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Understanding how to facilitate continence for people living with dementia in acute hospital settings: raising awareness and improving care

Submission date 05/08/2019	**Recruitment status** No longer recruiting	☐ Prospectively registered ☐ Protocol
Registration date 15/08/2019	**Overall study status** Completed	☐ Statistical analysis plan ☐ Results
Last Edited 18/11/2019	**Condition category** Mental and Behavioural Disorders	☐ Individual participant data ☐ Record updated in last year

Plain English summary of protocol

Background and study aims

Going to the toilet in private is one of the most fundamental measures of human dignity, and incontinence can impact on feelings of being a person and their wider social status. When people with dementia are admitted to hospital wards, this requires the assistance of nurses or health care assistants. During our current study examining what happens when patients with dementia refuse hospital care, we have noticed that toileting is an important trigger that can lead to significant distress for patients (if immediate toileting assistance needs are not met), for families (who see their loved one in undignified circumstances) and for other patients (who may become afraid by the other person's distress) and can increase the potential for dehumanization (staff not recognizing the person or their needs). When a patient with dementia is in hospital, it is often usual for staff to use incontinence pads or to insert a urinary catheter rather than help the person to go to the toilet. This is often because continence problems are a risk factor for falls. However, catheters can lead to significant risks of infection (that can become life-threatening) and not being able to independently go to the toilet, can reduce their opportunities to regain mobility and independence. This means that hospitals may be causing incontinence in patients with dementia.

Our consultations with carers identified that they had a lot of anger about continence care when their partner with dementia was in hospital. There was a general belief that catheterisation of patients with dementia was often for convenience, due to staff shortages, to prevent wet beds, and to reduce calls for help. Many reported that their partner with dementia, who was continent, became classified as incontinent within days of admission and required catheterisation.

In response, our study will conduct detailed research observing how ward staff and clinical teams care for patients with dementia during their admission. We will describe how toileting practices and routines impact on the care of people with dementia in acute hospital wards within three hospitals in different parts of England and Wales. During our observations we will carry out in-depth case studies of patients and interview them and their families about their experiences. Because there is very little published research on continence care for patients with dementia in hospitals, we will also review the literature to identify successful strategies used in other care settings. This will help us to bring together the knowledge that exists on how to promote the best ways to manage the toileting needs of patients with dementia in hospital wards.

At the end of the project we will provide a detailed understanding of how hospital care could change to improve care and the experiences of patients and their families. We will use this detailed research to develop new training and information for hospital staff and families. This will include raising awareness of the risks associated with current practices, and will have made this available across different organisations such as the Royal College of Nursing and open access formats accessible for anyone caring for a person with dementia via the Internet. We will also identify alternative ways to manage this important but neglected issue that can be implemented in wards and tested in future research studies. Our goal is to improve everyday care for patients with dementia in all hospitals.

Who can participate?
Patients with dementia, carers, family members and ward staff.

What does the study involve?
Patients with dementia, carers, family members and ward staff will be observed and interviewed over an 8-week period.

What are the possible benefits and risks of participating?
Benefits: participants will appreciate the interest and concern and the need for evidence to support the delivery of appropriate care for people living with dementia during a hospital admission.
Risks: there will be negligible risk to a participants physical health, but there is potential for intrusion, stress or distress as a result of being observed during data collection.

Where is the study run from?
Llanfrechfa Grange Hospital, UK

When is the study starting and how long is it expected to run for?
October 2018 to April 2020

Who is funding the study?
National Institute for Health Research (NIHR), UK

Who is the main contact?
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Contact information

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Scientific

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Additional identifiers

Clinical Trials Information System (CTIS)
Nil known

ClinicalTrials.gov (NCT)
Nil known

Protocol serial number
4804

Study information

Scientific Title
Understanding how to facilitate continence for people living with dementia in acute hospital settings: raising awareness and improving care

Study objectives

Evidence is required to identify appropriate strategies and service improvements that can support and assist nurses and HCAs to deliver effective care to people living with dementia.

Ethics approval required

Old ethics approval format

Ethics approval(s)

Approved 19/04/2018, NHS REC Wales REC 3 (Health and Care Research Wales Support and Delivery Centre, Castlebridge 4, 15-19 Cowbridge Road East, Cardiff, CF11 9AB; +44 (0) 2920785736; Wales.REC3@wales.nhs.uk), ref: 18/WA/0033

Study design

Observational qualitative study

Primary study design

Observational

Study type(s)

Quality of life

Health condition(s) or problem(s) studied

Dementia

Interventions

This ethnography will examine everyday continence care for people with dementia (PWD) in acute hospital wards. An initial systematic narrative review to identify successful strategies for the organization and culture of continence care used across care settings that could inform innovations will (1) refine our approach to fieldwork and analysis (2) inform the development and feasibility of interventions to inform continence care in terms of possible mechanisms, content, delivery, and potential outcomes (3) provide an overarching conceptual model.

