Research Protocol

Underserved and overlooked: Investigating the management of refusal of care in people with dementia admitted to hospital with an acute condition

HS&DR Project: 13/10/80

Summary

This study is an investigation of refusal and resistance to food, drink and medicines by people with dementia (PWD) admitted to an acute hospital with a co-morbid condition. In the UK there are an estimated 750,000 PWD, with this projected to rise to over 1 million by 2025 (Alzheimer's Society, 2011). PWD are known to be undertreated for co-morbid conditions such as cancer and arthritic pain, leading to unnecessary suffering, carer burden and healthcare costs.

UK health policy emphasizes the importance of keeping PWD out of hospital, however, when PWD have an acute co-morbid condition, such as a suspected heart attack or hip fracture, hospital admission is unavoidable. It is estimated that PWD are currently using up to one quarter of acute hospital beds at any one time. Hospitals focus on fixing acute injury or illness, which requires patient concordance. However, PWD do not fit comfortably within this setting and staff routinely consider this patient group do not belong (Tadd et al, 2011) and should be transferred to other services (Moyle et al, 2008).

Common features of dementia include behavioural and psychological symptoms (BPSD), which are reported in up to 90% of PWD. We are interested in examining a common feature of BPSD which is managed by healthcare workers on a daily basis; refusal of care (also labelled as resistance, resistive behaviours or rejection of care). It is characterised as non-compliant behaviour in response to healthcare staff (Kable et al, 2012) and PWD often refuse medications, food and personal care such as toileting, bathing and shaving as well as diagnostic or therapeutic procedures. Professional and family carers can find refusal and resistance to care time consuming and difficult to manage and importantly it has implications for morbidity, mortality and quality of life for PWD. For example, food refusal can lead to malnutrition, which is associated with poor clinical outcomes that include greater morbidity and mortality, reduced quality of life and increase hospital stays. Whilst, there is already a large body of literature examining primary and long-term service provision, little is known about how clinical teams in acute hospitals respond when they believe a PWD is refusing care. The evidence base to inform the organisation and delivery of this care is limited. The proposed research seeks to understand how nutritional care and medicines concordance might be improved for PWD in hospital. There is sound evidence that both adequate nutrition and drug treatments improve clinical and patient reported outcomes.

In response, this study will use an in-depth ethnographic approach to examine the work of nurses and healthcare assistants (HCAS) and other clinical staff who are responsible for feeding and medications within wards to explore how

they respond to refusal of food, drink and medicines in PWD. We will focus on care settings known to have a large number of people with cognitive impairment (Medical Admissions Unit (MAU) and Orthopaedic wards) within a purposive and maximum variation sample of 5 hospitals across the UK. Ethnography will enable an in-depth evidence based description of the management and context of food and drink refusal and medication refusal. This understanding will be examined in the context of a narrative synthesis of policy, practice guidelines and the existing literature about refusal of care more widely. Importantly, our analysis will identify ways in which the social organisation of nursing care and care processes can be structured to best effect support that facilitates adequate nutritional intake and drug concordance to improve patient and family care experience and the effectiveness of treatments. Recommendations will be made for best practice and innovation/intervention at service organisation and clinical practice levels that could improve patient experience and health outcomes in the acute setting.

In long-term care settings, the behavioural and psychological symptoms experienced by PWD can be effectively managed using psychosocial interventions. There may be potential for existing educational and organisational interventions to be tailored for the acute setting. The proposed study will provide an empirically informed theoretical underpinning for a follow-up programme of work to develop and test innovation in service organisation and clinical interventions to improve the care and support of PWD who refuse care within the acute hospital setting.

Why this research is needed now

The Francis report (2013) provides compelling evidence of the failure of the acute hospital setting to meet the needs of older people, including PWD. Response to the report has included recognition that quality care is about more than meeting financial targets. Across the UK, NHS providers are revising organisational strategies and delivery plans to increase focus on patient experience. In the case of PWD, improving their experience of acute hospital admission has the potential to i) enhance quality of care ii) improve clinical outcomes (effectiveness of treatments) and iii) lead to cost savings (through greater efficiency in bed use). Delivery of patient-centred compassionate care is likely to assist with meeting financial targets whilst improving health outcomes and quality of life. Understandings of how to minimise refusal of nutritional care and medications in an acute hospital setting is needed now.

