads leak, smell, and can damage skin. This meant they not only required removal and replacement, but also significant personal and intimate care including support with the personal care of undressing, washing, changing clothes, and changing sheets. For staff, this involved repeated trips to linen stores and sluice rooms, often located far from the patient's room or bay. This also required care that was far more personally invasive than if the patient had been supported to the toilet, invasiveness which routinely created significant distress in the person. In addition, even the use of pads in the care of people living with dementia who were assessed as "mobile" and "self-caring" created care work. The bulky nature of the wrap-around pads and the dexterity required to change and replace them meant that PLWD (and also included many older people without a diagnosis of dementia) required additional support in walking to toilets and in changing pads, which in at least some cases would not have been needed.

The pace of care at the bedside (expected and perceived) meant that the independence and autonomy of PLWD could become a reduced priority. Where staff perceived that they were "short" (understaffed) or were "falling behind" with the wider timetables of bedside care, the opportunities for patient independence became reduced and a reliance on the use of "pads" became further prioritised. At these junctures in shifts (we found that this typically occurred at some point during almost every shift), patterns of prompting and the procedures of assisting a PLWD to use a bathroom could quickly become perceived as too time consuming, and as clashing with and potentially delaying other institutionally mandated timetabled tasks of care (this included the observation, medication rounds, and the timetables of other teams, for example the arrival of medical teams or mealtime deliveries). While staff within these wards discussed and recognised the importance of providing care that supported independence, at these points in the shift, these routines could become "tightened"[52,124] and reduced to the use of a more limited range of (verbal and physical) techniques and approaches with a focus on increasing their efficiency, with pads used to contain both continence and the PLWD at the bedside. Instead of "prompting", "pad checks" or a reliance on containment came to the fore until the timetables permitted attendance to continence care.

This "tightening" also created its own forms of continence routines and rituals within these wards: the routines of "prompting", "pad rounds", and "pad checks", where ward staff (typically HCAs) prompted continence and "checked" whether "pads" required changing at points during shifts. In practice, within these wards these routines appeared to have transformed from "prompted voiding", an established approach combining a schedule to support toileting, with "prompting" from healthcare staff or carers for people with cognitive impairment[183] into more limited routines and practices at the bedside. These routines reduced opportunities for flexibility and for staff to see and respond to an individual's urgency. They also appeared to have transformed into the far more restrictive practice of "pad checks", which emphasised the centrality of checking and replacing continence pads at the bedside. “Pad checks” could also become a more sporadic and ad hoc practice, which could be interrupted or stalled during shifts once staff perceived they were at risk of “falling behind”, or could be prioritised and become viewed as only possible during “quiet” points in the shifts. In this way continence care often became transformed and reduced to containment practices and the “checking” and replacing of soiled or wet pads as part of other scheduled activities during a shift.

When ward staff attempted to fit the urgent continence needs of a PLWD within the timetabled order of bedside care, this could lead to significant patient distress, either through difficulties in recognising care needs and responding to urgency, or through the level of intimate continence care required. There also appeared to be little recognition of the urgency or distress for the person of being unable to reach a bathroom, being unable to avoid using a continence pad, or of wearing the soiled pad, and their immediate needs or the practical considerations once a person had “used” or soiled their pad. Importantly, such distress could also become viewed as a feature of a person’s dementia, and cause distress for family members and visitors. Our synthesis identified the significance of healthcare staff attitudes to continence care and incontinence.[140]

By reducing continence care to these forms of prompting and checks, this overlooked the important opportunity that continence care provides for staff to provide wider supportive care and comfort to the person, care and comfort which also requires time to see the person and to support their wider needs. Our synthesis[140] also identified the importance of language, and the need to incorporate interpersonal and communication skills into the context of continence care within training for those working with this patient group as crucial for continence to be maintained during an acute admission. Despite its apparent centrality within the everyday work of these wards, continence care for people living with dementia (and older patients) was often carried out in silence, or with staff using a restricted repertoire of language to communicate continence care and to explain and describe the intimate care that was happening or about to happen. The naming or failure to name body parts, in particular genitalia, bodily functions, urine and faecal matter, the naming and description of continence technology, and the language and etiquette of communicating continence needs, during personal care for people living with dementia (and older patients more widely) was notable. Some aspects of continence care were not discussed at all, or only by using humour, while others were talked around, or euphemisms used in their place. Importantly, there was little evidence that staff were able to check the person's comprehension or vary language to suit the individual.

Robustness of the results and limitations

This study set out to explore and establish how ward staff account for and make sense of the continence needs of PLWD, how staff respond to and rationalise these needs, and the consequences of staff actions over time. As a result, we have presented findings which provide an original and detailed understanding of the social and institutional forces that shape and influence everyday organisation and delivery of continence care within these acute wards for this significant patient population.

By collecting 180 days of observational data across 6 acute wards within three hospital sites, which included a range of institutions, geographies, and patient demographics, we were able to respond to the potential limitations of transferability. This long-term ethnographic engagement with these ward settings meant we were able to move our analysis beyond singular incidents and a descriptive account, to build up an analysis, grounded in the observations, that allowed us to achieve a theoretical interpretation of the data to deliver understandings of the cultures that shaped and reshaped the practices of continence care and the wider care of PLWD across these institutional settings. While the staffing, teams, technologies, expertise, and interventions to support PLWD, varied across sites and wards, within these ward settings the organisation and delivery of continence care, the prominence of "pad" technologies, and the "pad" cultures identified within this report, remained relatively stable within them, as embedded practices of everyday bedside care for PLWD.

As a complex and highly sensitive topic, our aim in using ethnography was to access the unspoken and tacitly understood[110] aspects of everyday continence care, an approach that enabled us to take into account the perspectives of ward staff, patients and families, and wider clinical and hospital staff[108,109] within these acute wards. However, as experienced ethnographic researchers, the team working within these ward settings were also acutely aware of the potential for the presence of observers to influence practice and contaminate data. Prior to the research we did consider the potential for the Hawthorne effect or "participant reactivity" and acknowledged that staff behaviour may be changed by the researcher's presence in the wards.

In response, based on our prior research within acute wards[105] our design included extended periods of observation within each ward, with each individual ward setting observed for 30 days over eight weeks, with periods of observations lasting from two to six hours. This timeframe meant staff became used to the presence of and developed relationships of trust with the researchers (KF and AN), which we hoped mitigated for the potential for observations to influence practice[184]. However, we recognise that the behaviour of the teams and individual members of staff working within these wards may have been changed by the researchers' presence within these wards.

Of course, it is not possible to eliminate the impacts of the presence of observers and a key strength of an ethnographic approach is that any performances observed, however staged or influenced by the researcher presence, can reveal critical insights by displaying how people see themselves and how they want to be seen.[184,185] Our grounded theory approach meant we carried out theoretical sampling *within* these ward sites and this also enabled us to focus on the representativeness and consistency of events and concepts, rather than individuals and people. We observed multiple rotations of staff, patient admissions, and events within these wards, that had the potential to influence care delivery, in order to identify and understand everyday practice. In situ ethnographic interviews with staff, PLWD, and their families, also provided the opportunity to test and refine our analysis during observations, in line with our grounded theory approach. This reflects a key strength of ethnography, and remedies a common weakness in many qualitative studies, that what people say in interviews may differ from what they do or from their private justifications to others.[126] These approaches were central to collecting high quality data, to achieve methodological rigour, and theoretical interpretation of the data.

As can be seen within the results presented, during our extended engagement within these wards, PLWD (and older people within these wards) would frequently tell us that they wanted to go to the bathroom and asked for support, and more widely, often shared their concerns (frequently not related to their admitting condition or present comfort but instead about loved ones, possessions, family and pets, or how they would afford to pay for their food or their care). The research team (with patient consent) would inform ward staff of these concerns. The researchers were often the only person present on or around these wards for uninterrupted periods of time. As a result of this sometimes, when ward staff were not present or able to be called quickly to a bay, we provided immediate support and help. For example, if we observed a patient placing themselves immediate risk of falling, injuring themselves or leaving the ward, we would call staff or, if necessary, intervene to protect the patient. Although we accept that this may have, on occasion, contaminated the purity of this research, the welfare of the people within these wards was always our priority.

Practical limitations presented themselves throughout the research. As a result of the ethics and governance permissions granted to the study, the team were unable to follow or track patients once they were transferred to other sites within these hospitals. This was mitigated by the inclusion of MAU units (where people are admitted for assessment and are either discharged or transferred elsewhere) and general medical (“Care of the Elderly”) COTE wards (which typically have additional support and services within them for people living with dementia), which enhanced the potential for data collection to include people living with dementia at admission, following transfer, and at discharge, and to support the ability of the study to explore whether there were variations in the organisation and delivery of continence care PLWD received across these acute settings.

Similarly, the researchers could observe and take fieldnotes for only a limited number of hours and shifts at each site. It was rarely possible for the researchers to continue observations within the wards for extended periods required to see a patient's response to and the impacts of continence care over the entire period of a shift or their admission. It was also not uncommon to arrive at a ward and be told that we had missed an incident. However, these incidents and events often represented the extraordinary, and not the everyday practices and cultures we wanted to explore. They also reflected that, while staff knew of the purpose of our research and our goal to improve care, they often misinterpreted the context of our observations and data collection.

A significant limitation of this study, that could not be predicted at the time of data collection and analysis, is the outbreak of Covid-19 during the production of this report. All data was collected between October 2018 and October 2019. It therefore reflects everyday acute ward organisation, culture, and practice prior to the outbreak of the Covid-19 pandemic, and the resulting changes to the delivery of care. Due to infection control measures, the researchers have not conducted any observations during the pandemic and cannot say if the measures taken to control the spread of Covid-19 within these wards has changed the ways in which continence care is delivered or that continence needs are met for PLWD.

Recommendations for future research

We had hoped to explore whether continence care was further impacted by the intersections of gender, race, and ethnicity[84] within this study. We have identified some complexities in continence care and its impacts and interactions with gender (this will be published separately). We did include the experiences of people within Black, Asian and minority ethnic communities who were living with dementia within the data collection and did explore these individual experiences of care to inform our broader analysis. However, to bring the experiences of the small number of individuals from diverse communities together within our analysis lacked methodological rigour. We do not want to further contribute to the longstanding "black box" research approach of grouping the experiences of individuals from diverse communities together, which has been widely critiqued.[186–188] Although research in the field has provided generalised understandings, it has yet to adequately address the specific needs of diverse populations[186,189] who are also living with dementia. We believe research is required that focusses on the experiences of specific communities and that explores the complexity of intersectional experiences of living with dementia. We are currently working to support researchers to take the lead in this research.

Our findings indicate a pressing need for a programme of research that examines the timetabled organisation and delivery of task-based routine bedside care carried out by nursing staff and healthcare assistants. The modern hospital is typically represented as a site of great technological advancements. However, there was typically little evidence of new knowledge or interventions within these acute wards, nor of their use in the organisation and delivery of care or in informing care at the bedside. The routine and timetabled practices of bedside care work do not appear to be recognised or valued, have remained relatively stable and constant in their mode of delivery, and remain relatively unexamined. A programme of research is required to deliver the evidence base needed to inform the timetabled organisation and delivery of care and care cultures for these seemingly invisible routines of care work delivered to significant populations of vulnerable acute older patients, care work which has powerful impacts on both experiences and outcomes of people living with dementia (and older people) within the acute setting, including the potential for deconditioning, iatrogenic impacts, and longer-term impacts including place of discharge and mortality.

Review of evidence and implication for decision makers

- Ward staff expressed the experience of feeling abandoned and of being isolated with the responsibility for continence care and for caring for large numbers of people living with dementia, who required highly supportive care. In response, we urge greater recognition institutionally of the importance of continence care as dignity and essential care work, which has significance not only for clinical outcomes, but also for the humanity of care, and for the personhood of PLWD, and other vulnerable populations within the acute setting.
- Training and resources are required to support ward staff, and hospital staff more widely working across the acute setting, to talk about the body, its management, and intimate care and care needs to people living with dementia and older people during an admission. Training in communication and in the interactional expertise required at the bedside, must reflect "work as done" rather than "work as imagined" and recognise and respond to the discomfort for staff across the acute setting in discussing body parts, processes and the practices surrounding intimate care, particularly with older people.
- The education of continence care is not a significant part of the undergraduate nursing curriculum, which typically does not provide "skill-based teaching", for what is widely perceived to be a practical routine task to be learnt predominantly at the bedside during clinical placements and within practice. This produces and reproduces current cultures of ward care as standard practice rather than delivering evidence-based training in a significant aspect of care within the acute ward setting, and which, as we have presented in the findings of this research, can have significant impacts on both PLWD the ward staff caring for them. The results of this study indicate there is an urgent need to invest in the development and delivery of evidence-based nursing education in continence care and in the care of PLWD in the acute setting within nursing education.
- Within this study, staff often expressed the view that although they wanted to support their patients' continence, they believed it was not possible to work in other ways. NHS organisations need to support wards and ward teams to develop ways of working, particularly the organisation and delivery of bedside

care for people living with dementia that supports continence, that responds more flexibly to their care needs, and their mobility and independence more widely.

