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

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Summary

This ethnography will use a number of sites of observation (Marcus, 1995, 1998) to examine everyday continence care for people living with dementia within acute hospital settings and how these routines impact on care trajectories and discharge pathways. An ethnographic approach is particularly useful to answer research questions and topics where measurement is either not easy or inappropriate, where the aim is to access the unspoken and tacitly understood (Dixon-Woods, 2003), for examining complex social relations, exposing institutional forces and cultures, as they influence every day interactions and routines (Greenhalgh and Swinglehurst, 2011;) and invisible work (Star, 1999).

A narrative synthesis (Popay et al, 2006) will be carried out to identify successful strategies in other care settings that could inform innovations in continence care for people living with dementia in the acute hospital setting. Fieldwork will be carried out within 3 acute hospitals in two different wards which exemplify the challenges of a large number admissions of people living with dementia (e.g. Medical Admissions Unit and general medical wards). Agreements are in place with 3 acute

hospitals in South Wales, the South of England and the Midlands to minimize the bias of a single site and allow for a diversity of geographic, demographic and practice variables. Data collection will involve:

- Observation will concentrate on the visible work of nurses and HCAs (Healthcare Assistants) who are responsible for continence care (30 x days/shifts per ward, total=180 days). Focusing on ward routines where toileting may take place or be prompted, including observation rounds, cleansing routines, medication rounds, meal times.
- Short ethnographic interviews: with ward staff (20-30 per ward, total=120-180) as they are caring for this patient group (focusing on nurses, HCAs, and may include other disciplines (Foundation Doctor (FY1/FY2), Speciality Registrar posts (SpR), consultants, AHPs (Physiotherapy, Occupational Therapy)), and staff with co-ordinating responsibilities (ward Clerk, discharge co-ordinators) when involved in continence care. This will allow us to question routine practice and decision-making when interacting with people living with dementia.
- Routine clinical setting data: (from ward managers and patient records) about staffing levels, overall work allocation, bed occupancy, patient acuity, turnover and the recorded levels of incontinence and catheterisation within each ward at the time of fieldwork to provide context and an understanding of workload.

A series of case studies with patients and their family carers: Detailing initial admission through to discharge and short-term care pathways (2 x patient per ward, total sample =12) to examine the impacts and consequences of continence practices on patient experiences and discharge pathways. Sampling will include patients who represent a range of presenting, diagnostic and prognostic factors, and where possible, socio-demographic factors to include patients with a range of continence, toileting and catheterisation needs:

- In-depth interviews with patients (n=12), and their family carers (n=12-24), to explore their experiences of care and continence needs during their stay in the ward and after discharge. Interviews will be carried out during admission and up to 8 weeks following discharge (n=48-72).
- Observation of continence care decision making, including where possible multidisciplinary best interests meetings, discharge and returning to home or to long-term care for this group.
- Medical records for each case study will also be examined.

Follow-up data collection (10 days/shifts over 8 weeks per site) will be required within each institution (to carry out interviews and additional observation of decision making processes, such as the multidisciplinary meetings) to examine the implications for more effective longer-term care and discharge planning.

The potential impact lies in the improved understandings of current service delivery, organizational, and interactional factors that may impede or facilitate dignified continence care and improved knowledge of how to enhance outcomes and experiences of care for this vulnerable group.

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Background

Continence care for people living with dementia within hospitals goes beyond basic care, it is also a Human Rights issue. 'Toilet Access and Use' is identified as a key marker of Human Rights and dignity (Morris, 2007). The Parliamentary Joint Select Committee on Human Rights highlights discrimination towards people living with dementia, and the lack of dignity around personal care needs (House of Lords, 2006-07). This is reflected in the experiences of carers and families (Alzheimer's Society, 2008; Lakey, 2009), with almost 60% believing that people living with dementia were not treated with dignity in acute hospitals (Alzhimer's Society, 2016). Quality care does not only encompass effectiveness but humanity and equity. This study brings rigour to improving all of these aspects of acute hospital care for people living with dementia.

Continence care (continence care, incontinence care, toileting, and catheter care) for people living with dementia in acute hospitals is a continued concern for families, carers (Alzheimer's Society 2008; Lakey, 2009; Patients Association, 2009; Department of Health, 2006) and policymakers (NICE and SCIE, 2006; Operating framework for the NHS, November 2011). The acknowledgement of systemic failure within the NHS in providing elderly and vulnerable patients with dignified, compassionate continence care is highlighted within a large number of service reviews and enquiries (Mid Staffordshire NHS Foundation Trust Public Inquiry 2013a; House of Lords House of Commons Joint Committee on Human Rights, 2006-7:15; Patients Association, 2009; Department of Health, 2006; Nottingham City and Nottinghamshire County Joint Health Scutiny Committee 2010). Carers report high dissatisfaction in continence care for people living with dementia (60%), with hospital-acquired incontinence frequently reported as the key long-term, physical result of their acute hospitalization post-discharge (Alzhimer's Society, 2016).