Currently there are over 750,000 PWD, with this projected to rise to over 1 million by 2025 (Alzheimer's Society, 2011; NAO, 2007). PWD over 65 years of age are using up to one quarter of acute hospital beds at any one time (Alzheimer's Society, 2009). They are also the group most at risk of delayed discharge (Barker and Halliday, 2005). Professional and family carers can find refusal and resistance to care time consuming and difficult to manage. Although evidence suggests staff consider this patient group do not belong in acute hospitals (Tadd et al, 2011) and should be transferred to other services (Moyle et al, 2008), when someone with dementia has an acute condition, such as a hip fracture, they require treatment that is only available in an acute hospital. A more realistic solution than transfer is to examine how the needs of PWD might be better met in an acute hospital setting. This solution is urged by consumer groups lobbying to improve the experience of PWD and their carers (Alzheimer's Society, 2008; Patients Association, 2010) and government enquiries (National Confidential Enquiry for Patient Deaths, 2009; Care Quality Commission, 2013). It is also the solution reflected in policy documents. Yet there are recent reports of inappropriate, sub-optimal or even unkind management of PWD in acute hospital settings, findings corroborated by our Carers Steering Group. New approaches are needed for improving what happens to PWD in acute hospitals. The management of BPSD in this setting needs to be better understood, as evidence from studies conducted in long-term care settings indicates there is potential for reducing refusal of care through attention to staff training and organisation of environment. The relevance of a study that attends to the question of how and why refusal of nutritional care and medicines occurs, lies in the immediate need to find solutions to the poor treatment outcomes and reported experience of people with dementia compared to other patient groups. Solutions that improve quality of care, are low cost, and can be easily integrated with existing social organisation of nursing care and care processes. A mixed-methods systematic review of policy, practice guidelines and the existing literature about refusal of care in other settings and populations can aid with conceptualising the problem and developing theoretically informed interventions, but to know what might work currently in an acute hospital setting requires solutions to be developed in partnership with service users, clinicians and an awareness of the nature of existing organisational and interactional factors that impact on nurses, HCAS and other clinical staff responses to refusal of care with a focus on medicines and food refusal amongst patients with co-morbid dementia.

Aims and objectives

The aim of our study is to establish an empirically based conceptual and theoretical foundation for the development of innovations in service organisation and clinical interventions, to improve the nursing and clinical management of resistance to care in PWD in an acute hospital setting. To achieve our aim the study objectives are:

- To provide a detailed understanding and concrete examples of the clinical and interactional processes that influence nurses, HCAS and other clinical staff (this may include, feeding assistants, SPRs, consultants, AHPs, and staff with managerial responsibilities) responses to 'refusal of care' with a focus on medication rounds and meal times. What they are doing and why: what are their caring practices when interacting with PWD and their carers, how do they respond to and manage refusal and what influences these approaches.

- To provide a detailed understanding of the context of care and concrete examples of the hospital organisational processes that impact on the care of this group. Specifically, map the response and management of this patients group and incidents of refusal and resistance of care with wards known to have a large number of people with cognitive impairment and dementia.
- To examine the experience of refusal of care within the acute hospital setting from the perspective of PWD and their carers. What is the impact of refusal of care and clinical responses to it, on their care and their experience of an acute admission.
- To identify markers of good care (as identified by our narrative synthesis), and understand the enablers and barriers to good care in response to refusal and how, where and why, individual and organisational expertise or ineffective care exists.
- To identify ways in which the social organisation of nursing care and care processes can be structured to best effect support that facilitates adequate nutritional intake and drug concordance to improve patient and family care experience and the effectiveness of treatments.
- To provide an understanding and assessment of the feasibility of potential interventions and their theoretical underpinning for the development of a follow-up programme of work.

Research plan/Methods

Summary

This is a multi-sited ethnography (Marcus, 1995, 1998), which uses multiple sites of observation to examine refusal and resistance to food, drink and medicines by people with dementia (PWD) admitted to an acute hospital. This 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 policy and practice (Caracelli, 2006). Our first stage will be to carry out a review of the existing literature about refusal of care to provide an overarching conceptual model and narrative synthesis (Popay et al, 2006), which will inform our ethnographic fieldwork and analysis, which in turn, will be used to further develop, test, and refine our conceptual model. Fieldwork will be carried out in sites of care, which are known to have a large number of people with cognitive impairment (MAU and Orthopaedic wards) within 5 hospitals across the UK. Data collection will focus on the work of nurses and HCAS who are responsible for feeding and medications within wards to explore how they respond to refusal and resistance to food, drink and medicines in PWD. By obtaining data from within each institution on the everyday work of nursing, HCAS, other clinical staff, and the perspectives of patients and their carers, we will provide an in-depth evidence based analysis of the management and context of food and drink refusal and medication refusal. Our focused observational strategy within each setting will:

- Concentrate on the work of nurses and HCAS who are responsible for feeding and medications, focusing on medication rounds and meal times. Clinical staff from a range of other disciplines and roles will be included when they are involved in the care of this population with a focus on medication rounds and meal times. This may include, feeding assistants, SPRs, consultants, AHPs, and staff with managerial responsibilities.
- Focus on observing handover, admissions, and conversations with carers, which are all opportunities for sharing information about refusal behaviours and how these might best be managed.
- Carry out ethnographic (during observation) interviews with staff as they are caring for this patient group within the acute setting (n=10-20 within each setting). This will allow us to question what they are doing and why: what are the caring practices of clinical and hospital staff when interacting with patients admitted with co-morbid dementia to an acute ward, what underpins and informs their response to refusal and resistance.
- Carry out ethnographic (during observation) interviews with a sample of patients and their carers (n=10-20 within each setting) to explore the impact on refusal of care and to explore the needs of this patient population.
- Collect routine data (from ward managers and within patient records) about ward staffing levels, overall work allocation, bed occupancy, patient acuity, turnover and the recorded levels of resistance and refusal at the time of fieldwork to provide context and an understanding of the workload of resistance and refusal within this setting.

Within each hospital setting we will carry out a detailed case study of one patient identified as refusing or resisting food or medicines (Total sample=5). This will allow us to extend our fieldwork to provide a detailed contextual analysis of the events, the clinical staff and expertise involved and the wider conditions of their care. This will provide an understanding of the broader care systems within the acute setting that impact on their care and provide a multi-perspectival analyses. Purposive sampling will be used, informed by our early analysis of observational data within each setting. Each case study will involve:

- Detailed systematic observation of the care of these patients during their admission, in-depth interviews with carers, family members and, where possible, patients, to explore the needs of this patient population and issues of refusal. Interviews (Total= 20-40) will be carried out during admission and 4 weeks following discharge.
- We will also carry out in-depth interviews with the nurses and HCAS and other clinical staff (this may include, feeding assistants, SPRs, consultants, AHPs, and staff with managerial responsibilities) (Total= 20-40) involved in the care of these patients to explore their response to refusal or resistive behavior with a focus on medication rounds and meal times.

Narrative Synthesis

Our first stage will be to extend our initial scoping review to carry out a systematic review taking a narrative approach to an evidence synthesis (Popay et al, 2006) of the wider literature to identify what is already known about refusal of care. Following our initial scoping exercise of three electronic data bases, Embase, CINAHL and Web of Science from 2002 to 2013, the UKCRN Portfolio Database and the Cochrane library, we identified only 30 relevant articles about refusal of care in dementia in the acute setting. Importantly, no systematic review was identified. Our objective is to identify: (1) What is already known about refusal of care for PWD; (2) interventions for refusal in PWD to identify what works, for whom & in what circumstances. (3) The expertise and organisational barriers to the provision of good care in response to refusal; (4) Markers of good care, what should care look like in the context of refusal.

A narrative approach to evidence synthesis is compatible with an examination of the complexities of health service settings and the delivery of services. This method allows for the management of these complexities within the synthesis by focussing on the underlying theories informing the interventions and how and why they work. It provides the tools to build a wider picture of service context and the ways in which circumstances can impact on the effectiveness of interventions. Importantly, it is sensitive to the range and diversity of services being delivered for this patient population and allows us to establish how they are subject to change over time. *Search strategy:* Recent reviews suggest we need to understand what constitutes 'good care' within the acute setting (Elliott et al, 2012; Moyle et al, 2008) and we believe that information about refusal of care for this population is hidden within literature focusing on other features of dementia (BPSD), ethics and autonomy, competence and capacity, and in other patient populations. For inclusion, articles that focus on or contain an element relating to each of the following: (1) The acute healthcare setting; (2) The care of PWD; (3) The terms 'cognitively impaired', 'confusion', 'confused' and 'mental disorder', all widely used within the literature; (4) Refusal of care within other populations and vulnerable groups; (5) The ethics of patient care, including refusal, autonomy, competence, and capacity; (6) Refusal, resistance, resistive, rejection; (7) policy and clinical practice guidelines. *Review strategy and strategy for reviewing literature:* The selection process will be staged: (1) Titles and abstracts of articles reviewed; (2) Entire texts of articles passing the first stage reviewed; (3) Key journals will be manually searched; (4) We will communicate directly with key authors, research teams and user communities to identify further articles and grey literature; (5) For each article, a narrative description will summarise the aims, methods, key findings and conclusions.