- The reduction of risk for this patient population, particularly of "falls", was deeply embedded within the rationales supporting "pad" cultures. This is a legitimate risk for many PLWD; however, staff were not simply motivated to reduce this risk for its own sake but were universally fearful of the sanctions (for the ward and for themselves) of a PLWD falling whilst in their care. The NHS and hospital institutions must recognise that the introduction of such policies and the associated sanctions can have unintended consequences on care cultures. Institutions need to monitor whether these policy interventions are informing the cultures of care within acute wards, in what ways, and with what consequences.

Outputs and dissemination

We are using this research to develop and deliver outputs focussed on service organisation and training staff within the acute setting. In response to COVID-19 restrictions we focussed our attention on delivering outputs that informed policy and connected with and developed networks of practice, taking full advantage of remote methods to offset access difficulties.

To inform policy, we have worked with the Welsh Assembly Government. KF attends the Welsh Assembly Government Cross-Party Group on Dementia, having been invited to join in March 2021. Study findings have **contributed to the Cross-Party Group report into Hospital Care for People living with dementia**, to be published in 2021. KF is also a member of the **Dementia Partners National Steering Group, Welsh Assembly Government**, chaired by Innovate Cymru, Public Health Wales, and contributes directly to the Dementia care programme to improve care in Wales. PB has been appointed as a member of the **European Commission Committee's** Atomium European Institute AI4People 2020 Committees, including the Committee on Healthcare, making recommendations on the implementation and deployment of Ethical AI within the healthcare sector. Our NIHR research directly informed and is cited within the national **Wales Safeguarding Procedures for children and adults at risk of abuse and neglect**, published April 2020.

The team have presented the study to a wide range of audiences, with invitations to speak to acute clinical staff, allied health professionals, people living with dementia and academics nationally:

- The East Midlands Dementia Education Day, Dec 2021.
- Continence Team, Aneurin Bevan University Health Board, October 2021,
- The All Wales Inpatient Falls Network, November 2021
- The Clinical Board of Dementia Champions, Cardiff and Vale University Health Board, July 2021,
- NIHR ARC North Thames and the Centre for Health Care Innovation Research, June 2021
- Alzheimer’s Society, Dementia Action Alliance and Public Health Wales event to support the Dementia-Friendly Hospital Charter (Wales), March 2021
- Framing Ageing: A Clinical, Cultural and Social Dialogue, Trinity College, Dublin, March 2021
- East Midlands Medical Sociology Group, British Sociological Association, Feb 2021
- The Salford Institute for Dementia, March 2021
- Wales international conference *Advancing Dementia Care Cymru*, a collaboration between Public Health Wales Improvement Cymru, The Royal College of Psychiatrists (Wales) Old Age Faculty and key partners from across Wales, Feb 2021
- Medicine, Science and Culture Group, Cardiff University, December 2020,
- Centre for Research in Communication and Culture Seminar Series, Loughborough University, Nov 2020
- 3 Nations Dementia Working Group - Our experiences of hospital care during a pandemic, Nov 2020
- World Hospice and Palliative Care Day event, De Montfort University, Oct 2020

A primary research goal was to update existing ward-based recommendations for models of care and the organisation of nursing and HCA care work to ensure support for the quality and humanity of continence care. This includes integrating continence care within existing risk assessment (falls), rehabilitation strategies and discharge planning. In response, we have worked with key dementia care, clinical, and policy networks to deliver new knowledge that has informed and contributed to:

- The development of **the Dementia-Friendly Hospital Charter** (supported by Welsh Assembly Government). The Charter sets out the standards for all hospitals in Wales to create dementia-friendly environments for people living with dementia, their families and carers. Its purpose is to focus on improvement and support the embedding of the dementia-friendly principles in hospitals. KF was a committee member and invited to present the research, to inform the discussion of what is required to improve care for people living with dementia in the acute setting, with the Charter drawing directly on this NIHR research.
- Presentation and discussion with the **All Wales Inpatient Falls Network**, Nov 2021. The goal is to develop awareness of the role of risk management and policies in ward cultures of continence care for people living with dementia
- Presentation and discussion with **Clinical Boards and Dementia Champions** to discuss ways to improve continence care within acute wards.
- Presentation and discussions with the **Executive Director of Nursing, Associate Director of Nursing and Continence Team, within a participating Health Board**. We are working together to develop and deliver training to support ward staff using an Improvement Collaboratives Approach.
- Presentation and discussion with the **Welsh Ambulance Service** and the Mental Health and Dementia Steering Group to discuss risk assessment, how to prevent inappropriate hospital admissions, and improve ambulance environments for people living with dementia, March & May 2021.

A further goal was the identification of factors in organisation and ward culture (practices, routines and interactional styles) that can improve or worsen the experiences and outcomes of PLWD who have continence needs. This may include approaches to facilitate the integration of key elements within handovers, observation rounds. In response, we have:

- Worked closely with one of our participating NHS sites to collaborate with and support the continence team. The R&D Director has recognised that the team and this NIHR research has "*supported nursing leadership around dementia care within our acute hospital care settings [which serve a population of 600,000] and promoted the research culture and capacity within our organisation*".
- We have collaborated with Dementia UK and Admiral nurses. Dementia UK's Head of Research has communicated that the team and this NIHR research "*have been particularly influential in helping us to refine the Admiral Nurse 'offer' in supporting the acute sector to deliver person-centred care … the numbers of acute care partnerships we have are increasing exponentially as a result*".
- We have also supported individual Dementia Specialist Nurses working in the acute setting, providing remote support via email and Zoom to support the development of organisational interventions to improve care for PLWD within the wards.

The research team are in discussions with Dementia UK to establish a community of practice focused on the care for people living with dementia within the acute setting. These networks and individuals will be invited to join when this is launched in 2022.

A goal was training to support continence care for people living with dementia targeted at acute staff (nurses, HCAs, AHPs), carers and families, which will include organisational and interactional techniques that facilitate the quality and humanity of continence care. In response, the findings of this study are already influencing practice:

- As a direct result of the research, Public Health Wales Improvement Cymru and NHS Cymru, invited KF, AN and JH, to design and deliver a training program for all seven NHS Health Boards in Wales. This was accompanied by training for nursing and ward staff from three NHS Trusts in collaboration with Dementia UK. Pilot training took place within one Health Board in November 2019. Nine further sessions were scheduled to take place from March 2020 onwards but were postponed due to Covid-19.

- In collaboration with NHS Health Boards in Wales and NHS Specialist teams in continence care, the research has directly contributed to and is cited in the development of the NHS e learning module "Continence". This will be available to all NHS staff via the Electronic Staff Record portal for Wales. Prior to our involvement this did not contain any specific advice on continence care for people living with dementia or the interactional or communication skills required.
- Masterclasses (via video and factsheets) were held for hospital staff on continence care, decision-making and management for PLWD, integrated into undergraduate Nursing and AHP curricula.
    - 3 hour masterclass, on Dementia care, patient safety, and risk, postgraduate nursing module, Cardiff University, Nov 2020.
    - 3 hour masterclass "Caring for the person with dementia in acute settings" for undergraduate nursing students (first year), Cardiff University, Dec 2020.
    - 2 hour masterclass Ageing & Health (360 third year undergraduate students) DMU Health and Wellbeing in Society programme.

Capacity building

The researchers believe the potential for impact from this study, improving continence practice, continence awareness, and the experience people living with dementia have during a hospital admission, is significant.

- Discussions are underway with Innovation Cymru, Public Health Wales, Dementia UK, and members of acute hospital trusts in England and Wales to use the study findings to pilot interventions to improve continence care.
- KF developed and coordinated **a training network to support ECR and mid-career academics working in the field of dementia research** via the NIHR

Portfolio Development group (NIHR funding). A series (2019 - 2021) of monthly on-line workshops delivering research training and mentoring to a cohort of 12 ECRs, **evaluated highly** by participants. In response, Alzheimer's Research UK have contacted KF, leading to ongoing discussions of how to build on this initiative and expand its reach to develop a larger programme of capacity building to support the development of ECRs working in the field of dementia research. In addition, KF was invited to present the programme to The Dementia Research Funders Forum (DRFF) (Jan 2021).

- Developing a research network with leaders in the field of continence care and dementia, which includes international collaborations with colleagues in Australia, New Zealand and Finland to build on this study with further research and publications, currently in development.

A publication strategy is in place following this report, which will target high impact journals in nursing, sociology and dementia:

- Theoretical developments from this research are expanded on within *Wandering the Wards: An Ethnography of Hospital Care and its Consequences for People Living with Dementia,* authors KF and AN (2020). This open access publication has remained in the top 10 anthropology books on the Amazon Kindle store since publication, and was shortlisted for the 2021 Foundation for the Sociology of Health and Illness Book Prize (https://bit.ly/3DbqS7d).

Chapter 9: Patient and public involvement

Patient and public involvement was central to and integrated within all stages of this study and our overarching goal was to ensure we included a wide range of experiences of living with the condition, which includes supporting those who are often under-represented in research or who may find verbal communication difficult. We were also aware that the experiences of people living with dementia and carers may be very personal and have often been silenced, with traditional research methods or public consultation approaches, in turn, eliciting emotions that can be hard to express. In response, to support involvement we employed four interlocking and integrated approaches:

1. Working closely with our Carer Steering Group and Study Steering Group, which included PLWD and carers to facilitate regular involvement in the direction and governance of the research.
2. Organising large scale consultation events attended by 60 people living with dementia and carers (Cardiff in 2018 and 2019) to involve PLWD and family carers in regular discussions about the direction of the research, the analysis, and development of the findings, and through regular discussions with the researchers and the wider team.
3. Participants engaged in an arts-for-health enquiry where they collaborated with an artist to produce creative pieces (25) reflecting their personal experiences of being in hospital or caring for someone with dementia who has been hospitalised, and the opportunity to record their stories (n=7) on camera in collaboration with filmmakers to raise awareness through sharing their personal stories.
4. We delivered five engagement events in Cardiff, which involved 80 older people and people living with dementia from within ethnically and racially minoritised, LGBT, and disability communities, to discuss dementia care and involvement preferences in the research. We also developed collaborative relationships with organisations with a specific remit to support communities living with dementia who are often excluded from research: Diverse Cymru, Alzheimer’s Society,

> Women Connect First, British Deaf Association, Downs Syndrome Association, Action on Hearing Loss, Stonewall Cymru, the Mentor Ring, Nubian Life and the Sub-Saharan Advisory Panel. The PI lead (SV) also conducted 20 in-depth interviews (face to face, telephone or zoom) to explore the experiences of people living with dementia as well as those of their families and carers.

Across these activities, key experiences and concerns for people living with dementia and family carers were identified:

Continence care: Ward staff were described by participants as expecting all PLWD to be incontinent. A significant belief across these groups was that people living with dementia who were previously continent, became incontinent as a result of a hospital admission, and that this was caused by these assumptions and the clinical care they received during an admission. During the workshops, a carer tells her story through the collage to depict the obstacles her mother faced regaining mobility and self-care during her last stay in hospital. The groups strongly believed that these approaches to continence care was a result of poor staffing and high staff turnover within acute wards caused by NHS funding cuts. Carers also reported a lack of dignity in the continence care provided to people living with dementia, with continence care for this patient group witnessed as public and visible to others within the wards.

Discharge delays: The groups described that becoming incontinent during an admission had long-term implications for the person, for the organisation of their social care support, and for their opportunities to return home. Carers were key advocates in the discharge of people living with dementia from hospital, however, they expressed frustration at how long this took and how much pressure was required to get a relative living with dementia discharged. During the workshops, one carer described how her mother believed she was in an asylum whilst in hospital and her delayed discharge was likened to the transition from darkness to light, to going from the “mess and tangle” of “hell” back to a luxurious “feather bed” of home surrounded by the warmth of those who knew and loved her.

The experience of stigma associated with a diagnosis of dementia: Participants spoke about the invisibility of living with dementia as both a physiological and social experience. Hospital staff were described as not seeing the person but instead labelling patients by their condition "dementia". Carers reported that staff responses to a diagnosis of dementia included giving memory tests (Montreal Cognitive Assessment - MOCA or mini mental test) to the person when they were acutely ill, while other acute admitting conditions remained undiagnosed or diagnosed late. One carer noted that ward and medical staff assumed all symptoms were related to a person's dementia, which meant other common conditions such as sepsis and delirium remained undiagnosed. Within the workshops, experiences of depersonalisation and invisibility of the person living with dementia during an admission were depicted in black and white drawing to represent the loss of identity within institutions and a family carer shaped her creative piece to resemble a form of loudspeaker, covered with the phrases she heard repeated by her mother's during her hospital admission: "What are you doing to me", "HELP!", "What do you want?" and "Where am I?".