Patients with dementia in the acute setting may be at high risk of 'functional incontinence', when their cognitive impairment, mobility problems, or medication means they cannot reach the toilet in time (Yap and Tan, 2006; van Houten, 2008) as a result of the environment they are in, rather than a feature of their dementia (Alzheimer's Europe, 2014). A small number of international audits in acute hospital settings reflect these high rates, and have identified that people living with dementia who are not incontinent at admission are at significant risk of developing incontinence during an acute hospital admission with this persisting and becoming permanent by discharge (Furlanetto and Emond 2016; Zisberg et al 2011; Mecocci et al 2005). It is estimated that between 17% (Zisberg et al 2011) and 36% (Furlanetto and Emond, 2016) of previously continent people living with dementia will have lost their continence following an acute hospital admission.

These high rates of the development of incontinence during hospitalization were associated with a number of hospital organisational, treatment, and demographic factors. A primary provisional diagnosis of delirium, dementia or cognitive impairment being the most significant risk factors (Mecocci et al 2005), more than doubling the risk of developing incontinence (Rabinowitz et al 2011), increasing length of stay (Furlanetto and Emond, 2016), advanced age (85+ years) (Mecocci et al 2005; Rabinowitz et al 2011), gender (women are more at risk) (Rabinowitz et al 2011), and poorer mobility and physical functioning (Rabinowitz et al 2011). The use of adult diapers, pads and urinary catheters (Zisberg et al 2011), use of chair restraint (Rabinowitz et al 2011) and patients experiencing the symptoms of drowsiness, daily pain, and sleep problems (Rabinowitz et al 2011), were all associated with increased risk of developing incontinence by discharge leading to a permanent diagnosis.

However, there is a paucity of evidence of understanding the impact of continence care, and the development of new onset incontinence among older adults and people living with dementia during their hospitalization is an understudied phenomenon (Hägglund, 2010). Prior to developing interventions, detailed research is required to develop evidence-based and appropriate interventions to manage continence care for people living with dementia (Hägglund, 2010).

Research question

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?

Aims and objectives

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

Research plan/Methods

This ethnography will use a number of sites of observation (Marcus, 1995, 1998) to examine everyday continence care for people living with dementia within acute hospital settings and how these routines impact on care trajectories and discharge pathways. An ethnographic approach is particularly useful to answer research questions and topics where measurement is either not easy or inappropriate, where the aim is to access the unspoken and tacitly understood (Dixon-Woods, 2003), for examining complex social relations, exposing institutional forces and cultures, as they influence every day interactions and routines (Greenhalgh and Swinglehurst, 2011;) and invisible work (Star, 1999).

Narrative Synthesis Prior to data collection, we will carry out a mixed methods systematic narrative review to identify successful strategies in care settings that could inform innovations in continence care for people living with dementia in the acute hospital setting. Our objectives are to identify: (1) What is already known about continence practices for people living with dementia; (2) Interventions for continence care in people living with dementia to identify what works, for whom and in what circumstances. (3) The expertise and organisational barriers to the provision of good care in response to continence for people living with dementia. Informed by the Evidence for Policy and Practice Information and Co-ordinating Centre (EPPI, 2007) approach, we will include quantitative, qualitative, and non-research material (e.g. policies and guidelines) and bring these strands together into an overall synthesis.

Search strategy: A search (database inception to current) will be undertaken across a number of bibliographic databases (ASSIA, CINAHL, the Cochrane library, EMBASE, ERIC, Medline, PsycINFO, BNI, DARE, TRIP, Scopus, Web of Science, OpenGrey) for English language publications. Keywords and index terms identified as relevant and reflecting the project's agreed priorities will be used and individual search strategies developed for each database. Articles will be included that focus on or contain an element relating to each of the following: (1) The care of people living with dementia or Alzheimer's or cognitive impairment (2) The long-term and community healthcare and home settings (4) urinary or faecal continence/incontinence issues or toileting or catheterisation.

Screening, selection and appraisal: This will be conducted using the Centre for Reviews and Dissemination approach (CRD, 2009). Titles and abstracts of articles retrieved; relevant full papers retrieved, read by 2 team members and assessed against inclusion criteria, with a third reviewer consulted where there are disagreements. Next full text papers of relevant citations will be retrieved and screened against inclusion criteria. Quality of research will be appraised using checklist (CASP, 2013) or other checklists where appropriate. Data from all included papers will be extracted into tables.