Evidence will be initially organized and synthesized within three separate streams (intervention, other quantitative, and qualitative), providing an overarching conceptual model and narrative synthesis. The model will produce concepts and relationships between concepts important for understanding refusal of care in PWD. It will provide a summary of the literature synthesis that will help with decision making in relation to the assessment and feasibility of intervention for refusal of care in dementia in terms of possible mechanisms of action & intervention content, appropriate methods of delivery, and potential outcomes that may be achieved in the acute setting. The synthesis will inform our ethnographic fieldwork and analysis, which in turn, will also be used to further develop, test and refine the conceptual model provided by our narrative synthesis.

Our design and theoretical framework: Why ethnography

Ethnography can provide sophisticated tools for understanding the complexities of the everyday work within an organisational culture and the interrelationships between different elements of an organisation. It involves the in-depth study of a small number of cases, studying people's actions and accounts within their natural everyday settings, collecting relatively 'unstructured' data from a range of sources (including observation, informal interviews and documentary evidence) (Hammersley and Atkinson, 1989). Importantly, it takes into account the perspectives of patient, carer, clinical, and hospital staff (Caracelli, 2006). Our approach to ethnography is informed by the symbolic interactionist research tradition, which aims to provide an interpretive understanding of the social world, with an emphasis on interaction, focusing on understanding how action and meaning are constructed within a setting (Housley and Atkinson, 2003). The value of this approach is the depth of understanding and theory generation it can provide, with a key objective to provide findings transferable to other settings (Hammersley, 1987).

Institutional ethnography examines the everyday work of people, their routine behavior and practices, and the interactions between individuals and material objects within local organisations (Quinlan, 2009). It also focusses on the articulation work of people within those settings, how people account for and make sense of their actions (Star, 1999). An important focus is the frequently understudied, what is often characterised as the mundane, everyday, and boring. Within any organisation there are always groups whose everyday work is not recognised formally and is often unnoticed and invisible (Star, 1999), and in the hospital setting this includes carers and HCAS. In the context of understanding how healthcare services within hospital settings are delivered and the organisation underlying its delivery, ethnography can examine the social and institutional forces that shape and influence the work of health care providers (Greenhalgh and Swinglehurst, 2011).

Thus this study will focus on the mundane and often invisible work of feeding and medications that are part of the everyday routine care carried out by nurses and HCAS in the acute setting. We will provide a detailed understanding of the social and institutional forces that shape and influence this work. Our ethnographic approach will enable us to understand how staff respond to resistance and refusal and allows us to follow the consequences of their actions on patients and carers. Importantly, we will also examine how they account for and make sense of their response to refusal and resistance in these contexts. Ethnography allows us to examine these elements, but importantly, the interplay between them (Atkinson et al, 2008).

Data collection and analysis

Data collection (observations and interviews) and analysis will be informed by the analytic tradition of grounded theory (Glaser and Strauss, 1967), a practical and flexible approach for ethnographic research (Charmaz and Mitchell, 2001). It will use 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). Data collection and analysis will also be theoretically informed by our narrative synthesis, which will in turn, be used to further develop, test and refine the conceptual model provided by our narrative synthesis. 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 study: as data is collected in one site, preliminary analysis of this will proceed in parallel, with this preliminary analysis informing the focus of later stages of data collection and analysis.

Whilst these traditions have developed independently, they are complementary and grounded theory strengthens 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). This approach provides a middle ground in which the ethnographer, often seen as a passive observer of the social world, can use 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 this 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 not always verbal and is also expressed non-verbally and 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 and Bruner 1986:24). Thus, it is important to observe interaction and performance; how care work is organised and delivered, how refusal 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).

Pilot study: Our pilot feasibility study will establish the practical identification of this patient population, their diagnosis and management within these ward settings. This includes an audit of case notes of admissions and this will enable us to establish how long it will take us to identify patients with a definitive diagnosis of dementia within these clinical settings and how prevalent the issue of refusal and resistance is in their recorded medical records and the challenges that staff face. We will use this to guide our initial entry into fieldwork. This will allow us to refine our initial target plan for each setting, flexibility is important within this process (Watters and Biernacki, 1989).