Communication: Once a diagnosis of dementia was discussed, the groups believed this overshadowed all interactions. Within the workshops a PLWD created Empty boxes? look inside..... to reflect his experiences of ward staff seeing only his dementia diagnosis and to emphasise his individuality "These boxes might look the same, but people are very different from each other. Don't put me in a box because I have a label of dementia". People living with dementia felt that their diagnosis meant they were treated with less respect compared to other patients, with staff spending less time explaining procedures to them and instead continued with care delivery without taking time to introduce or explain procedures to the person. Ward staff communication with people living with dementia were described by carers as emphasising prohibitions and reinforcing what they were not allowed to do. Carers also reported a lack of awareness among ward staff that PLWD often communicate non-verbally, which meant ward staff did not recognise or respond to non-verbal cues indicating underlying care needs. The therapeutic value of touch was identified as important but lacking in the acute setting. Within the workshops a man living with dementia chose an image depicting a hug to represent supportive care, while a family carer traced her own hands with blue chalk, writing around it "hands in dementia provide, assurance, comfort, safety, security, friendship and stability", and she became visibly moved and emotional, as she described its significance to the wider group.

Restrictive practice: During his admission, one man living with early onset dementia described the experience of observing ward staff regularly shouting at another patient living with advanced dementia, which made him fear for the future. Carers also believed there was an overuse of antipsychotic medication in the care of people living with dementia during an admission because it suited the hospital environment, rather than reflecting a person's medical need.

Feelings of fear and vulnerability during a hospital admission: Overall, across the groups there was a lot of fear about hospital admissions. One person living with dementia described feeling very scared and vulnerable during her admission, and when her husband could not visit and there was nobody to talk to, staff would not spend time with her or comfort her, even when she was crying. Across these groups, carers raised significant concerns and fears about what happened when they were not there. A carer described their fear of witnessing screaming behind closed doors and finding bruising on their partner living with dementia during an admission. Creative pieces during the workshops reflecting these feelings included a woolly string placed in a pile in the middle of the paper with the description "Life all tangled up, Trying to cope, A mess", while a ballpen drawing of a rose reflect the vulnerability and helplessness experienced by people living with dementia and their family carers.

Carers: Carers described wanting to be more involved in their partners care during a hospital admission, but believed they were not listened to, did not have rights in the acute ward setting, and could be kept away from the ward. Within the workshops, letters in the screw-top glass jar represent the "communication nightmare" of trying to convey the care needs of a PLWD to ward-staff and the difficulty of the person in finding words to make their care needs known during an admission. One carer noted that there was antipathy towards carers on the ward, even though their presence could minimise anxiety in a person living with dementia, and instead wards prefer to use expensive agency one-to-one staff. Being ignored on a ward was a familiar experience for these carers and during the workshops the de-stabilizing impact of this experience was represented by the stitched-felt portrait pressed onto to a cold, hard surface.

Diversity and Dementia: We delivered five engagement events in Cardiff, which involved 80 older people and people living with dementia from within BAME, LGBT and disability communities to discuss their experiences and involve them in the research. We also developed collaborative relationships with organisations with a specific remit to support communities living with dementia who are often excluded from research: Diverse Cymru, Alzheimer's Society, Women Connect First, British Deaf Association, Downs Syndrome Association, Action on Hearing Loss, Stonewall Cymru, the Mentor Ring, Nubian Life and the Sub-Saharan Advisory Panel.

The consultation process led to the development of three collaborative performances exploring dementia and ethnicity, hearing loss, and sexuality, informed by the research findings and co-produced with people with lived experiences who actively contributed to script development. Although we heard many positive stories of care, many people living with dementia and carers reported negative and discriminatory experiences, including microaggressions and discriminatory language used by ward staff across care settings. These people living with dementia and family carers described feeling additionally vulnerable during a hospital admission and we have explored these in the co-produced films: Next of Kin explores the issues raised by the D/deaf community, More Time explores the issues raised by the BAME community and BAME healthcare workers and Back in the Closet explores the issues for LGBT older adults raised by the LGBT community.

For her work developing this programme, Sofia Vougioukalou was awarded the Alzheimer's Society Cymru Dementia Friendly Diversity Award winner 2021 and the Public Involvement Award (https://bit.ly/2ZoveZS) by Health and Care Research Wales (2021). Full details of these activities and outputs can be found in our Programme of Patient and Public Involvement Report.

Chapter 10: Conclusions

Our detailed analysis provides understandings of the complex social relations that occurred within these wards, the ways in which the organisation and delivery of continence care at the bedside connected closely with and was informed by wider institutional expectations, policies, and priorities, which in turn, shaped the personal impacts of continence care for both patients living with dementia and ward staff. Given the scope of our data set, within this report, we focus on presenting the 5 major themes that emerged within our analysis: 1) Continence as significant, visible and public phenomena, 2) Continence communication, 3) Rationales of safety, 4) Pad cultures and 5) Impacts of continence care.

Theme 1: Continence as significant, visible and public phenomena

Continence was a significant, visible, and public phenomena, representing a considerable aspect of the care for people living with dementia within the everyday bedside care routines predominantly carried out by HCAs, but also significant within the routines of nursing. Considerations of privacy were often overridden by the recording practices and required documentation of these wards. This could also lead to close monitoring and control of the person living with dementia at the bedside.

Theme 2: Continence communication

Despite its apparent centrality within the everyday work of these wards, communication was significant in the silencing of continence and the work of continence care. The discomfort surrounding continence care for ward staff could be seen within the strategies of communication and the language used within these wards during bedside care for people living with dementia, but also extended to staff discussions of continence within team meetings. Euphemisms particularly for genitalia, bodily functions, urine and faecal matter was notable during intimate personal care, and a restricted repertoire of language used to communicate intimate continence and personal care to people living with dementia. Importantly, there was little evidence that staff were able to check the person's comprehension or vary language to suit the individual.

Within these wards there was the explicit requirement that people living with dementia must communicate urgency and request continence care at the bedside using institutionally recognised forms of communication, through verbal requests and using the personal call button to seek help. Permission was also required to leave the bedside and walk to a toilet, even if the person was able to do so independently. For people living with dementia, the communication of an urgent continence care need was often not verbalized (either through difficulties in communication or embarrassment), but rather was embodied, and could only be identified in the body and via changes in behaviour. It was unusual for staff to recognise or respond to these non-verbal forms of communicating an underlying continence care need.

Theme 3: Rationales of safety

Ensuring safety and minimizing risks often featured within discussions of continence care for people living with dementia. A person living with dementia leaving or repeatedly attempting to leave the bed or bedside was always interpreted by ward staff as a risk to be managed and ward staff typically focussed on the immediate behaviour with the goal typically to contain and reposition the patient within the bed or bedside chair. This focus on immediate risks of falling may reduce one risk, but meant staff typically did not recognise immediate continence needs, or other potential impacts on the person and the reduced opportunities for independence and rehabilitation, such as regaining the ability to walk.

Theme 4: Pad cultures

We identified “Pad cultures” as the routine use of continence pads in the care of a wider group of people living with dementia (regardless of continence and independence) as a precautionary strategy, essential to provide safeguards, ensure containment and preventing “accidents” or incontinence episodes, but with an expectation that patients living with dementia not only wear pads, but that they could and should use the pad. These cultures enabled wards to reduce unscheduled interruptions and ensure containment at the bedside. This approach meant continence care could become reduced to containment practices and the “checking” and replacing of soiled or wet pads as part of other scheduled task-based bedside care during a shift. Ward staff described continence care as a “heavy” burden, and a “heavy load”, which expressed not only the physically demanding nature of this care, but also the experience of isolation and of feeling abandoned with the responsibility of caring for large numbers of people living with dementia, who required highly supportive care.

Theme 5: Impacts of continence care

This characterization of the dependency of people living with dementia within these wards had wider and significant impacts on the person and their identities. These impacts were intrinsically linked to “pad cultures”. Placing a person into “pads” and institutional gowns during bedside care could lead to the reclassification of people living with dementia (and could become applied to a wider group of older people) grouped together within a given bay or ward area as being highly dependent. The everyday use of institutional gowns was also a response to the routine failure of “pads” as a containment technology, which meant clothing also needed to be routinely changed along with pads. Thus, the requirements and failures of the pad technology itself, were expected, normalized, and prioritized.

This could also extend to recognition and understandings of individual behaviour. Walking to the bathroom could become understood by staff as “wandering”, no longer a sign of continence, capacity, and capability, but a potential risk of “falls” and recognised by staff as a potential sign of confusion or resistance to ward care. Distress at experiencing intimate continence care from strangers, often carried out in silence or without adequate warning, could also become quickly perceived as “aggression”. Forms of embodied communication of continence care needs could be viewed as transgressive or as a form of behaviour constituting a feature of their dementia, rather than an expression of urgent and underlying need.

This study identified “pad cultures” as an embedded practice within these acute wards. We recognise that the use of continence “pads” was often required to support people living with dementia in response to incontinence in the person. However, “pad cultures” refers to the routine use of continence pads in the care of a wider group of people living with dementia (regardless of continence and independence) as a precautionary strategy, essential to provide safeguards, ensure containment and preventing “accidents” or incontinent episodes, but with an expectation that patients living with dementia not only wear pads, but that they could and should use the pad. These cultures enabled wards to reduce unscheduled interruptions to the timetabled work of these wards, and to ensure containment at the bedside. This approach meant continence care could become reduced to containment practices and the “checking” and replacing of soiled or wet pads as part of other scheduled task-based organisation and delivery of bedside care during a shift.

These pad cultures had significant impacts on people living with dementia and ward staff. These practices informed wider understandings and characterizations of people living with dementia (cohorted individuals and groups) within these wards as being highly dependent, which had wider and significant impacts on the person and their identities. In turn, ward staff described continence care as a “heavy” burden, and a “heavy load”, which expressed not only the physically demanding nature of these pad cultures, but also the experience of isolation and of feeling abandoned with the responsibility of caring for large numbers of people living with dementia. Staff also often expressed the view that although they wanted to support their patients’ continence, they believed it was not possible to work in other ways.

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Author Contributions

Katie Featherstone was Principal Investigator for this project, conducted data collection and analysis and was a primary author of this report. Andy Northcott was research lead for this project, conducted data collection and analysis and was a primary author of this report. Deborah Edwards and Jane Harden were responsible for the scoping and review. Deborah Edwards was the primary author of the mixed methods review and thematic synthesis. Paula Boddington contirbuted significantly to data analysis and to the writng, editing and reviewing of this report. Karen Logan provided expertise in clinical continence care throughout the analytic process and production of this report. Daniel Kelly, Aled Jones, Jane Harden, Sue Bale and Rosie Tope provided nursing and clinical expertise throughout the analytic process and in the production of this report. Jackie Askey, Karen Harrison Dening, Rosie Tope and Sofia Vougioukalou gave patient and carer insight contributing to the events and production of the PPI section of this report. Sofia Vougioukalou was primary author of the PPI section of this report. Katie Featherstone, Andy Northcott, Paula Boddington and Deborah Edwards were responsible for significant editing of this report.

Data Sharing Statement

This is a qualitative study and therefore the data generated is not suitable for sharing beyond that contained within the report. Further information can be obtained from the corresponding author.

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Appendices

Appendix 1: Profiles of observations sites

Assessment Units

This is where unscheduled admissions arrive for assessment from A&E, the outpatient department clinic or their GP. Following assessment, patients are discharged, transferred to a specialist centre, or admitted to an inpatient bed. These are high turnover settings, designed to manage the bottlenecks associated with A&E, with the goal of discharging or transferring patients within 24 hours. There is a different routine within this setting, with staff geared to manage acute admissions with fast turnaround, with a lack of apparent continuity or personalised care, and often a chaotic atmosphere. Our Carer Steering Group all had poor experiences of this setting and found it a frightening time, where they felt they were not listened to, and were often separated from their partner.

General Medical Wards

This is where patients are transferred to an inpatient bed following their emergency admission or from the assessment units. These wards usually provide greater continuity and more structured routines. However, although there is an increasing number of admissions of people living with dementia within general medical wards, they are typically not designed for this patient population. A routine admission for people living with dementia is 10-20 days, however, for many this is much longer.[8] Our Carer Steering Group all reported poor experiences of this setting and found that general wards did not understand the needs of their partner with dementia.