Consultation with stakeholders: To ensure the focus of the review is relevant to the needs of people living with dementia, and to the context of the acute setting, we will follow the EPPI Centre approach (EPPI, 2007) by presenting and discussing initial thematic findings with stakeholders to invite debate and opinions to identify the priority areas to be taken within the review. The stakeholder consultation (n=15-20) will include experts in continence care, dementia and the acute setting: people living with dementia and family carers (Kennedy, 2003; Johansson, 2014), and staff working in the acute setting.

Outputs: EPPI use the aggregated approach to synthesis (Sandelowski, et al, 2012), and the likely heterogeneity of the papers to be included, means that the materials will be brought together within a series of individual narrative syntheses focusing on the priority areas identified from the stakeholder consultation, a final over synthesis will be carried out. A narrative approach bridges the gap between research, policy and practice (Popay et al 2006:2). It is of particular use to examine the complexities of health service settings and where the evidence of intervention effectiveness is weak, because it can be used to hypothesise how to develop and refine interventions (Snilstveit et al 2016:425). The narrative syntheses generated will be used in three ways (1) refine our approach to fieldwork and analysis, (2) inform the development and feasibility of interventions for continence care in terms of possible mechanisms, content, delivery, and potential outcomes achievable in the acute hospital setting, and (3) provide an overarching conceptual model.

Data collection and analysis

Our approach will be in the analytic tradition of grounded theory and employ the constant comparative method and theoretical sampling whereby data collection and analysis are interrelated (Glaser and Strauss, 1967; Corbin and Strauss, 1990) and carried out concurrently (Green, 1998; Suddaby, 2006). The flexible nature of this approach is important, because it can allow us to increase the 'analytic incisiveness'

(Charmaz and Mitchell, 2001:160) of the ethnography: as data are collected in one site, preliminary analysis of this will proceed in parallel, with this preliminary analysis informing the focus of later data collection within the next site and the further stages of analysis.

Grounded theory (Glaser and Strauss,1967) is a practical and flexible approach for ethnographic research (Charmaz and Mitchell, 2001). It reinforces the ethnographic aims of achieving a theoretical interpretation of the data, whilst the ethnographic approach prevents grounded theory from being applied in a mechanistic and rigid way (Charmaz and Mitchell, 2001). A common concern with an ethnographic approach is that it can treat everything within a setting as data, which can lead to the ethnographer collecting large volumes of unconnected data and producing a heavily descriptive analysis (Atkinson and Coffey, 1996). Grounded theory provides the ethnographer with focus and strategies for data collection in order to study social processes. This approach provides a middle ground in which the ethnographer, often seen as a passive observer of the social world, uses grounded theory to provide a systematic approach to data collection that can be used to develop theory to address the interpretive realities of the range of actors within a setting (Charmaz and Mitchell, 2001).

Data collection

Multi-sited ethnography is an exercise in 'mapping terrain', where the goal is not 'representation' but to identify social processes within the data. Although we are interested in speech acts, communication is also expressed non-verbally. There are multiple complex and nuanced interactions within these clinical settings that are capable of 'communicating many messages at once, even of subverting on one level what it appears to be "saying" on another' (Turner 1986:24). Thus, it is important to observe interaction and performance; how continence care work is organised and delivered, how continence is managed, plus the backstage talk and informal conversations within the setting. It 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 (Charmaz and Mitchell, 2001). By obtaining data from within each institution we can explore how acute hospital organisation, procedures and everyday care, impact on continence care and the implications for longer-term care.

Ethnographic observation

Fieldwork will be carried out within 3 acute hospitals across the UK in sites of care (2x wards), which are known to have a large number of people living with dementia (MAU and general medical wards). By obtaining data from within each institution on everyday continence care practices, the perspectives of patients, their family carers and the nursing and health care assistants who carry out this work, we can explore how acute hospital organisation, procedures and everyday care, impact on the patient experience of continence care during an acute hospital stay.

Within each institution we will carry out 8 weeks of detailed fieldwork, followed by a further 8 weeks of follow-up data collection (case study interviews and additional observation) so that we can examine the implications of continence care practices for discharge and long-term care trajectories. Fieldwork will always preserve patient dignity (*this study will not and does not need to go 'behind the screen' to observe intimate care*) and our observational strategy will provide an in-depth evidence based analysis of the management and context of continence care within wards:

- Non-participant observation, concentrating on the visible work of nurses and HCAs who are responsible for continence, toileting and catheter care. Other healthcare staff will also be included as they are involved in wider assessment and decision-making around continence for this patient group.
- Focus on ward routines where toileting may take place or be prompted, including observation rounds, cleansing routines, medication rounds, meal times.
- Focus on responses to personal alarms, calls for assistance and decisions to prioritize or defer, to examine the classification, urgency and management of patient toileting needs when it may disrupt ward routines and schedules.
- Examine communication and language around continence, toileting and catheterisation and everyday interaction and strategies used within the wards between staff, with people living with dementia and with their families.
- Focus on the ward practices of assessment and management of continence and incontinence for people living with dementia by ward staff (nurses and HCAs), the medical teams and other staff (particularly nurse practitioners, or equivalent, AHPs) when they are involved in continence care, assessment and decision-making.
- Observe shift handovers to examine everyday ward classification practices of continence and incontinence and explore how these inform the organisation and planning of patient care within the shift and how these classifications enter risk assessment and discharge planning.
- Examine the technical and procedural work around continence management (e.g. types and use of pads) and catheterisation monitoring, assessment and recording.
- Focus on observing conversations with carers, which are all opportunities for sharing information about continence and how these might best be managed and decisions about discharge and place of discharge.

Ethnographic interviews with nurses and HCAs: We will provide a detailed understanding of the influences on acute hospital staff understandings of and responses to continence needs. Ethnographic (during observation) interviews will be carried out with nursing (across all grades), healthcare assistants (HCAs) and clinical staff from a range of disciplines (may include FY1/FY2, SpR, consultants, AHPs) when involved in continence care and staff with co-ordinating responsibilities (ward clerk, discharge co-ordinators) where appropriate. This will allow us to question routine practice and decision making, what they are doing and why:

- What is the articulation work within those settings, how do staff account for and make sense of their actions.
- What is the experience and training of working with people living with dementia and continence care, what informs their practice.

- What aspects of caring are defined as difficult, demanding or rewarding and what is their confidence in competence with working with this group. What are the barriers and enablers to supporting people living with dementia.
- What is the recognition and rewards of providing care for this group from patients, relatives, colleagues, managers.

Routine data: (from ward managers and patient records) about ward staffing levels, overall work allocation, bed occupancy, patient acuity, turnover and the recorded levels of incontinence and catheterisation at the time of fieldwork to provide context and an understanding of the total workload within each setting.

A series of case studies with patients and their family carers: An in-depth longitudinal examination of a series of cases (2 x patient per ward, total sample =12) to help to explain and understand ward continence practices and processes and their impacts on discharge outcomes through detailed systematic observation, reconstruction and analysis of the cases under investigation (Tellis, 1997; Yin, 1994). The case studies will follow individuals from initial admission in the acute ward through to discharge planning (multidisciplinary best interests meetings), to place of discharge (home, long-term care) and short term care pathways (packages of care). This will allow us to observe encounters with acute hospital staff to gain insights into how the continence needs of people living with dementia are assessed, managed and cared for and their implications for discharge planning and place of discharge. Sampling will include patients who represent a range of presenting, diagnostic and prognostic factors, and where possible, socio-demographic factors to include patients with a range of continence, toileting and catheterisation needs (routine admissions for this patient group are 10-20 days, however, for many this is much longer, Royal College of Psychiatrists, 2013):

- Carry out in-depth interviews with patients (n=12), and their family carers (n=12-24), to explore the needs of this patient population and issues of continence during their stay in the ward and leading up to and after discharge. Interviews will be carried out during admission and up to 8 weeks following discharge (n=48-72).
- Observation of ward routines as they impact on these individuals, and where possible the multidisciplinary best interests meetings through to discharge and returning to home or to long-term care.
- Examine communication and language and decision-making around continence, toileting and catheterisation and everyday interaction and strategies used within the wards by staff with people living with dementia and with their families.
- Medical records for each case study will also be examined to explore practices of recording, language and visibility of management, assessment and classification of continence.

Approach to analysis Data collection (observations and interviews and case studies) will utilize the constant comparative method and theoretical sampling whereby data collection (observation and interview data) and analysis are interrelated (Glaser and Strauss, 1967; Corbin and Strauss, 1990) and carried out concurrently (Green, 1998;

Suddaby, 2006). Field notes of observation, experience, and near verbatim text will be written up into word files (Van Maanen, 2011; Emerson, Fretz, & Shaw, 2011) and all audio recordings of interviews (ethnographic and in-depth) will be transcribed verbatim by a professional transcription service. The researcher will check transcripts against recordings for quality and to ensure participant anonymity, however, the analytic process will involve the wider team. Computer software (Atlas ti) will be used to assist the management of data and facilitate team access (Friese, 2012).