Ethnographic fieldwork: Within each hospital setting we will conduct non-participant observation over a 6 week period within sites of care that are known to have a large number of people with cognitive impairment (MAU and Orthopaedic wards) to examine everyday clinical and care processes of refusal and resistance to care. Multi-sited ethnography defines the object of study via a number of techniques or tracking strategies and within the fieldwork we recognise the importance of focussing on the 'busy intersections' (Rosaldo, 1989:28) and of seeking out sites of tension where a large number of interests and identities are expressed. It is argued that it is at these points that identity and culture become articulated, enacted and constructed. Our aim is to provide a detailed understanding of the clinical and interactional processes that influence nursing, HCAS and other clinical staff (this may include, feeding assistants, SPRs, consultants, AHPs, and staff with managerial responsibilities) response to 'refusal of care' with a focus on medication rounds and meal times. We will study actions and accounts within their natural everyday settings to explore how individuals, wards, and hospitals, respond to and manage refusal and what influences these approaches. Our focused observational strategy within each setting will:

- Concentrate on the work of nurses and HCAS who are responsible for feeding and medications, and other clinical staff from a range of disciplines and roles when they are involved in the care of this population, focusing on medication rounds and meal times. Map the organisation of care, responses to refusal, management, communication and recording of refusal of care with wards.
- Follow nurses and HCAS within each ward setting to explore their everyday work, and what informs this work. What are the processes of decision-making, the management of uncertainty and treatment procedures in response to refusal of care. Examining the everyday routine behaviours of individuals and within wards.
- Focus on observing handover, admissions, and conversations with carers, which are all opportunities for sharing information about refusal behaviours and how these might best be managed.
- Collect routine data (from ward managers and within patient records) about ward staffing levels, overall work allocation, bed occupancy, patient acuity, turnover and the recorded levels of resistance and refusal at the

time of fieldwork to provide context and an understanding of the workload of resistance and refusal within this setting.

This will provide a detailed understanding of organisational and care processes that impact on the management of refusal and resistance within this group. We will examine the everyday work of staff, their practices and the interactions between staff and with patients and carers within these local organisations.

Ethnographic interviews with patients who refuse and their carers: A key aim is to explore the impact on refusal of care on patient and carer experience and what factors would lead to improved care and support. We will carry out ethnographic (during observation) interviews with patients and their carers within the ward setting to explore the experiences and needs of this patient population and issues of refusal from their perspectives. Sampling will be informed by our pilot and each setting, however we estimate at least 10-20 interviews within each ward. Importantly, where possible, this study will obtain the patient perspectives:

- Experiences of admission and care, what is the impact of the physical environment and wider hospital structures
- Being listened to, communication and decision-making
- Fears and concerns about treatment and management, particularly around refusal and resistive behaviours
- Identification of refusal of care and involvement and recognition of carer expertise

We will draw on research demonstrating that the perspective of PWD can be examined (Roger, 2006; Samsi and Manthorpe, 2013; Tanner, 2012; Pipon-Young et al, 2012; Clemerson, et al, 2013) and a small but growing body of literature on ways to include the voice of this population within research (Lloyd et al, 2006; Barnes, 1992; Barnes and Mercer 1997; Lindsay et al, 2012). We explore how this will guide us in practice within the ethics section below.

Ethnographic interviews with nurses and HCAS: We will provide a detailed understanding of the influences on healthcare professionals response to 'refusal of care'. Ethnographic (during observation) interviews will be carried out with nursing and healthcare assistant and clinical staff from a range of disciplines (this may include, feeding assistants, SPRs, consultants, AHPs, and staff with managerial responsibilities) (n= 10-25) as they are caring for this patient group within each ward with a focus on medication rounds and meal times. This will allow us to question 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 PWD and refusal of 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 this patient group.

- What is the recognition and rewards of providing care for this group from patients, relatives, colleagues, managers.

Case studies: Within each hospital setting we will carry out a detailed case study of one patient identified as refusing or resisting food or medicines (Total sample=5). This will allow us to extend our fieldwork to provide a detailed contextual analysis of the events, the clinical staff and expertise involved and the wider conditions of their care. This will provide an understanding of the broader care systems within the acute setting that impact on their care and provide a multi-perspectival analyses. Purposive sampling will be used, informed by our early analysis of observational data within each setting. Each case study will involve:

- Detailed systematic observation of the care of these patients during their admission, in-depth interviews with carers, family members and, where possible, patients, to explore the needs of this patient population and issues of refusal. Interviews (Total= 20-40) will be carried out during admission and 4 weeks following discharge.
- We will also carry out in-depth interviews with the nurses and HCAS and other clinical staff (this may include, feeding assistants, SPRs, consultants, AHPs, and staff with managerial responsibilities) (Total= 20-45) involved in the care of these patients to explore their response to refusal or resistive behavior with a focus on medication rounds and meal times.