Site F:

A district general hospital (200 beds) serving a largely rural population, located in a town of approximately 10k people but serving a wider population of small towns and villages, which represented both rural and post-industrial communities. The hospital was built entirely in the latter half of the twentieth century. While the town in which the hospital is based is relatively affluent the surrounding areas had significant wealth inequalities and areas of deprivation. Patient admissions were largely White British, with English as a first language. This hospital had a specialist frailty unit for the treatment of older people. Staffing at this hospital was largely drawn from the area and staff often knew patients (or their families) from previous admissions or through local social networks. There was ample free parking at this hospital for visitors. This site is not in jurisdiction of the Care Quality Commission.

Emergency Assessment Unit

30 beds (4 bays of 6 beds, 6 side rooms) plus a triage bay. 3 neighbouring bays along one corridor used for older patients, in which rates of dementia diagnosis and cognitive impairment were high. A final bay was reserved for ambulatory and younger patients. 4 toilets lined the corridor. It is an open unlocked unit with three entry/exit points. A RAID (Rapid Assessment, Intervention and Discharge) team was in place for older patients admitted to the unit. Each bay has a designated RN and an HCA. DoLS and one-to-one care interventions were rarely used.

Acute Medical Ward

32 bed Nightingale style ward (4 bays of 6 beds, 8 side rooms). Two main intakes, cardio and gastro, thus includes heart and liver failure (alcohol and non-alcohol related), but with the majority of admissions for general acute conditions, including falls, UTIs and “confusion”. It was typically staffed by 1 x nurse in charge of the ward, 4 x RNs and 3 x HCAs during a day shift, with high continuity across the ward team. All the toilets and bathrooms were in the corridor running through the ward. There is a small plainly decorated day room with a communal TV that also doubles as a meeting room for MDTs. Patients are typically in their 70s or 80s, with a minority in their 60s (up to 10) and a smaller number in their 90s (2-3). On average, approximately 10-12 patients have a formal diagnosis of dementia in the board handover notes each day. Only a small number (2-3) are identified as having continence issues in the handover notes. This is a locked ward with one entrance accessed via a code or buzzer. DoLS and one-to-one care were rarely used.

Site G

A teaching hospital (900 beds) in a regional city with an urban/suburban population of approximately 500k people. The hospital is typical of many large NHS hospitals, comprising a mix of very new and very old buildings and units, linked by corridors and walkways. The city itself has significant economic inequalities and areas of deprivation, while the surrounding areas are affluent. Patient admissions were representative of the demographics of the city and its outlying areas, meaning a multicultural mix of patients with a range of first languages spoken by patients and staff. This hospital had recently built a number of specialist assessment units for older people, serving one of the largest accident and emergency units in the UK. Staff were from a heterogeneous range of backgrounds, served by nursing and medical schools at two large local Universities. There was ample parking for visitors, but this was quite expensive.

At the time of observations hospitals in this trust were classified by the CQC as requiring improvement, in part because of a lack of understandings around mental capacity assessments at the site. This trust has since been reclassified as good.

Acute Frailty Unit

16 beds (3 bays of 4 beds plus 4 side rooms) set around a small central hub, from which beds cannot be seen. Each bay and bedroom has its own toilet. This is a locked ward with two entrance/exits, one leading from A&E and towards an exit, the other leading to “Memory Lane”, an area painted to look like a promenade with a fake coffee shop at one end. Both entrances/exits are accessed via security card or intercom. This unit is next to, but is separated from , the main Medical Assessment Unit, and is for older patients, with an aim for discharge or transfer within 24 hours of admission. Each bay (plus neighbouring side room(s)) is designated to an RN and an HCA.

Acute Older People Ward

This has acute intakes of older people with a range of admitting conditions (pneumonia, sepsis, urinary system disorders, fractures, “falls” and “confusion). It is an old build design with a “Nightingale” style 32 beds (4 bays of 6 beds plus 8 side rooms), with the bays and single rooms dissected by a long corridor, with a large and busy nurses’ station in the centre of the corridor. It is typically staffed by 1 x nurse in charge, 3 x nurses, 1 x discharge co-ordinator, and 4 x HCAs, however, nursing staff were often “transferred” to other wards during shifts, which meant they were sometimes as low as 3 x nurses and 2 x HCAs “on the floor” (the institutional staffing levels for this ward are 6 nurses: 1 x nurse in charge, 4 x nurse and 1 x discharge coordinator and 4 x HCAs). This is a large team with some continuity of longstanding staff members, but also includes a large number of agency staff and a high use of one-to-one agency staff (often 2-3 per day shift). All the toilets and bathrooms are also in the main corridor. There is a large day room decorated with and containing a large amount of “dementia friendly” resources. Most patients are in their 70s and 80s, but sometimes as many as 5 patients in their 90s. On average approximately 10, but up to 15, have a formal diagnosis of dementia in the board handover notes, but staff anecdotally report “all” patients as having the condition. On average 7 – 10 patients are identified as having continence issues in each day’s handover notes, but staff describe “majority” as incontinent or “doubles”. This is a locked ward with one entrance accessed via a code or buzzer.

Site H

A teaching hospital (800 beds) in a major metropolitan city with an urban population of over one million people. This hospital was entirely rebuilt very recently and is set in an area of significant social deprivation. Patient admissions were multicultural/national with a range of first languages spoken. A significant number of admissions spoke only Bengali, a language not commonly spoken by ward staff. This hospital had specialist teams within general units and wards. Staff were from a heterogeneous range of backgrounds, served by nursing and medical schools from several local Universities. Staff typically did not live near the hospital or have a connection with the local area, commuting considerable distances to work. There was no parking for visitors, who were encouraged to use public transport.

At the time of observations this trust and site were classified by the CQC as good, which included direct inspection of the Acute Assessment Unit and of older people's care.

Acute Assessment Unit

AAU has 26 beds (4 bays of 4 beds plus 10 side rooms) set around a long horse shoe shaped corridor. It is next to a similar unit, also with 26 beds, which typically admits younger patients, with staff rotated and shared across the two units. The unit is on a double-digit floor of a large tower, accessed by a single hub of lifts or a staircase. Staffing of 5 RNs, each assigned 5-6 beds, which cut across physical bays. 2 HCAs are allocated 13 beds each, 2 bays and the neighbouring side rooms. The unit is a locked ward, accessed via intercom or security card.

Care of The Elderly Ward

This has acute intakes of older people (26 beds) with a range of admitting conditions (pneumonia, sepsis, urinary system disorders). It is a new build, approximately double the size of traditional wards with 4 large bays with 4 patients, with each bay also with its own large bathroom. There are 10 single occupancy rooms and each has their own en-suite large bathroom within them. There are additional toilets within the hall. It is typically staffed by 1 x nurse in charge (plus a FT discharge co-ordinator), 4 x nurses and 4 x HCAs (9) during the day shifts, although they were often "short" (the institutional staff levels for this ward is 9: 5 nurses and 4 HCAs for a day shift). Here there was some continuity of staff. There are two nursing stations situated within a large and wide circular corridor. The patients are typically in their 70s and 80s, with anywhere from 4-10 having a formal diagnosis of dementia in the handover notes each day. Similar numbers are recorded for continence issues in the handover. However, overall, ward staff describe "all" patients as incontinent highlighting singular continent patients as exceptions. There is a small "dementia friendly café" for patients and visitors and this is a locked ward with one entrance accessed via ID cards or buzzer.

Appendix 2: Stakeholders who took part in the consultation exercise

Stakeholders	**Source of contact**
DCAs Young onset team DCA (n=1) REACT crisis team DCA (n=1) (when a person has an additional mental health crisis on top of their dementia) Community DCAs (n=3)	SOLACE A service within the local University Health Board which exists to provide support to carers and those diagnosed with dementia, depression or severe later life mental illness. Their aim to help prevent admission to hospital and deterioration in relation to being in hospital.
DCAs (n=2)	Liaison Psychiatry A service that covers wards in the general hospital setting. Their role is to help PLWD when they are in hospital if they are struggling and are exhibiting behaviours that challenge or if they are anxious or agitated such as walking around a lot and the staff aren't able to cope
Continence service team Nurse consultant (n=1) CNSs (n=7)	NHS Continence Service An outpatient-based service. The role of the team is to accept and take referrals from primary care general practitioners (GPs), district nurses and others to see patients with incontinence and to assess and put in place a suitable management plan for them
Occupational therapist (n=1)	Facebook Currently works on an elderly ward with both functional patients and PLWD. Previous employment was on a specific dementia ward in a community hospital
PLWD (n=2) Family carers (n=11) DCA (n=10) One activities coordinator of local care home (n=1) Volunteer from the Alzheimer's Society (n=1)	Public Consultation Event A whole day event in which issues around toileting and continence were explored through narrative and creative presentations (through pictures, poems and artistic expression, arts and discussion).

Key: CNS: clinical nurse specialists; DCA: dementia care advisors; PLWD: people living with dementia

Ethical approval for the public consultation event was obtained from the School Research Ethics Committee, Healthcare Sciences, Cardiff University, on the February 8th 2018.

Appendix 3: Inclusion criteria

Participants	PLWD or cognitive impairment and/or carers, family members and HCPs of PLWD or cognitive impairment. All dementia subtypes were included for example AD, vascular dementia, frontotemporal dementia, etc.
Interventions / Phenomena of interest:	Any communication strategy or individualised care plan/s that carers', family members and HCPs have employed to manage toileting and continence for PLWD. Perceptions and experiences of communication and/or individualised care planning for PLWD with regard to toileting and continence
Comparators	All comparisons were considered
Outcomes	All outcomes as presented across the primary studies that related to communication and individualised care planning
Study designs	All quantitative and qualitative research studies and non-research material (e.g. policies (UK only), guidelines, reports of practice initiatives and clinical case studies).
Context	A PLWD and all those involved in their care in acute, long-term and community healthcare and home settings

Key: PLWD: Patient living with dementia

Appendix 4: Search strategies for systematic review

Ovid MEDLINE(R) ALL: communication

1 dement*.mp.
2 alzheimer*.mp.
3 exp Dementia/)
4 ((cognit* or memory* or mental*) adj3 (declin* or impair* or los* or deteriorat*)).mp.
5 exp DEMENTIA, MULTI-INFARCT/
6 exp FRONTOTEMPORAL DEMENTIA/
7 exp DEMENTIA, VASCULAR/
8 exp senile dementia/
9 exp Alzheimer Disease/
10 exp Cognition Disorders/
11 exp mild cognitive impairment/
12 ("limited cognitive disturbance*" or "mild cognitive disorder*").mp.
13 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12
14 exp urinary incontinence/
15 (incontinen$ or continen$).tw.
16 exp fecal incontinence/
17 ((fecal or faecal) adj2 (incontinen$ or continen$)).tw.
18 (stool$ adj2 (incontinen$ or continen$)).tw.
19 (Conservative adj2 (intervention$ or measure$)).ti,ab.
20 (Continence adj2 restoration).ti,ab.
21 (Continence adj2 care).ti,ab.
22 ((UI or Incontinence) adj2 (care or manag$ or reduc$ or assess$ or contain$)).tw.
23 toilet training/
24 toilet$.tw.
25 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24
26 exp NONVERBAL COMMUNICATION/ or exp COMMUNICATION/
27 (cues or behavio?r* or word* or signs* or signage or promp* or reassur* or speak* or reinforc* or language or visual or language or expression* or voice).ti,ab.
28 (discour* or dialog* or disclos* or intera* or communica* or talk* or speak* or verbal or non-verbal or interpersonal or convers*or relation*).ti,ab.
29 26 or 27 or 28
30 13 and 25 and 29
31 limit 30 to English language

Ovid MEDLINE(R) ALL: Individualised care plans

1 dement*.mp.
2 alzheimer*.mp.
3 exp Dementia/
4 ((cognit* or memory* or mental*) adj3 (declin* or impair* or los* or deteriorat*)).mp.
5 exp DEMENTIA, MULTI-INFARCT/
6 exp FRONTOTEMPORAL DEMENTIA/
7 exp DEMENTIA, VASCULAR/
8 exp senile dementia/
9 exp Alzheimer Disease/ (
10 exp Cognition Disorders/
11 exp mild cognitive impairment/
12 ("limited cognitive disturbance*" or "mild cognitive disorder*").mp.
13 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12
14 exp urinary incontinence/
15 (incontinen$ or continen$).tw.
16 exp fecal incontinence/
17 ((fecal or faecal) adj2 (incontinen$ or continen$)).tw.
18 (stool$ adj2 (incontinen$ or continen$)).tw.
19 (Conservative adj2 (intervention$ or measure$)).ti,ab.
20 (Continence adj2 restoration).ti,ab.
21 (Continence adj2 care).ti,ab.
22 ((UI or Incontinence) adj2 (care or manag$ or reduc$ or assess$ or contain$)).tw.