We will apply an inductive approach to our analysis, a widely used approach, which means developing our hypothesis from the data, rather than a priori (Pope et al, 2000). Analysis will involve the development and testing of analytic concepts and categories, and strategies for their development include careful reading of the data, looking for patterns and relationships, noting anything surprising and inconsistencies and contradictions across the range of perspectives gathered. Initially this will produce a collection of 'sensitizing concepts' (Blumer, 1954) and analytic memos, which will inform the development of more refined and stable analytic concepts. Line-by-line coding is not appropriate for fieldnotes, where coding is selective and involves whole events or scenarios (Charmaz and Mitchell, 2001). The constant comparative method means that the coding of data into categories is a recurrent process. The data will then be examined in the context of previous fieldwork and the analytic memos generated will inform further data collection within the next site and the next, more focused, stages of analysis (Charmaz and Mitchell, 2001). The analytic concepts that emerge from this process will be tested, refined to develop stable concepts that transcend local contexts to identify broader structural conditions (Corbin and Strauss, 1990) influencing responses to continence care.

The analysis will be shared with the Project Advisory Group and Carer Steering Group which will include service users, experts in dementia care and clinical psychology able to advise on the appropriate boundaries of innovtative interventions for the acute setting and the interface with families. Our group has previously used this analytic approach to intervention development; namely synthesis of literature with findings from an empirical study to devise a conceptual model and generate hypotheses enabling intervention development.

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 not appropriate for an ethnographic approach. In contrast, non-probability sampling is appropriate to study organizations or a clearly defined population and can provide analytically rather than statistically generalizable findings (Curtis et al, 2000). Thus we will identify a range of variables that may influence the phenomena, and what is known based on our narrative synthesis and will utilize both purposive and maximum variation sampling to select our research sites, clinical settings for observation, interview samples and our case studies. This ethnographic approach emphasizes the importance of comparisons across sites (Vogt, 2002) ensuring that it optimizes the generalizability of findings (Herriott and Firestone, 1983) and enhances the ability of the results to have an impact on practice and policy (Caracelli, 2006).

Setting and access to hospitals Acute hospital settings are suited to an ethnographic approach. At first glance, hospitals, and wards within them, may look and appear to operate in similar ways, however, they often have their own unique culture informed by local dominant cultures and belief systems, which in turn means that care and decision making can vary widely across and within institutions (van der Geest and Finkler, 2004; Goodson and Vassar, 2011). We have developed strong collaborations with hospitals across England and Wales via our current study (NIHR HS&DR Project: 13/10/80) and from our wider network, 3 acute hospital sites have been identified to represent: type of acute hospital; geographical location; demographic population; settings that can provide specialist dementia care and those that do not. We have identified local partners and agreements are in place as follows:

- The Royal Gwent Hospital, Aneurin Bevan Health Board, South Wales: A district general hospital, a population of 600,000, with 35,000 urgent admissions annually. Serving the second most deprived County in Wales, with an ageing population and increasing rates of migration. Contact Michael Morgan, Research and Development; Professor Sue Bale, Director of R&D (Site PI).
- Leicester Royal Infirmary, University Hospitals of Leicester University Trust. A teaching hospital serving a population of 1.1M, it has approximately 890 beds and provides Leicestershire's only accident and emergency service treating 89,300 each year. It has a specialist Dementia Meaningful Activity Service. It serves an ethnically diverse inner-city and rural area, with a large Asian/Asian British population (37%). Contacts: Jayne Hill, Research Governance Lead; Aidan Dunphy Senior Research Nurse; Dr Simon Conroy, Geriatrician (Site PI).
- Queen Alexandra Hospital, Portsmouth Hospitals NHS Trust. Serving a population of 675,000, with 1,200 beds, and one of the largest in the UK, treating over 500,000 patients a year and with the busiest Emergency department the UK, treating in excess of 132,000 patients each year. Densely populated catchment area, the majority of the population are White British (84.0%). Contacts: George Sylvester, Research Support Officer; Anne Suttling, Senior Research Nurse; Dr Sue Poulton, Consultant Orthogeriatrician; Phillipa Cheeseman, Senior Sister; Greta Westwood, Director of Research and Innovation (Site PI).

Sampling within each acute hospital site: Whilst our data collection sites (acute hospitals) are standardized, with sequentially and systematic data collection, there will be some variation within each site. We will use theoretical sampling *within* sites to ensure that representativeness and consistency of concepts and events is achieved within the study, rather than sites and people. Informed by grounded theory, sensitizing concepts from the ongoing analysis will feed into the next stage of data collection to expand the research process and to capture relevant aspects as they emerge into the ongoing analysis. The focus is on 'discovery' to ensure the grounding of emerging concepts within data and the reality of the settings (Glaser and Strauss, 1967).