This will allow us to follow the impact of the everyday routine care carried out by nurses HCAS and other clinical staff and the consequences of their response and management of refusal and resistive behavior for this patient group and their carers.

Analysis

Data collection (observations and interviews) and analysis will be informed by the analytic tradition of grounded theory (Glaser and Strauss, 1967), as indicated in our sections above. It 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 observations and 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, particularly team members with a strong track-record of collecting and analysing ethnographic data within clinical settings (c.f. Featherstone and Atkinson, 2012; Somerville et al, 2008; Featherstone et al, 2005). 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 we will develop 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 our strategies for their development include careful reading of the data, looking for patterns and relationships, noting anything that seems surprising and for any 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 focussed, stages of analysis (Charmaz and Mitchell, 2001). The analytic concepts that emerge from this process will be tested, refined and developed in an attempt to develop stable concepts that transcend local contexts to identify broader structural conditions (Corbin and Strauss, 1990) influencing responses to refusal of care.

The analysis will be shared with the Project Advisory Group and Carer Steering Group who will include service users, experts in dementia care and clinical psychology able to advise on the appropriate boundaries of any 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, instead non-probability sampling, which is not representative of the wider population is used to provide analytically rather than statistically generalizable findings (Curtis et al, 2000; Mays and Pope, 2000). This is the most appropriate to study organisations or a clearly defined group and the size of the sample required for this approach is determined by the nature and scope of the study aims. The number of sites and participants in the sample can be considered to be appropriate not on the basis of size, but on the quality and appropriateness of the sample and when saturation of data has been achieved (Mays and Pope, 2000).

Setting and access of hospitals: This approach emphasizes the importance of comparisons across sites (Vogt, 2002) allowing for and optimizing the generalizability of findings (Herriott and Firestone, 1983) and enhancing the ability for the findings to impact on policy and practice (Caracelli, 2006). Hospital settings are well suited to an ethnographic approach. At first glance, hospitals may 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 within institutions (Van Der Geest and Finkler, 2004; Goodson and Vassar, 2011). Thus we have identified a range of variables that may influence the phenomena using purposive and maximum variation sampling to include 5 hospitals that represent hospitals types, geographical location, expertise, interventions and quality (Marshall, 1996). Our 5 acute hospital settings (plus pilot) have been identified from across the UK to represent the:

- Types of acute hospital (2 large district hospitals, 1 medium sized general hospital and 2 smaller general hospitals)
- Geographical locations to include rural, urban and inner city sites and situated across England and Wales in the north, south, west, and the greater London area.
- Sites with a range of specialists and interventions.
- Sites with a range of expertise to include a major teaching hospital and where there are concerns about the safety and quality of services as identified by the Care Quality Commission.

The majority of our sites are agreed.

Sampling within each 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). The ethnographic fieldwork will involve the researcher being immersed in ward settings (3 weeks in each ward) to examine the everyday work of nurses, HCAS and other clinical staff who are responsible for feeding and medications, focusing on medication rounds and meal times. We will also focus on observing handover, admissions, and conversations with carers, all opportunities for sharing information about refusal behaviours and how these might best be managed.

Thus, within each hospital setting we will conduct non-participant observation in two ward settings (MAU and Orthopaedic wards) over a 6 week period, with an additional period of fieldwork via follow-up visits to explore emergent analytic themes more fully. This approach is based on the successful fieldwork strategy employed by the NIHR Research for Patient Benefit (RfPB) Programme study (PB-PG-0909-20262, Featherstone co-applicant), a hospital ethnography that involved data collection in 9 acute settings over a period of two weeks in each site (carrying out observation in relevant hospital wards in order to follow the patient's journey from admission to discharge in each site) across the UK. This study collected significant data and insights into the research question. Based on learning from this earlier study, we have decided a 3 week period of observation is required within each clinical area to ensure fieldwork saturation and supervision of the RA by an expert ethnographer in the field is essential to the generation of a high quality data set and the rigour of the study.