23 toilet training/
24 toilet$.tw.
25 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24
26 exp Patient Care Planning/
27 (Individual* adj3 plan*).tw.
28 (Personal* adj3 plan*).tw.
29 26 or 27 or 28
30 13 and 25 and 29
31 limit 30 to English language

CINAHL: communication

S1 TI dement* OR AB dement*
S2 TI alzheimer* OR alzheimer*
S3 TI (cognit* W2 declin*) OR AB (cognit* W2 declin*)
S4 TI (cognit* W2 deteriorat*) OR AB (cognit* W2 deteriorat*)
S5 AB (cognit* W2 fail*) OR TI (cognit* W2 fail*)
S6 TI (cognit* W2 los*) OR AB (cognit* W2 los*)
S7 TI (cognitive impairment*) OR AB (cognitive impairment*)
S8 TI MCI OR AB MCI
S9 TI (cognitive disorder*) OR AB (cognitive disorder*)
S10 (MH "Dementia, Vascular+")
S11 (MH "Delirium, Dementia, Amnestic, Cognitive Disorders+")
S12 (MH "Dementia, Multi-Infarct")
S13 (MH "Dementia, Presenile")
S14 (MH "Dementia, Senile")
S15 (MH "Alzheimer's Disease")
S16 (MH "Cognition Disorders+")
S17 (MM "Cognition")
S18 TX (incontinen* or continen*)
S19 TX (fecal OR faecal) N2 (incontinen* OR continen*)
S20 TX stool* N2 (incontinen* or continen*)
S21 MH urinary incontinence+
S22 MH fecal incontinence+
S23 TI (Conservative W2 (intervention* or measure*)) OR AB (Conservative W2 (intervention* or measure*))
S24 TI Continence N2 restoration OR AB Continence N2 restoration
S25 TI Continence W2 care OR AB Continence W2 care
S26 TX (UI or Incontinence) N2 (care or manag* or reduc* or assess* or contain*)
S27 (MM "Toilet Training")
S28 TX toilet*
S29 S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17
S30 S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28
S31 (MM "Communication+") OR (MM "Nonverbal Communication+") OR (MH "Communication Skills")
S32 ((TI discour* or TI dialog* or TI disclos* or TI intera* or TI communica* or TI talk* or TI speak* or TI verbal or TI non-verbal or TI interpersonal or TI convers*or TI relation*) OR (AB discour* or AB dialog* or AB disclos* or AB intera* or AB communica* or AB talk* or AB speak* or AB verbal or AB non-verbal or AB interpersonal or AB convers*or AB relation*))
S33 S31 OR S32
S34 S29 AND S30 AND S33
S35 S29 AND S30 AND S33 (Limit English)

CINAHL: individualised care plans

S1 TI dement* OR AB dement*
S2 TI alzheimer* OR alzheimer*
S3 TI (cognit* W2 declin*) OR AB (cognit* W2 declin*)
S4 TI (cognit* W2 deteriorat*) OR AB (cognit* W2 deteriorat*)
S5 AB (cognit* W2 fail*) OR TI (cognit* W2 fail*)
S6 TI (cognit* W2 los*) OR AB (cognit* W2 los*)

S7 TI (cognitive impairment*) OR AB (cognitive impairment*)
S8 TI MCI OR AB MCI
S9 TI (cognitive disorder*) OR AB (cognitive disorder*)
S10 (MH "Dementia, Vascular+")
S11 (MH "Delirium, Dementia, Amnestic, Cognitive Disorders+")
S12 (MH "Dementia, Multi-Infarct")
S13 (MH "Dementia, Presenile")
S14 (MH "Dementia, Senile")
S15 (MH "Alzheimer's Disease")
S16 (MH "Cognition Disorders+")
S17 (MM "Cognition")
S18 TX (incontinen* or continen*)
S19 TX (fecal OR faecal) N2 (incontinen* OR continen*)
S20 TX stool* N2 (incontinen* or continen*)
S21 MH urinary incontinence+
S22 MH fecal incontinence+
S23 TI (Conservative W2 (intervention* or measure*)) OR AB (Conservative W2 (intervention* or measure*))
S24 TI Continence N2 restoration OR AB Continence N2 restoration
S25 TI Continence W2 care OR AB Continence W2 care
S26 TX (UI or Incontinence) N2 (care or manag* or reduc* or assess* or contain*)
S27 (MM "Toilet Training")
S28 TX toilet*
S29 S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17
S30 S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28
S31 TX ((patient-cent* W3 care) or (patient-cent* W3 toilet*))
S32 TX ((person-cent* W3 care) or (person-cent* W3 toilet*))
S33 TX ((person-cent* W3 care) or (person-cent* W3 toilet*))
S34 TX ((individual* W3 care) or (individual W3 approach*) or (individual* W3 intervention*) or (Individual* W2 program*) or (Individual* W3 plan*))
S35 TX ((personal* W3 care) or (personal* W3 plan*) or (personal* W3 approach*) or (personal* W3 intervention*) or (personal* W3 plan*))
S36 TX ((tailor* N3 care) or tailor* N3 plan* or (tailor* N3 approach*) or (tailor* N3 intervention*))
S37 (MM "Patient Centered Care")
S38 (MM "Patient Care Plans+") OR (MM "Nursing Care Plans+")
S39 S31 OR S32 OR S33 OR S34 OR S35 OR S36 OR S37 OR S38
S40 S29 AND S30 AND S39
S41 S29 AND S30 AND S39 (Limit English)

EMBASE: communication
1 dement*.mp.
2 alzheimer*.mp.
3 exp Dementia/
4 ((cognit* or memory* or mental*) adj3 (declin* or impair* or los* or deteriorat*)).mp.
5 exp DEMENTIA, MULTI-INFARCT/
6 exp FRONTOTEMPORAL DEMENTIA/
7 exp DEMENTIA, VASCULAR/
8 exp senile dementia/
9 exp Alzheimer Disease/
10 exp Cognition Disorders/
11 exp mild cognitive impairment/
12 ("limited cognitive disturbance*" or "mild cognitive disorder*").mp.
13 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12
14 exp urinary incontinence/
15 (incontinen$ or continen$).tw.
16 exp fecal incontinence/
17 ((fecal or faecal) adj2 (incontinen$ or continen$)).tw.
18 (stool$ adj2 (incontinen$ or continen$)).tw.
19 (Conservative adj2 (intervention$ or measure$)).ti,ab.

20 (Continence adj2 restoration).ti,ab.
21 (Continence adj2 care).ti,ab.
22 ((UI or Incontinence) adj2 (care or manag$ or reduc$ or assess$ or contain$)).tw.
23 toilet training/
24 toilet$.tw.
25 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24
26 exp *interpersonal communication/
27 (cues or behavio?r* or word* or signs* or signage or promp* or reassur* or speak* or reinforc* or language or visual or language or expression* or voice).ti,ab.
28 (discour* or dialog* or disclos* or intera* or communica* or talk* or speak* or verbal or non-verbal or interpersonal or convers*or relation*).ti,ab.
29 26 or 27 or 28
30 13 and 25 and 29
31 limit 30 to English language

EMBASE: individualised care plans
1 dement*.tw.
2 alzheimer*.tw.
3 exp Dementia/
4 ((cognit* or memory* or mental*) adj3 (declin* or impair* or los* or deteriorat*)).tw.
5 exp DEMENTIA, MULTI-INFARCT/
6 exp FRONTOTEMPORAL DEMENTIA/
7 exp DEMENTIA, VASCULAR/
8 exp senile dementia/
9 exp Alzheimer Disease/
10 exp Cognition Disorders/
11 exp mild cognitive impairment/
12 ("limited cognitive disturbance*" or "mild cognitive disorder*").tw.
13 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12
14 exp urinary incontinence/
15 (incontinen$ or continen$).tw.
16 exp fecal incontinence/
17 ((fecal or faecal) adj2 (incontinen$ or continen$)).tw.
18 (stool$ adj2 (incontinen$ or continen$)).tw.
19 (Conservative adj2 (intervention$ or measure$)).tw.
20 (Continence adj2 restoration).tw.
21 (Continence adj2 care).tw.
22 ((UI or Incontinence) adj2 (care or manag$ or reduc$ or assess$ or contain$)).tw.
23 toilet training/
24 toilet$.tw.
25 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24
26 exp Patient Care Planning/
27 exp *Patient-Centered Care/
28 ((patient-cent* adj3 care) or (patient-cent* adj3 toilet*)).tw.
29 ((person-cent* adj3 care) or (person-cent* adj3 toilet*)).tw.
30 ((individual* adj3 care) or (individual adj3 approach*) or (individual* adj3 intervention*) or (Individual* adj2 program*) or (Individual* adj3 plan*)).tw.
31 ((personal* adj3 care) or (personal* adj3 plan*) or (personal* adj3 approach*) or (personal* adj3 intervention*) or (personal* adj3 plan*)).tw.
32 ((tailor* adj5 individual) or (tailor* adj3 patient*) or (tailor* adj3 person*)).tw.
33 26 or 27 or 28 or 29 or 30 or 31 or 32
34 13 and 25 and 33
35 limit 34 to English language

PsycINFO: communication
1 exp urinary incontinence/
2 (incontinen$ or continen$).tw.
3 exp fecal incontinence/
4 ((fecal or faecal) adj2 (incontinen$ or continen$)).tw.
5 (stool$ adj2 (incontinen$ or continen$)).tw. (10)

6 (Conservative adj2 (intervention$ or measure$)).ti,ab.
7 (Continence adj2 restoration).ti,ab.
8 (Continence adj2 care).ti,ab.
9 ((UI or Incontinence) adj2 (care or manag$ or reduc$ or assess$ or contain$)).tw.
10 toilet training/
11 toilet$.tw.
12 dement*.mp.
13 alzheimer*.mp.
14 exp Dementia/
15 ((cognit* or memory* or mental*) adj3 (declin* or impair* or los* or deteriorat*)).mp.
16 exp DEMENTIA, MULTI-INFARCT/
17 exp FRONTOTEMPORAL DEMENTIA/
18 exp senile dementia/
19 exp Alzheimer Disease/
20 ("limited cognitive disturbance*" or "mild cognitive disorder*").mp.
21 exp presenile dementia/
22 exp semantic dementia/
23 2 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22
24 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11
25 exp *VERBAL COMMUNICATION/ or exp *INTERPERSONAL COMMUNICATION/ or exp *NONVERBAL COMMUNICATION/ or exp *COMMUNICATION/ or exp *COMMUNICATION SKILLS/
26 (cues or behavio?r* or word* or signs* or signage or promp* or reassur* or speak* or reinforc* or language or visual or language or expression* or voice).ti,ab.
27 (discour* or dialog* or disclos* or intera* or communica* or talk* or speak* or verbal or non-verbal or interpersonal or convers*or relation*).ti,ab.
28 25 or 26 or 27
29 23 and 24 and 28
30 limit 29 to English language

PsycINFO: individualised care plans

1 exp urinary incontinence/
2 (incontinen$ or continen$).tw.
3 exp fecal incontinence/
4 ((fecal or faecal) adj2 (incontinen$ or continen$)).tw.
5 (stool$ adj2 (incontinen$ or continen$)).tw.
6 exp *Urinary Function Disorders/
7 (Conservative adj2 (intervention$ or measure$)).tw.
8 (Continence adj2 restoration).tw.
9 (Continence adj2 care).tw.
10 ((UI or Incontinence) adj2 (care or manag$ or reduc$ or assess$ or contain$)).tw.
11 toilet training/ (
12 toilet$.tw.
13 dement*.tw.
14 alzheimer*.tw.
15 exp Dementia/
16 ((cognit* or memory* or mental*) adj3 (declin* or impair* or los* or deteriorat*)).tw.
17 exp DEMENTIA, MULTI-INFARCT/
18 exp FRONTOTEMPORAL DEMENTIA/
19 exp senile dementia/
20 exp Alzheimer Disease/
21 ("limited cognitive disturbance*" or "mild cognitive disorder*").tw.
22 exp presenile dementia/
23 exp semantic dementia/
24 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23
25 ((patient-cent* adj3 care) or (patient-cent* adj3 toilet*)).tw.
26 ((person-cent* adj3 care) or (person-cent* adj3 toilet*)).tw.
27 ((individual* adj3 care) or (individual adj3 approach*) or (individual* adj3 intervention*) or (Individual* adj2 program*) or (Individual* adj3 plan*)).tw.