Data collection (observation, ethnographic and in-depth interviews) will take place in wards that exemplify the challenges of caring for a large number of PWD within 3 acute hospitals (1xMAU and 1x general medical, total: 6 wards). Potential impacts lie in the new learning drawn from the systematic and detailed observation of everyday continence care for PWD in acute wards.

People living with dementia are also at significant risk of developing incontinence and classified as incontinent during an acute hospital admission. However, incontinence has important implications for patient outcomes. It is a common risk factor for falls and infections, which in turn are associated with prolonged hospitalisation, re-admission and increased mortality. Enhancing the opportunities for people living with dementia to keep control over their most private of functions can enhance independence, rehabilitation and reduce lengths of stay. Although new approaches are needed, the research agenda lags behind. While there is a larger body of work providing the evidence base for continence treatment and care management interventions in long-term care settings, no UK studies have examined toileting practices or continence care in acute hospital wards.

Ethnographic observation will focus on the visible work of nurses and healthcare assistants (HCAs) involved in continence care (30 x days/shifts per ward, total = 180 days) to explore how staff respond to continence needs for people living with dementia. Within each acute hospital ward we will carry out 8 weeks of detailed data collection, followed by a further 8 weeks follow-up (case study interviews and additional observation) to examine the implications of continence care practices for PWD discharge and care trajectories. Fieldwork will always preserve patient dignity (this study will not and does not need to go 'behind the screens' to observe intimate care. Short ethnographic interviews with ward staff (20-30 per ward, total = 120-180) as they are caring for this patient group (focus on nurses, HCAs, including the medical team (FY1/2, StRs, consultants), AHPs (physiotherapy, OT) when relevant to continence care). This allows us to question routine practice and decision making when interacting with PWD.

Routine data (from ward managers and patient records) about staffing levels, work allocation, bed occupancy, patient acuity, turnover and the recorded levels of incontinence and catheterization, to provide context and an understanding of workload.
Case studies with people living with dementia and family carers will be identified using purposive sampling will be followed from admission through to discharge and short term care pathways into the community (2 x PWD per ward, total = 12) to examine the impacts and consequences of continence care on patient experiences and discharge pathways. Interviews with PWD (12) and family carers (12-24) (total= 24-36) and observation of decision-making processes, (e.g. multidisciplinary meetings) to examine the implications for discharge planning.

Analysis will follow the analytic tradition of grounded theory and employ the constant comparative method and theoretical sampling whereby data collection and analysis are interrelated and occur concurrently. Analysis of observational data will be triangulated with patient, carer, and staff interviews.

Intervention Type
Other

Primary outcome(s)
1. A systematic narrative review to identify strategies to inform the organization and culture of continence care that could inform innovations in continence care for people living with dementia in the acute hospital setting
2. Ethnographic observation will focus on the visible work of nurses and healthcare assistants involved in continence care to explore how staff respond to continence needs for people living with dementia
3. Short ethnographic interviews with ward staff will allow us to question routine practice and decision making when interacting with people living with dementia
4. Case studies with people living with dementia and family carer to examine the impacts and consequences of continence care on patient experiences and discharge pathways

Key secondary outcome(s))
None

Completion date
30/04/2020

Eligibility

Key inclusion criteria
Diagnosis of dementia present in medical records

Participant type(s)

Patient

Healthy volunteers allowed
No

Age group
Adult

Sex
All

Total final enrolment
108

Key exclusion criteria
Does not meet inclusion criteria

Date of first enrolment
01/10/2018

Date of final enrolment
31/10/2019

Locations

Countries of recruitment
United Kingdom

Wales

Study participating centre
Aneurin Bevan University Health Board
Llanfrechfa Grange Hospital
Llanfrechfa
Cwmbran
United Kingdom
NP44 8YN

Sponsor information

Organisation
Cardiff University

ROR
https://ror.org/03kk7td41

Funder(s)

Funder type
Government

Funder Name
Health Services and Delivery Research Programme

Alternative Name(s)
Health Services and Delivery Research (HS&DR) Programme, NIHR Health Services and Delivery Research (HS&DR) Programme, NIHR Health Services and Delivery Research Programme, HS&DR Programme, HS&DR

Funding Body Type
Government organisation

Funding Body Subtype
National government

Location
United Kingdom

Results and Publications

Individual participant data (IPD) sharing plan
The datasets generated during and/or analysed during the current study are not expected to be made available. For reasons of participant anonymity, the full dataset for this study will be stored privately and securely by Cardiff University and destroyed after 15 years in line with Cardiff University's data management rules. Anonymised sections of data will be published where appropriate, for example in academic journals.

IPD sharing plan summary
Available on request

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
HRA research summary			28/06/2023	No	No
Participant information sheet	Participant information sheet	11/11/2025	11/11/2025	No	Yes
Study website	Study website	11/11/2025	11/11/2025	No	Yes