Hawthorne effect: We are aware of the Hawthorne or researcher effect. However, we have a number of strategies to minimise this potential effect within our fieldwork:

- A number of meetings with participants to emphasize that the aim of the data collection is to observe their usual work patterns.
- Fieldworkers will spend the first couple of days in the hospital prior formal observations commenced, so that the participants can become used to their presence.
- A research team (the RA and the PI) will carry out fieldwork and this will facilitate reflection and critical peer review, enabling discussion of the extent that people are thought to have behaved differently under observation.
- Staff interviews which will explore the perceived impact of the presence of the researchers and how staff felt they would like patient care within their ward .
- Interviews with patients and carers will also explore this and they will be explicitly asked if they experienced any changes in the care they received when the research team were in the ward and when their care was being observed.

Importantly, ethnography does not aim to achieve distance and detachment, with one of the strengths of this approach is the development of close ties with social actors (those being observed) in the field. It has been argued (Monahan and Fisher, 2010) that any performances observed, however staged or influenced by the presence of researchers, often reveal critical insights by displaying how people see themselves and how they want to be seen. We acknowledge that behaviour may be changed by the researchers presence in the wards and believe it is important to explore this potential effect and learn from it.

Sampling of wards for observation: A diagnosis of dementia is associated with increased risk of hospitalization (Phelan et al, 2012), with a hip fracture (Holmes, 1999; Pinkert and Holle, 2012), urinary tract infection (Sampson et al, 2009), pneumonia (Sampson et al, 2009), and nutritional disorders (Pinkert and Holle, 2012) often the principal cause of admission amongst this group. A national review of case notes for PWD (n=7987) found the majority of their 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 Orthopaedic wards which receive a high volume of patients who have dementia, who are often unstable and require acute medical attention, and they will allow us to observe the care of patients who have both scheduled and unscheduled admissions:

MAU (Medical Assessment Unit) or SAU (Surgical 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 of A&E, with the goal of discharging or transferring patients within 24 hours. There is no routine within this setting, with staff geared to deal with acute admissions with fast turnaround, with no continuity or personalised care, and a chaotic atmosphere. Thus, they are not an area designed or conducive to patients who have any cognitive deficit or dementia at a critical time where escalation of symptoms may occur. 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.

Orthopaedic wards: These settings will allow us to observe routine ward care, with staff geared to deal with planned admissions and where services and staff are focussed on providing patients with continuity and personalised care. Within these settings we will observe the nursing and healthcare staff care for PWD with scheduled care where dementia support has been put in place and patients who have an unscheduled admission following an accident where there may be no opportunity to provide additional support.

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 nursing, nurse associate, entry level nurse, nurse specialist, nurse team leader, advanced nurse, nurse team manager, modern matron, nurse consultant) and other clinical staff (this may include, feeding assistants, SPRs, consultants, AHPs, and staff with managerial responsibilities) responses to 'refusal of care' with a focus on medication rounds and meal times. Within each acute setting we will work with our key contact, the senior nurse responsible for care of the elderly and PWD within each trust, who will facilitate the process of identifying and introducing the team to key informants at hospital and ward levels. These key informants will also provide introductions to our wards and our initial sample of nurses and healthcare workers within each hospital setting. The majority of our hospital sites have been recruited or are in process. However, the general enquiry at ward level of being involved in research will be made several months in advance of the period of observation. If there is general agreement, the research team will visit the wards to discuss with relevant staff the study aims. Initial consent will be gained from team leaders within wards and following this, all individuals will be given information about the study and asked for consent.

Sampling and recruitment of patients and carers for interview and observation: Within wards this will focus on capturing the "incidents, events, and happenings that denote the work that they do, the conditions that facilitate, interrupt, or prevent their work, the action/interaction by which it is expressed and the consequences that result" (Corbin and Strauss, 1990: 421). Importantly, the focus of observation will be on the daily practice of nurses and HCAS and other clinical staff during feeding and medication. It is not possible to predict the patients and carers within each hospital ward during the fieldwork period, however we are confident that this is a large population within these settings. A NAO survey of bed usage found that PWD were usually within acute wards, even if there was no clinical need for them to be there, (NAO, 2007). A recent survey found that the majority were inpatients for 4-10 days (38%), 11-20 days (28%), however, for many this was much longer, with 13% dying in hospital (Royal College of Psychiatrists, 2013).