28 ((personal* adj3 care) or (personal* adj3 plan*) or (personal* adj3 approach*) or (personal* adj3 intervention*) or (personal* adj3 plan*)).tw.
29 ((tailor* adj3 care) or tailor*adj3 plan* or (tailor* adj3 approach*) or (tailor* adj3 intervention*)).tw.
30 25 or 26 or 27 or 28 or 29
31 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12
32 24 and 30 and 31
33 limit 32 to English language

BN/ASSIA: communication
ti(dementia OR Alzheimer*) OR ab(dementia OR Alzheimer*) AND ti(cues or behavio?r* or word* or signs* or signage or promp* or reassur* or speak* or reinforc* or language OR visual OR language OR expression* or voice or discour* or dialog* or disclos* or intera* or communica* or talk* or speak* or verbal or non-verbal or interpersonal or convers*or relation*) or aB (cues or behavio?r* or word* or signs* or signage or promp* or reassur* or speak* or reinforc* or language OR visual OR language OR expression* or voice or discour* or dialog* or disclos* or intera* or communica* or talk* or speak* or verbal or non-verbal or interpersonal or convers*or relation*) AND ti(toilet* OR incontinen* OR continen*) OR aby (toilet* OR incontinen* OR continen*)

BNI/ASSIA: individualised care plans
(ti(dementia OR Alzheimer*) OR ab(dementia OR Alzheimer*)) AND (ti(toilet* OR incontinen* OR continen*) OR aby (toilet* OR incontinen* OR continen*)) AND (ti(patient-cent* NEAR/3 care) OR (patient-cent* NEAR/3 toilet*) OR (person-cent* NEAR/3 care) OR (person-cent* NEAR/3 toilet*) OR (individual* NEAR/3 care) OR (individual NEAR/3 approach*) OR (individual* NEAR/3 intervention*) OR (personal* NEAR/3 care) or (personal* NEAR/3 plan*) or (personal* NEAR/3 approach*) or (personal* NEAR/3 intervention*) or (personal* NEAR/3 plan*) OR (tailor* NEAR/3 care) or tailor*NEAR/3 plan* or (tailor* NEAR/3 approach*) or (tailor* NEAR/3 intervention*) (Individual* NEAR/2 program*) OR (Individual* NEAR/3 plan*) OR ab(patient-cent* NEAR/3 care) OR (patient-cent* NEAR/3 toilet*) OR (person-cent* NEAR/3 care) OR (person-cent* NEAR/3 toilet*) OR (individual* NEAR/3 care) OR (individual NEAR/3 approach*) OR (individual* NEAR/3 intervention*) OR (Individual* NEAR/2 program*) OR (Individual* NEAR/3 plan*) or (personal* NEAR/3 care) or (personal* NEAR/3 plan*) or (personal* NEAR/3 approach*) or (personal* NEAR/3 intervention*) or (personal* NEAR/3 plan*) OR (tailor* NEAR/3 care) or tailor*NEAR/3 plan* or (tailor* NEAR/3 approach*) or (tailor* NEAR/3 intervention*))

Web of Science: communication
Indexes=SCI-EXPANDED, SSCI, ESCI
TOPIC: (dementia OR Alzheimer*)
AND
TOPIC: (toilet* OR incontinen* OR continen*)
AND
TOPIC: (cues or behavio?r* or word* or signs* or signage or promp* or reassur* or speak* or reinforc* or language OR visual OR language OR expression* or voice or discour* or dialog* or disclos* or intera* or communica* or talk* or speak* or verbal or non-verbal or interpersonal or convers*or relation*)

Web of Science: Individualised care plans
Indexes=SCI-EXPANDED, SSCI, ESCI
TOPIC: (dementia OR Alzheimer*)
AND
TOPIC: (toilet* OR incontinen* OR continen*)
AND
TOPIC: (cues or behavio?r* or word* or signs* or signage or promp* or reassur* or speak* or reinforc* or language OR visual OR language OR expression* or voice or discour* or dialog* or disclos* or intera* or communica* or talk* or speak* or verbal or non-verbal or interpersonal or convers*or relation*)

ERIC: communication
S1 TI dement* OR AB dement*
S2 TI alzheimer* OR alzheimer*
S3 TI (cognit* W2 declin*) OR AB (cognit* W2 declin*)
S4 TI (cognit* W2 deteriorat*) OR AB (cognit* W2 deteriorat*)
S5 AB (cognit* W2 fail*) OR TI (cognit* W2 fail*)
S6 TI (cognit* W2 los*) OR AB (cognit* W2 los*)

S7	TI (cognitive impairment*) OR AB (cognitive impairment*)
S8	TI MCI OR AB MCI
S9	TI (cognitive disorder*) OR AB (cognitive disorder*)
S10	TX (incontinen* or continen*)
S11	TX (fecal OR faecal) N2 (incontinen* OR continen*)
S12	TI (Conservative W2 (intervention* or measure*)) OR AB (Conservative W2 (intervention* or measure*))
S13	TI Continence W2 care OR AB Continence W2 care
S14	TX toilet*
S15	((TI discour* or TI dialog* or TI disclos* or TI intera* or TI communica* or TI talk* or TI speak* or TI verbal or TI non-verbal or TI interpersonal or TI convers*or TI relation*) OR (AB discour* or AB dialog* or AB disclos* or AB intera* or AB communica* or AB talk* or AB speak* or AB verbal or AB non-verbal or AB interpersonal or AB convers*or AB relation*))
S16	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9
S17	S10 OR S11 OR S12 OR S13 OR S14
S18	S15 AND S16 AND S17
S21	S21 AND S22

ERIC: care plans

S24	S15 AND S16 AND S23
S23	S17 OR S18 OR S19 OR S20 OR S21 OR S22
S22	TX ((tailor* N3 care) or tailor* N3 plan* or (tailor* N3 approach*) or (tailor* N3 intervention*))
S21	TX ((personal* W3 care) or (personal* W3 plan*) or (personal* W3 approach*) or (personal* W3 intervention*) or (personal* W3 plan*))
S20	TX ((individual* W3 care) or (individual W3 approach*) or (individual* W3 intervention*) or (Individual* W2 program*) or (Individual* W3 plan*))
S19	TX ((person-cent* W3 care) or (person-cent* W3 toilet*))
S18	TX ((person-cent* W3 care) or (person-cent* W3 toilet*))
S17	TX ((patient-cent* W3 care) or (patient-cent* W3 toilet*))
S16	S10 OR S11 OR S12 OR S13 OR S14
S15	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9
S14	TX toilet*
S13	TI Continence W2 care OR AB Continence W2 care
S12	TI (Conservative W2 (intervention* or measure*)) OR AB (Conservative W2 (intervention* or measure*))
S11	TX (fecal OR faecal) N2 (incontinen* OR continen*)
S10	TX (incontinen* or continen*)
S9	TI (cognitive disorder*) OR AB (cognitive disorder*)
S8	TI MCI OR AB MCI
S7	TI (cognitive impairment*) OR AB (cognitive impairment*)
S6	TI (cognit* W2 los*) OR AB (cognit* W2 los*)
S5	AB (cognit* W2 fail*) OR TI (cognit* W2 fail*)
S4	TI (cognit* W2 deteriorat*) OR AB (cognit* W2 deteriorat*)
S3	TI (cognit* W2 declin*) OR AB (cognit* W2 declin*)
S2	TI alzheimer* OR alzheimer*
S1	TI dement* OR AB dement*

Open Grey

dementia AND communication and toilet or continence
dementia AND care plans and toilet or continence

Appendix 5: List of organisational websites searched and key journals hand searched

Organisational websites

Alzheimer Europe Alzheimer Society

British Geriatrics Society

Care Quality Commission

Care Inspectorate

Dementia UK

NHS England

Department of Health, England

Kings Fund

National Collaborating Centre for Mental Health

National Institute of Clinical Excellence

Northern Ireland Executive

Royal College of Nursing

Royal College of Physician's

Scottish Executive

Scottish Intercollegiate Guidelines Network

Social Care Institute for Excellence

The Queens Nursing Institute

Welsh Government

United Kingdom Continence Society

The International Continence Society

Journals hand searched within past year

Journal of Gerontological Nursing

American Journal of Alzheimer's Disease & Other Dementia

Journal of the American Geriatrics Society

Journal of Wound, Ostomy, & Continence Nursing

Appendix 6: Characteristics of included studies (communication)

Table 4: Characteristics of included studies (communication): Qualitative studies

Author/s, Year, Country **Aim**	**Setting** **Participants**	**Demographic details for PLWD**	**Methods** **MMAT score**
Study 1: Bliss et al. 2013[160] USA To describe health literacy needs related to incontinence and skin care among family or friend caregivers of individuals with AD and develop supportive and educational materials that address these	Setting Home Participants Family/friend adult caregivers (n=48) Spouses (44%), daughters (31%), or extended family members/friends (25%) Recruited from community-based agencies	Gender Female (75%) Age (Mean±SD) years 64 ± 14 Mental status AD or Dementia	Methods Focus groups and Interviews MMAT score: 100%
Study 1: Mullins et al. 2016[162] USA To examine barriers to communicating with healthcare professionals and health literacy about incontinence among different types of informal caregivers of individuals with AD	Same as Bliss et al. 2013	see Bliss et al. 2013	see Bliss et al. 2013 MMAT score: 100%
Study 2: Hutchinson et al. 1996[178] USA To addresses the range and variation of toileting problems, management strategies used by family and employed caregivers	Setting AD specific day Centre Home Participants Family members who participated in the centre support groups (n=16) Staff members employed at the day care centre (n=13)	Demographic characteristics of patients with AD who attended the day centre were not reported Mental status AD	Methods Participant observation at the day care centre, clients' home and support groups Interviews with families and staff members Based on qualitative ethology MMAT score: 75%
Study 3: Rolnick et al. 2013[164] USA To examine healthcare providers' perspectives regarding improving communication with patients and their caregivers about incontinence and dementia	Setting Secondary care providers Participants Physicians (n=8) / Nurse practitioners (n=2) / Pharmacist (n=1) Potential participants suggested by advisory committee	Not applicable Mental status Dementia	Methods Interviews MMAT score: 100%
Study 4: Ostaszkiewicz et al. 2018[163] Australia To explore nursing home staff members' beliefs and expectations about what constitutes "quality continence care" for people living in nursing homes	Setting Nursing Home Participants Nursing home staff (n=19) Registered nurses (n=8) Enrolled nurses (n=4) Personal care workers (n=7) Recruited using snowballing technique; selective placement of information in print and electronic media; and information sessions at several nursing homes	Not applicable Mental status Most nursing home residents were cognitively impaired	Methods Interviews Naturalistic inquiry using a qualitative exploratory descriptive research approach MMAT score: 100%
Study 14: Scerri et al. 2018[165]	Setting	Gender	Methods

Malta To categorise the perceived and observed needs of persons with dementia admitted in acute medical wards and to explore whether these needs are being or have been met.	Acute medical wards (n=3) Participants PLWD and their family members (n=12)	Age (Mean) years 84.7 Range 71 to 93 Mental status Dementia	Interviews Observations using Dementia Care Mapping MMAT score: 75%

Key: AD: Alzheimer 's disease; MMAT: Mixed methods appraisal tool; PLWD: people living with dementia; SD: standard deviation

Table 5: **Characteristics of included studies (communication): Quantitative experimental studies**

Author/s, Year **Country** **Aim**	**Setting** **Participants** **Demographic details for PLWD**	**Intervention**	**Data collection** **Outcome measures** **MMAT score**
Case series with non-concurrent multiple baseline design			
Study 5: Lancioni et al. 2009[150] USA The present three pilot studies assessed the effectiveness of verbal instructions, presented automatically through simple technology, in helping persons with mild-to-moderate Alzheimer's disease recapture basic daily activities	Setting Alzheimer rehabilitation centre Participants Residents with AD (n=3) Gender: Female (100%) Age (years): 79, 81, 86 Mental status AD MMSE scores: 10, 19, 22	Intervention Baseline: Pilot study 1: The participants were to perform the bathroom routine without the help of the technology and related verbal instructions Intervention: Pilot study 1: The participants performed all bathroom-routine steps with the help of the technology, which presented the instructions. 17 steps in total and step 1 was "to sit on the toilet"	Data collection The participants' performance of a step was recorded as "correct" if it matched the description of such step (and the instruction available for it during the intervention) and occurred independent of prompting by research assistants Outcome measures Percentage of correct steps performed MMAT score: 100%
Study 6: Lancioni et al. 2009[151] USA To assess the effectiveness of verbal instructions (presented automatically through simple technology) in helping persons with mild or moderate Alzheimer's disease perform daily living activities	Setting Alzheimer rehabilitation centre Participants Residents with AD (n=4) Gender: Female (100%) Age (years): 59, 76, 79, 85 Mental status AD MMSE scores: 11, 12, 16, 20	Intervention Same as Lancioni et al 2009a Four studies with the first one aimed at replicating pilot study 1 from Lancioni et al. 2009a. Efforts directed at re-establishing the performance of morning bathroom routine	Data collection Same as Lancioni et al 2009a Outcome measures Same as Lancioni et al 2009a MMAT score: 100%