Sampling of wards for observation: A diagnosis of dementia is associated with increased risk of acute hospitalization (Phelan et al, 2012), with UTIs (Sampson et al, 2009), pneumonia (Sampson et al, 2009), nutritional disorders (Pinkert and Holle, 2012) and hip fracture (Holmes, 1999; Pinkert and Holle, 2012), often the principal cause of admission amongst this group. A national review of case notes for people living with dementia (n=7987) found the majority of their acute admissions were within care of the elderly (40%), general medical (25%) and orthopaedics (11%) (Royal College of Psychiatrists, 2013). Thus, we will observe episodes of care involving patients within the MAU and general medical wards which receive a high volume of patients who have dementia, who are often unstable, require acute medical attention, and will all have a wide range of continence care needs:
MAU (Medical Assessment Unit): 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 (Collins et al, 2010). 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 deal with 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 will be transferred to an inpatient bed following their emergency admission or from the MAU. These wards usually provide greater continuity, personalised care, and more structured routines. However, although there is an increasing number of admissions of people living with dementia within general wards, they are typically not designed for this patient population. A routine admission for people living with dementia is 10-20 days, and for many this is much longer (Royal College of Psychiatrists, 2013). 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.

Sampling and recruitment of staff for observation and interviews: We will follow the work of nurses and HCAs. We will purposively sample to ensure that across the ward settings we will include the range of clinical grades (clinical support worker, nurse associate, entry level nurse, nurse specialist, nurse team leader, advanced nurse, nurse team manager, modern matron, nurse consultant) and other clinical staff (e.g. FY1/FY2, SpR, consultants, AHPs), and staff with co-ordinating responsibilities (ward Clerk, discharge co-ordinators) with a focus on continence care. Our acute hospitals and wards have been recruited. Several months in advance of the period of observation, the research team will visit the wards to discuss with relevant staff the study aims.

Sampling and recruitment of patients for observation: It is not possible to predict the type of patients available within each acute hospital ward during the fieldwork period, however we are confident from our previous research in acute hospitals (NIHR HS&DR 13/10/80) that people living with dementia will be a significant population. People living with dementia are one of the largest populations cared for within the acute setting, currently using up to one quarter of acute hospital beds at any one time (Alzheimer's Society, 2009; DoH, November 2014, within Alzheimer's Society 2016). A National Audit Office survey of bed usage found that people living with dementia were usually within acute wards, even if there was no clinical need for them to be there (NAO, 2007), with most people living with dementia admitted for between 4 and 20 days (Royal College of Psychiatrists, 2013).

Case studies: We will carry out a focused series of individual case studies (n=12), identified using purposive sampling informed by our early analysis of observational data. The development of the study will be aided by including a range of participants (using maximum variation sampling) who have had particular experiences within the setting (critical case sampling). Thus, we will include patients to represent a range of presenting, diagnostic and prognostic factors, and where possible, socio-demographic factors:

- Patients with a range of continence, toileting and catheterisation needs.
- Expected length of stay. This can be highly variable for this group, from days to weeks and months, thus we have an additional period of fieldwork to follow patients for up to 8 weeks within each acute hospital setting and a further follow-up period to examine pathways to discharge and place of discharge.
- Individuals aged over 65 with unplanned admission and an accompanying co-morbid diagnosis of dementia formally recorded in their medical records.

We are aware that there will be patients within each setting who have features of dementia who either do not have a formal diagnosis or may have different underlying causes of cognitive impairment (e.g. delirium), however, this group will fall outside of our focus due to their unique needs.

Dissemination and projected outputs

Our analytic outputs will provide a theoretically informed, evidenced based understanding of clinical practice and service user experience grounded in detailed analysis of the realities of frontline continence 'work-as-done' (Hollnagel, 2012). Outputs will focus on service organisation (processes, identification, assessment, models of care) and training (factsheets, masterclasses, MOOC). Development will be in close collaboration with our Carers Steering Group and participating sites to establish relevance and feasibility within wards, and their utility and transferability to acute hospital settings with different organisational contexts (Pawson &Tilley, 1997):

- Develop ward based structured tools (evidence based care bundles; identification and assessment tools) to support appropriate continence care strategies for people living with dementia at ward level. A bundle is a structured way of improving the processes of care and patient outcomes via a small set of evidence-based practices (Resar et al, 2005). Our bundle will focus on 'how' to organize and deliver the most effective process of continence care, by bringing together a small number of practices to support their consistent delivery to improve patient outcomes.

- Update existing ward based recommendations for models of care and the organisation of nursing and HCAs work to ensure they support the quality and humanity of continence care. For example, integrating continence care within existing risk assessment (falls), rehabilitation strategies and discharge planning.
- Identification of factors in acute hospital organisation and ward culture (practices, routines and interactional styles) that can improve or worsen the experiences and outcomes of people living with dementia who have continence needs. For example, this may include approaches to facilitate the integration of key elements within handovers, observation rounds.
- Training to support continence care for people living with dementia targeted at acute care staff (nurses, HCAs, AHPs), carers and families. This will include organisational and interactional techniques that facilitate the quality and humanity of continence care.