Key: AD: Alzheimer's Disease; MMAT: Mixed methods appraisal tool; PLWD: people living with dementia

Table 6: **Characteristics of included studies (communication): Quantitative non-experimental studies**

Author/s, Year **Country** **Aim**	**Setting** **Participants**	**Demographic details for PLWD**	**Data collection** **Outcome measures** **MMAT score**
Cross sectional surveys			
Study 7: Wilkinson et al. 1995[157] Australia To evaluate the comparative suitability of a range of words or symbols to label a toilet for people with dementia	Setting Phase 1: Hostel care for ambulant people with dementia (n=24/28, rr 86%) Phase 2: Aged care complex with hostel and nursing home facilities (n=28) and an acute hospital ward (n=20) Participants Phase 1: n=24 institutions Phase 2: n=24 patients	Gender No details provided Age (years) 80.4 (95%CI 77.1-83.1) Mental status Folstein MSE Normal cognition (n=21) Mild dementia (n=11) Moderate dementia (n=16) Severe dementia excluded The study comprised two phases and questionnaires were used in both	Data collection Phase 1: questions posed to hostel management on what word and/or symbols were already in use in that institution to label toilet and/or bathroom facilities Phase 2: questions asking preference for toilet door labelling Outcome measures Preferred symbol according to cognitive state Preferred word according to cognitive state MMAT score: 100%

Key: CI: confidence intervals: MMAT: mixed methods evaluation tool; MSE: mental state examination, PLWD: people living with dementia; RR: response rate

Appendix 7: Characteristics of included studies (care planning)

Table 7: **Characteristics of included studies (care planning): Quantitative experimental studies**

Author/s, Year **Country** **Aim**	**Setting** **Participants** **Demographic details for PLWD**	**Intervention**	**Data collection** **Outcome measures** **MMAT score**
Randomised control trials			
Study 8: Jirovec and Templin 2001[152] USA To evaluate the effectiveness of an individualized scheduled toileting program on incontinent, memory impaired elders being cared for at home	Setting: Home Participants Caregivers (n=118) Memory impaired elders (n=118) Randomised to I (n=77), C (n-41) Recruited through announcements in newsletters, flyers on bulletin boards, and newspaper advertisements asking for volunteers who were caring for a memory-impaired elder Gender: Female (69%) Age (mean±SD) years 79.89±7.93 Mental status SPMSQ: Mean 6.69±2.28	Intervention Individualized scheduled toileting program The intervention group was taught an IST procedure that compensated for cognitive impairment by providing memory-impaired patients toileting reminders Initially, assignment was to one of two intervention groups: one group of participants was visited every 2 months, and the other group after a 6-month interval. There was also a control group At the 6-month follow-up the two intervention groups did not differ with respect to UI. The original two intervention groups were combined, leaving a single intervention group and a control group.	Data collection Incontinence was calculated as the percentage of time the patient was incontinent by dividing the incontinent episodes by the total number of voiding episodes, both continent and incontinent Voiding record Outcome measures Decrease in percentage of incontinent episodes versus staying the same or not showing improvement in incontinence Incontinence frequency Mobility Consistency in implementing the IST protocol MMAT score: 75%
Pre-Test/Post-test			
Study 9: Tanaka et al. 2009[153] Japan To investigate whether a system of individualized and comprehensive care was able to increase the intake of fluids and food, and to reduce the proportion of diaper users and the size of their diaper pads, thus leading to an enhanced quality of life	Setting Nursing homes (n=17) Participants Nursing home residents (n=122) Gender Female (85.2%) Age (mean) years 85.2 Mental status Dementia	Intervention Individualized and comprehensive care that focused on providing adequate fluids and meals, encouraging patients to use toilets and reducing the size of their diaper pads. This approach would differ significantly from the usual UI care in which diapers would be changed only at scheduled times	Data collection methods Water intake volume, condition of diapers (dry or wet), when residents wet their diapers were recorded in residents check sheets by staff Hours spent in wet diapers were calculated by subtracting the total time spent in dry diapers from 24h Types of pants or diapers (cloth pants, training pants, diaper, cloth diapers) and the size of pads (S, M, L, XL, 2XL) Method of daytime urination (Toilet, commode chair, urinary chamber pot, diaper Outcome measures Mean water intake volume Time spent in wet diapers (hours/day) Changing types of pants or diapers and the size of pads during daytime Change in method of daytime night-time urination

			MMAT score: 100%
Post intervention descriptive surveys			
Study 10: Gitlin and Corcoran 1993[156] USA To describe the use of the home environment by 17 spouse caregivers to manage problems associated with bathing and incontinence	Setting: Home Participants Spouse caregivers of elderly with dementia (n=17) Recruited from a network of local social services agencies Demographic characteristics of elderly PLWD not provided Mental status Physician's diagnosis of dementia	Intervention Individual treatment strategies delivered by an OT and designed to enhance the caregiver's ability to problem solve about their environment and to develop effective solutions to situations they considered problematic Data collection Data recording form completed by OT	Outcome measures Number of solutions which were implemented by a caregiver Number of solutions deemed ineffective and which were eliminated by the caregiver MMAT score: 75%
Study 11: Corcoran and Gitlin 2001[155] USA To describe the specific aspects of treatment that were accepted and utilized by 100 family caregivers	Setting: Home Participants Family caregivers in the treatment arm of a RCT (n=100) Recruited using media announcements and social service referrals Demographic characteristics of elderly PLWD not provided Mental status Physician's diagnosis of dementia	Intervention Environmental Skill-Building Program Home environment intervention delivered by OTs and included toileting and incontinence same as Gitlin and Corcoran 1993 Data collection Interviews to ascertain: The specific problems areas that were addressed in the intervention The specific strategies that the caregiver indicated a willingness to try (attempted) The strategies the caregiver actually used	Outcome measures Number and type of problem area Strategies for specific problems Strategies by environmental layers Acceptance and use of environmental strategies MMAT score: 75%
Study 15: Wijk et al., 2018[154] Sweden To operationalise, assess and evaluate the feasibility and preliminary effects of implementing a person-centred approach to incontinence care for older adults with cognitive decline in residential care facilities in Sweden	Setting Residential care facilities (n=3) Participants Health care workers (n=20) Residents with cognitive decline (n=54) Gender Female (59.9%) Age (mean+SD) years 83.9+8.72 Range 68 to 99 Mental status Cognitive decline MMSE score of 9.28 ±7.94	Intervention Person-centred approach focused on assessment and care planning to incontinence care over a 10-month period Training was provided over 5 sessions to teach participants how to tailor a person-centred incontinence plan At the end of the 10-month period the participants created guidelines to make change towards person-centred incontinence care sustainable	Data collection Health care records assessed by research team at baseline, immediately after and at 6 months Process outcome measures of the person-centred approach Impact outcome measures of participants quality of life Impact outcome measures of participants quality of care Outcome measures Quality of life in late stage dementia Continence status (totally independent – using the toilet with no need of any containment product; partly continent – continent if assisted when needing to go to the toilet with or without use of a containment product; totally incontinent – being dependent on containment products 24/7 and not managing by oneself

			Has basal assessment of incontinence been conducted? Have person centred actions been taken regrading incontinence? Has the resident been given adapted continence aids? MMAT score 75%

Key: CI: confidence intervals: C: control; I: intervention; IST: individualized scheduled toileting; MMAT: mixed methods evaluation tool; MSE: mental state examination; OT: occupational therapist; PLWD: people living with dementia; RCT: randomised controlled trial; RR: response rate; SPMSQ: Short Portable Mental Status Questionnaire; UI: urinary incontinence

Table 8: **Characteristics of included studies (care planning): Quantitative non-experimental studies**

Author/s, Year, Country **Aim**	**Setting** **Participants**	**Demographic details for PLWD**	**Methods** **MMAT score**
Cross sectional surveys			
Study 12: Shih et al. 2015[158] Taiwan To understand and compare the behavioural characteristics of bowel movement and urination needs in patients with dementia	Setting Long term care facilities (n=8) Day centre (n=1) Participants Residents (n=187)	Gender: Female (59%) Age (mean±SD) years 80.1 ±9.6 / Range 70 to 90 Mental status AD 38.5% Unspecified dementia 32.6% Vascular dementia 18.7% Other dementia 10.2%	Data collection Behaviour checklist for bowel and urination developed for the study Outcomes measures Symptoms and signs of bowel movement and urination expressed by the patient MMAT score: 100%
An adapted three-stage Delphi consultation study			
Study 13: Iliffe et al. 2015[159] UK Phase 4 The aim of this study was to develop and test a continence assessment tool and supporting resources for people with dementia, to be used by primary care professionals, primarily community nurses (p 95)	Setting Community Participants Stage 1 Carers and professionals (n=10) Stage 2 Carers and professionals (n=10) Specialist continence professionals (n=10) Stage 3 Carers (n=8) General Practitioner (n=2), Geriatrician/psychogeriatrician (n=1) Continence nurse specialist (n=3) District nurse/community nurse (n=7) Occupational Therapist (n=2) Other (n=3) (rr=26/50)	Not applicable Mental Status Dementia	Data Collection Stage 1: Face to face consultations were facilitated to describe a broad range of principles and issues that would underpin an assessment tool designed to address the needs of people with dementia Stage 2: A prototype dementia-focused continence assessment tool was developed using the data generated in stage 1, asking for agreement or disagreement to items plus suggestions for further items. This was used to consult, in writing, both the expert group in stage 1 and also a further group of carers and specialist continence professionals. The prototype was further adapted. Stage 3: A different, wider group of experts (carers and professionals) was consulted in writing. They were sent the draft dementia-focused assessment tool together with a questionnaire to test its face and content validity.

			Outcome measures Recipients were asked (1) whether or not the tool would improve recognition of the problems (face validity) and (b) to rate each item for importance and identify missing or unnecessary items (content validity) MMAT score: 75%

Key: AD: Alzheimer's disease

Appendix 8: Details of included grey literature

Document details	**Focus of material relevant to the review**
Web page 1. Alzheimer's Society 2011[166] Managing toilet problems and incontinence, Factsheet 502 Alzheimer's Society, London, UK	**Individualised care planning**
Book 2. Alzheimer's Society and Gray 2014[167] Support and care for people with dementia at home: A guide for homecare workers Alzheimer's Society, London, UK	**Communication**
Webpage 3. Dementia UK 2017[168] Continence Dementia UK, London, UK	**Communication**
Web page 4. Social care Institute for Excellence 2015[169] When people with dementia experience problems related to using the toilet Social Care Institute for Excellence, London, UK	**Communication**
Guideline 5. Alzheimer's Europe 2014[87] Guidelines on continence care for people with dementia living at home Alzheimer's Europe, Luzembourg	**Individualised care planning** **Communication**
Guideline 6. National Collaborating Centre for Mental Health (updated 2007)[1] A NICE-SCIE guideline on supporting people with dementia and their carers in health and social care Clinical guideline [CG42] The British Psychological Society & The Royal College of Psychiatrists, Leicester, UK	**Communication**
Report 7. Thompson et al. 2013[172] Dementia: Commitment to the care of people with dementia in hospital settings Royal College of Nursing, London, UK	**Individualised care planning**
Guidance	**Individualised care planning**

8. Potter 2015[174] Excellence in continence care; Practical guidance for commissioners, providers, health and social care staff and information for the public NHS England, Reading, UK	
Report 9. Care Quality Commission 2014[171] Cracks in the pathway. People's experiences of dementia care as they move between care homes and hospitals Care Quality Commission, Gallowgate, UK	**Communication**
Web based booklet 10. Care Inspectorate 2015[170] Promoting continence for people living with dementia and long term conditions Care Inspectorate, UK	**Individualised care planning** **Communication**
Framework 11. Ostaszkiewicz et al. 2017[175] Dignity in Continence Care Framework Ostaszkiewicz et al., Australia	**Communication** **Individualised care planning**
Model 12. Ostaszkiewicz et al. 2018[176] Model of Attributes to Abuse of Dependent Elders in Continence Care" (MADE-CC) Ostaszkiewicz et al., Australia	**Communication**
Guideline 13. Abrams et al, 2017[173] 6th International Consultation on Incontinence International Continence Society, Bristol, UK	**Individualised care planning**
Information sheet 14. Alzheimer Scotland 2009[177] Continence management – advice for carers of people with dementia Alzheimer Scotland, UK	**Communication**

Appendix 9: Studies excluded after full text screening

Burkhard et al. 2018: Clinical guideline for the European association of Urology: Urinary incontinence.
Reasons for exclusion: No data on people living with dementia, Alzheimer's disease or cognitive impairment within the guideline