NHS health service managers and ward sisters need to be provided with cost neutral ways in which the social organisation of nursing and HCAs care practices can be structured to improve the identification and response to people living with dementia and their continence needs. Our aim is to provide in-depth evidence based knowledge about the most effective and humane management of continence care to inform the development of evidence based training and organisation of nursing and HCAs that will lead to shorter acute hospital stays, more effective symptom management, treatment, and care; all factors that mitigate suffering in patient and family members and support the effective use of resources.

We believe that what we learn will have relevance to all patients in acute hospitals. Toileting, continence promotion and catheterisation are significant issue for patients in acute hospital settings who may have mobilization or communication issues associated with their admitting condition. It is of relevance to patients with many other conditions, including learning disabilities and movement disorders, conditions that impact children and young people and older patients e.g. chronic conditions such as COPD, stroke and diabetes.

Plan of investigation and timetable

Total 30 months: 1st September 2017 – 29th February 2020.

***1-8 months**:* Preparation: Confirm recruitment of NHS Trusts/LHBs; obtain NHS REC ethics and R&D approvals; draft systematic narrative review and carry out consultation process. Confirm service users and advisory board membership.

9-23 months: Data collection within acute wards (observations, interviews, case studies), including a further follow-up period (case study observation and interviews) to examine pathways to discharge and place of discharge, write up fieldnotes, complete preliminary analysis. With an additional month to work with

each ward to develop pilot outputs/interventions in collaboration with sites. Within 3 acute hospitals (total: 6 wards), 5 months per hospital site is requested.
24- 30 months: Analysis and theory development; report, academic and clinical publication writing; drafting, piloting and development of ward based tools; training via masterclasses, factsheets, on-line materials, modules and MOOC; workshops and symposium. Building on the pilots to develop an intervention proposal.

	1-3	4-6	7-9	10-12	13-15	16-18	19-21	22-24	25-27	28-30
Narrative synthesis	***	***	**					***		
Recruitment, access and sampling	***	**	*	*	*	*				
Data collection			--*	**	**	**	**	**		
Analysis and theory development			-**	-**	-**	-**	***	***	*	
Report and academic and clinical publication writing		--*	**			--*	***	***	***	***
Drafting, piloting and development -ward based tools					*	*	*	***	***	***
Workshops and symposium		*							*	*
Training – masterclasses, factsheets, on-line materials, modules and MOOC		*	*	*	*	*	*	*	*	*
Advisory group, Project Team, Carer steering group	*		*		*		*		*	

Approval by ethics committees

Data collection will always preserve patient dignity (*this study will not and does not need to go 'behind the screens' to observe intimate care*, our approach, processes and documentation for observation of people living with dementia in acute hospitals and observing the everyday work of ward staff will be informed by REC approval:15/WA/0191). We will follow NHS and Cardiff University governance procedures, the university's Research Governance Framework sets out the professional standards and basic requirements that are fundamental to all research, as well as the ethical and external regulations that govern research [http://www.cardiff.ac.uk/racdv/resgov/governance/index.html]. We will follow recommendations and practical guidelines for conducting research involving elderly participants (c.f. High and Doole, 1995, Harris and Dyson, 2001; Loue, 2004), people living with dementia (Slaughter et al, 2007), and the cognitively impaired (Berg, 1996).

Involving people living with dementia in research: It has been argued that the lack of research exploring the perspective of people living with dementia (Taylor, et al, 2012) is an effective silencing of people experiencing cognitive decline (Roger, 2006). The inclusion and involvement of people living with dementia in research is increasingly recognised as vital for the production of high quality research (Alzheimers Europe, 2014), with prioritizing their views and experiences a key goal (The Scottish Dementia Working Group Research Sub-Group, 2014). Participation usually outweighs the risks (Hellstrom et al, 2007), with inclusion in research enhancing dignity and personal identity. People living with dementia also make a compelling argument for their inclusion in research, emphasising its positive and empowering effects (McKillop 2002; Robinson, 2002).

In response, this study includes a significant focus on the perspectives of people living with dementia and their carers and on understanding their thoughts, feelings and experiences of care within the acute hospital setting. We do this through ethnographic observation of the care they receive, ethnographic (during observation) interviews with them during their stay within the ward and interviews following discharge (case studies). We will draw on a small but growing body of research demonstrating that the perspective of people living with dementia can be obtained (Roger, 2006; Samsi and Manthorpe, 2013; Tanner, 2012; Pipon-Young et al, 2012; Clemerson, et al, 2013). The experiences of people living with dementia are now increasingly included within research (Wilkinson 2002) that examines their experiences of health and social care (Barnett 2000) and uses methods that can elicit personal stories and narratives of people living with dementia (c.f. Bryden, 2005; Goldsmith, 1996).

To ensure that the research respects the dignity, integrity and personhood of the participants, a person centred approach is interwoven throughout this study. A person centred approach is essential when working alongside people living with dementia and this includes research (Ballard et al 2001, Brooker 2004). We believe that the use of an ethnographic approach in this study will promote the integrity of the participants through the use of observation and interviews about clinical encounters, because these will focus on the whole person and provide insight into their thoughts and feelings and experiences of care within the acute hospital setting. We are aware of how challenging it can be to maintain a person centred approach with this population, and in response the research team will constantly monitor their own achievement of this approach.

Capacity to consent: We will follow recommendations and guidelines for conducting research involving elderly participants, people living with dementia, and the cognitively impaired. The Mental Capacity Act 2005 (England and Wales) provides a legal framework safeguarding the rights of people with cognitive decline to make decisions for as long as is possible. It is important to make clear that incapacity to provide informed consent and participate in research cannot be assumed simply on the basis of a particular illness or condition (Moye et al 2007); having choice and control over decisions is a key component of quality of life (Samsi and Manthorpe, 2013). Some of the participants will be at a very early stage in their experience of memory problems and, even those experiencing more severe impairment, capacity must be assessed in relation to the specific activity being proposed so that incompetence in one area of life does not automatically mean incompetence in others (Holm 1983). Dewing (2007) has demonstrated that people who may appear unable to give consent are able ethically to participate and where this is not against their will or their general wishes.

Informed consent: Our goal is to ensure 'maximally informed consent' (Hellstrom et al 2007) and this study sees informed consent as a process that is more inclusionary, considering the capacity of people with memory problems or dementia in 'situation-specific contexts' that highlight their remaining strengths (Hellstrom et al 2007). Dewing (2007) argues that capacity to consent should not be decided on the basis of a low score on a cognitive test, rather this should be seen as an opportunity for the research team to find ways to include them in research. The research team has experience of carrying out research with people living with dementia (Featherstone, Northcott), patients who are acutely ill with a range of life threatening conditions including acute coronary events, cancer and dementia (Featherstone, Kelly) and incontinence (Kelly). The team will seek fully free and maximally informed consent that takes into account how willing the person is to take part as well as their level of understanding, to ensure that there is no element of coercion.

Process consent: Study participation will be open to people living with dementia at all stages of the disease process and with different types of dementia who are being cared for within these acute ward settings. People living with dementia may have varying degrees of capacity and their capacity may fluctuate depending on the dementia, their psychosocial, situational, medical, psychiatric and neurological factors. Symptoms of dementia include cognitive impairment, short term memory loss, difficulties in verbal and non-verbal communication and poor concentration and understanding, which can make it difficult to gain informed consent. It is also important to recognise that the capacity to consent can change quickly for this group of patients, particularly within an acute setting. Consequently, this study will utilise Dewing's model of process consent (2007), which conceptualises consent as a continuous process with researchers considering if the study participants are consenting to each decision across the course of the study. Process consent is a pathway and this is a key feature of this approach by 'ensuring initial consent is revisited and re-established on every occasion or even within the same occasion' (p19). The key role of the researcher throughout the study is to continually assess whether the person is prepared to continue with their participation. If there is a possibility that their feelings about participation have altered, then their consent must be revisited. To increase the transparency of this process, someone known to the people living with dementia can act as an independent validator. The approach and method (including documentation) developed by Dewing has been approved by various research ethics committees in universities and health care provider organizations such as NHS Trusts across the UK, Republic of Ireland and Australia in recent years.

Training: The research team have received training in understanding people living with dementia, how to maintain the personhood of the participant and to reflect the right behaviour and attitude in order to communicate in a person centred manner. KF and AN have received training to be a Dementia Friend, attended undergraduate nursing modules on dementia care (Cardiff University), and shadowed clinical staff (including gerontologists, specialist dementia nurses and dementia specialist workers) caring for people living with dementia. The researchers will use appropriate language when speaking to the person with dementia, avoid stereotypical words about the condition, and make every effort to be with the participant in a genuine, respectful and human exchange, with an understanding that verbal communication is often challenging for the person with dementia (Alzheimers Europe, 2014). Thus, the researchers will use both verbal and non-verbal communication methods to aid interaction and will draw on "dementia specific" approaches and best practice outlined in the literature (McKillop, 2002). It is essential that the researchers establish a rapport with the participants and develops a relationship that is based on mutual respect.

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