Billing et al. (2009): Privacy and Dignity in continence care project
Reasons for exclusion: Sample was people over 65 years of age who had the cognitive and linguistic ability to participate

National Institute for Health and Care Excellence (2014): Faecal incontinence in adults. Clinical guideline 49
Reasons for exclusion: No data on communication of individualised care plans in the section relevant for people living with dementia

Royal College of Psychiatrists: National audit of dementia care in general hospitals 2016-2017. Third round of audit report
Reasons for exclusion: Continence only mentioned in relation to assessment

Royal College of Physicians 2010: National audit of continence care
Reasons for exclusion: No data on for people living with dementia, Alzheimer's disease or cognitive impairment within the guideline

Albert 1999: The caregiver as part of the dementia management team
Reasons for exclusion: Not about toileting or incontinence

Allwood et al. 2017: Should I stay or should I go? How healthcare professionals close encounters with people with dementia in the acute hospital setting
Reasons for exclusion: Not about toileting or incontinence

Burgener et al. 1992: Caregiver and environmental variables related to difficult behaviors in institutionalized, demented elderly persons
Reasons for exclusion: Not about communication in relation to toileting

DiZazzo et al. 2014: Addressing everyday challenges: feasibility of a family caregiver training program for people with dementia
Reasons for exclusion: Research covers communication in relation to nutrition and transfer and toileting but not about communication in relation to toileting

Ghatak 2011: A unique support model for dementia patients and their families in a tertiary hospital setting: description and preliminary data
Reasons for exclusion: Support program for dementia carers and not about communication in relating to toileting

Lanciono et al. 2013: Supporting daily activities and indoor travel of persons with moderate Alzheimer's disease through standard technology resources
Reasons for exclusion: Not about communication in relation to toileting

Moyle et al. 2016: They rush you and push you too much ... and you can't really get any good response off them': A qualitative examination of family involvement in care of people with dementia in acute care
Reasons for exclusion: Not about communication in relation to toileting

Norbergh et al. 2001: How patients with dementia spend their time in a psycho-geriatric unit
Reasons for exclusion: Not about communication in relation to toileting

Panella 1986: Toileting strategies in day care programs for dementia
Reasons for exclusion: Discussion article

Perilli et al. 2013: Video prompting versus other instruction strategies for persons with Alzheimer's disease
Reasons for exclusion: Not about communication in relation to toileting

Tales et al. 2017: Dementia-friendly public toilets
Reasons for exclusion: Correspondence piece

Uchimoto et al. 2013: Investigation of toilet activities in elderly patients with dementia from the viewpoint of motivation and self-awareness
Reasons for exclusion: Not about communication in relation to toileting

Warkentin 1992: Implementation of a urinary continence program
Reasons for exclusion: Not about communication in relation to toileting

Williams et al. 1995: Patients with dementia and their caregivers 3 years after diagnosis. A longitudinal study
Reasons for exclusion: Not about communication in relation to toileting

Svedas and Wise 2012: Improving bowel care in residential aged care facilities
Reasons for exclusion: Not about individualised care plans and continence care

Bucci 2007: Be a continence champion: Use the CHAMP tool to individualise the plan of care
Reasons for exclusion: Discussion article

Rogers et al. 1999: Improving bowel care in residential aged care facilities
Reasons for exclusion: Not about individualised care plans and continence care

Corcoran et al. 2002: An occupational therapy home-based intervention to address dementia-related problems identified by family caregivers

Reasons for exclusion: No data regarding individualised care plans and continence care

Prizer and Zimmerman 2018: Progressive support for activities of daily living for persons living with dementia
Reasons for exclusion: Not about individualised care plans and continence care

Drennan et al. 2017: Meeting the needs of older people living at home with dementia who have problems with continence
Reasons for exclusion: Not about individualised care plans and continence care

Olthof-Nefke et al. 2018: Improving communication between persons with mild dementia and their caregivers: Qualitative analysis of a practice-based logopaedic intervention
Reasons for exclusion: Not about communication in relation to toileting

Soderman et al. 2018: Caring and uncaring encounters between assistant nurses and immigrants with dementia symptoms in two group homes in Sweden - an observational study
Reasons for exclusion: Not about communication in relation to toileting

Dahlke et al. 2019: The educational needs of nursing staff when working with hospitalised older people
Reasons for exclusion: Not about the care of people living with dementia

Foster et al. 2019: Patient-centred care training needs of health care assistants who provide care for people with dementia
Reasons for exclusion: Not about toileting or incontinence

Samuelsson et al. 2019: Digital communication support in interaction involving people with dementia
Reasons for exclusion: Not about communication in relation to toileting

Stanyon et al. 2019: Effects of care assistant communication style on communicative behaviours of residents with dementia: a systematic multiple case study
Reasons for exclusion: Not about communication in relation to toileting

Mariana et al. 2018: The impact of a shared decision-making training program on dementia care planning in long-term care
Reasons for exclusion: Not about toileting or incontinence

Villar et al. 2018: Involving institutionalised people with dementia in their care-planning meetings: lessons learnt by the staff
Reasons for exclusion: Not about toileting or incontinence

Yenisehir et al. 2019: Knowledge and practice of nursing home caregivers about urinary incontinence

Reasons for exclusion: Not about toileting or incontinence

Commented [PB1]: Duh? Is this right?

Appendix 10: Studies excluded on critical appraisal

Tarrier and Larner 1983: The effects of manipulation of social reinforcement on toilet requests on a geriatric ward
MMAT[144] score 50% with the following questions being answered no:
Are participants (organizations) recruited in a way that minimizes selection bias?
In the groups being compared, are the participants comparable, or do researchers take into account the difference between these groups?

Colling et al. 1992: The effects of patterned urge-response toileting (PURT) on urinary incontinence among nursing home residents
MMAT[144] score 25% with the following questions being answered no:
Are participants (organizations) recruited in a way that minimizes selection bias?
In the groups being compared, are the participants comparable, or do researchers take into account the difference between these groups?
Are there complete outcome data (80% or above), and when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?

Williams 2011: Hospital programme for dementia-specific care
MMAT[144] score 0% all the questions were given an answer of no

Duncan 2002: Development of a continence management chart for carers of people with dementia who have functional incontinence
MMAT[144] score 0% all the questions were given an answer of no

Appendix 11: Methodological quality

Qualitative studies

Four of the six qualitative studies fulfilled all four quality criteria on the MMAT, with the remaining two studies fulfilling three of the quality criteria, but did not report whether the researchers' role might influence the outcome of the study.[165,178]

Quantitative studies

One study was a quantitative randomised controlled trial which fulfilled three out of the four quality criteria, with the complete outcome data (80% or above) not reported.[152] There were six quantitative non-randomised studies and of these three fulfilled all four quality criteria,[150,151,153] within the remaining three studies the criteria that were not fulfilled was that we were unable to ascertain the response rate for the sample.[155,156] and the authors did not compare the baseline characteristics between those in the control and intervention groups.[154] The remaining three studies were quantitative descriptive and two studies fulfilled all four criteria[157,158] and for the study that that didn't, we were unable to ascertain what the response rate was for the sample.[159]

Appendix 12: CerQual and GRADE summary statements

Theme 1: Communication that is dignified, person centred and respectful

Communicating in a dignified way

1. PLWD & their carers find talking about incontinence distressing and embarrassing
CERQual:Moderate / Studies 2, 3,4

2. HCPs to build trust and rapport through using humour, having appropriate knowledge and skills by speaking quietly and keeping incontinence issues secret
CERQual:Moderate / Studies 2, 3,4

The attitudes of HCPs towards continence and continence care

3. HCPs often ignore toileting requests or avoid routine toileting citing being busy or being uncomfortable with or disinterested in toileting
CERQual: Moderate/ Studies 2, 14

4. Staff in acute settings do not consistently promote continence
CERQual: Very Low / Study 14

5. HCPs having respect building relationships and using appropriate language
CERQual: Very Low / Study 2

6. Interpersonal and communication skills are important and should be a focus of education programs [175,176]
(non-research: ungraded)

The importance of non- verbal cues

7. PLWD are not always able to recognise and communicate that they need to go to the toilet or indicate that they assistance [87,169–171] and they use a variety of non-verbal cues [1,87,168,170,171,174,176]
CERQual: High: Studies 1, 2, 3, 4, 5, 6, 7, 10, 11, 12 and non-research: ungraded

8. HCPs checking PLWD awareness of communication techniques including non-verbal cues through communicating with the family
CERQual: Moderate/ Studies 2, 13

9. HCPs being able to recognize the non-verbal signals, body language, facial expressions, behaviours and signs that PLWD use to communicate that they need to go toilet is crucial [168–170] and this should be a focus education programs for new staff CERQual: Moderate/ Studies 2, 12 and non-research: ungraded
Finding the appropriate words and symbols to describe the toilet
10. Finding out what words or phrases that PLWD use for describing the toilet is seen as important [1,168,170,171] CERQual: Very Low Study 7 and non-research: ungraded 11. People living with moderate dementia preferred the word toilet compared to those with no cognitive impairments and those with advanced dementia preferred the international symbol for toilet compared to those with mild dementia or no cognitive impairment CERQual: Very Low / Study 7
Strategies for improving communication
12. HCPs introducing themselves and seeking PLWD approval before performing tasks CERQual: Very Low / Study 4 13. A range of strategies have been identified that include getting to know the PLWD & how they communicate and manage their continence, communicating with the family, prompting, seeing the person has an individual, and checking HCPs communication skills [1,87,169–171] CERQual: Moderate / Studies 4, 13 and non-research: ungraded
Using technology to present instructions
14. Verbal instructions, presented automatically through simple technology has the potential to be effective in helping persons with mild or moderate AD go to the toilet independently by presenting simple step wise sequential instructions Grade: Very Low / Studies 5, 6
Theme 2: Communication during outpatient appointments
Presence of PLWD during outpatient consultations
15. Caregivers felt having the PLWD with them during outpatient consultations could cause unnecessary anxiety CERQual: Very Low / Study 1 16. Caregivers felt having the PLWD with them during outpatient consultations would allow greater cooperation with management strategies

CERQual: Very Low / Study 1

17. HCPs felt it was important that PLWD were present at appointments
CERQual: Very Low / Study 3

Initiating conversations during outpatient consultations

18. Uncertainty over who should initiate conversations during consultations
CERQual: Very Low / Study 3

19. HCPs suggested developing a pre-visit checklist to prompt conversation during consultations
CERQual: Very Low / Study 3

The language of incontinence during outpatient consultations

20. Incontinence and management options are often explained in terms that caregiver find difficult to understand.
CERQual: Low / Studies 1, 3

21. Caregivers and HCPs suggested a variety of written information resources that could be provided
CERQual: Low / Studies 1, 3

Theme 3: Delivering individualised continence care

Importance of individualised continence care

22. Targeted and individualised/person centred continence care that is established after a thorough assessment has taken place is seen as important [87,166,170,172,173,175–177]
non-research: ungraded

23. Individualized continence care is about what is best for the PLWD and avoiding harm and about promoting autonomy and independent living.[87]
non-research: ungraded

Components of individualised care planning

24. Individualised care planning should consider the needs of both PLWD and their caregivers and involve multi-components exploring both day-time and night care of incontinence are helpful in addressing incontinence in the home care setting.[87,166,172–175]
non-research: ungraded

25. An intervention that involved individualized and comprehensive care for residents in a care home that focused on providing adequate fluids and meal by encouraging patients to use toilets was effective for 19% of residents in reducing the proportion of continence pads used
Grade: Very Low / Study 9

26. An intervention that involved individual treatment strategies delivered by an occupational therapist and designed to enhance the caregiver's ability to problem solve about their environment. A post intervention survey reported that this approach enabled caregivers to develop effective solutions to situations they considered problematic which included toileting
CERQual: Low / Studies 10, 11

27. An intervention that involved training health workers in person centred care was effective in improving the quality of care and a reduction in the number of aids needed to manage incontinence
GRADE: Very Low / Study 15

Health care professionals and caregivers working in partnership

28. It is important that HCPs and caregivers work together to deliver individualised/person centred continence care.[166,170,172,174]
non-research: ungraded

Establishing a toileting routine within the home environment

29. The importance of developing a regular toileting schedule was highlighted by caregivers [87]
CerQUAL: Very Low / Study 10 / non research: ungraded

30. An individualized scheduled toileting program that compensated for cognitive impairment by providing memory-impaired patients with toileting reminders was not shown to have any significant benefits in terms of improving the number of incontinent episodes for PLWD in a home care setting
Grade: Very Low / Study 8

Key: HCP: health care professional; PLWD: People living with dementia