Case studies: We will carry out a focused series of individual case studies (n=5), 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 subjects (maximum variation sampling) who have had particular types of experiences within the setting (critical case sampling). Thus, sampling will include patients to represent a range of presenting, diagnostic and prognostic factors, and where possible, socio-demographic factors:

- Refusal and resistance present and identified by clinical staff or carers.
- Expected length of stay. This can be highly variable for this group, from days to weeks and months, thus we will follow patients for up to 6 weeks within each hospital setting. If our sample includes patients who have a longer stay, we will carry out telephone or day visit follow-ups.
- Individuals aged over 65 with unplanned admission and an accompanying co-morbid diagnosis of dementia (late onset) formally recorded in their medical records.

Challenges in identifying this patient population

We acknowledge that establishing the presence or absence of a formal diagnosis of dementia in general hospitals can be problematic, however, our patient group are well represented within the acute setting. In addition, an important focus will be an exploration of how underlying symptomology influences the management, treatment and response to refusal and resistive behaviours within these settings. Thus, we will not examine PWD in isolation, their care and experiences must be examined within the wider context of care and the management of refusal within wards.

A diagnosis of dementia is associated with increased risk of hospitalization (Phelan et al, 2012). The Royal College of Psychiatrists report (2005) estimates that a local DGH will have at least four times as many older people with mental disorders on its wards than within local mental health services. In an average day in a typical 500 bed DGH, the majority will be occupied by older people (330), of which 102 will have dementia. A national review of case notes for PWD (7987) found the majority were admitted within care of the elderly (40%), general medical (25%) and orthopaedics (11%) (Royal College of Psychiatrists, 2013). A significant number of PWD may have their first assessment when they are admitted with an acute condition (Holmes, 1999) and in addition, PWD are more likely to be hospitalized due to infectious diseases, fractures, or nutritional disorders than other groups (Pinkert and Holle, 2012). Amongst older patients admitted to hospital following a hip fracture, 40% had dementia, however, 27% of these patients were diagnosed during their admission (Holmes, 1999), with urinary tract infection or pneumonia often the principal cause of admission amongst this group (Sampson et al, 2009).

Although prevalence rates will differ by hospital and be dependent on their specific population, current estimates are likely to be low due to underreporting or late diagnosis of this population (NAO, 2007). Estimates suggest that within the acute setting, approximately 50% of those affected do not have a formal diagnosis in their medical records (Goldberg et al, 2012; Sampson et al, 2009; Russ et al, 2012). There are a range of reasons for the underdiagnosis (Koch et al, 2010) and delayed diagnosis (Albert et al, 2011) of dementia, with much of this due to clinical teams not having the appropriate expertise (Koch et al, 2010). This setting will also contain patients who have features of dementia who may have different underlying causes of cognitive decline including delirium or sub-syndromal delirium, with one screening study of a large cohort of older patients following an unplanned admission within an acute hospital setting (MAU) not only found a high prevalence of delirium (15.5%), but a high rate of undiagnosed (72%) delirium amongst this population (Collins et al, 2010). Other studies have identified similar high levels of co-morbid mental health in this group (Cooper, 1987; Goldberg et al, 2012). Medication and co-morbid chronic conditions such as diabetes can also impact on cognitive function (Russ et al, 2012).

Within the broad classification of dementia, there is also a wide range of major sub-types including Alzheimer’s disease (AD), vascular dementia, Parkinson’s dementia and rare sub-types including Fronto Temporal Dementia, Lewy Body Dementia and Progressive Supranuclear Palsy (Launer, 2011). The literature further suggests an overlap between the different types and underlying causes of dementia, making it hard to establish the extent of each disease contribution to an individuals cognitive decline (Grinberg and Heinsen, 2010). In addition, the emergence of a range of prodromal categories in an attempt to shore up these classificatory problems, in turn leads to further uncertainty in the diagnostic categories at both clinical, scientific and regulatory levels (Moreira et al, 2009). Mild cognitive impairment (MCI) describes the point after normal aging and prior to the development of AD in which memory loss is present, but not at a level to meet the clinical criteria for AD (Petersen et al, 1999). It has been suggested that there is a wide variation in the use of MCI as a diagnosis and its use as a diagnostic category remains controversial (Moreira et al, 2008).

To address these classificatory challenges we have two strategies: (1) Our pilot feasibility study will establish the practical identification of this patient population, their diagnosis and management within these ward settings. This includes an audit of case notes of admissions, which will enable us to establish how long it will take us to identify patients with a diagnosis of dementia within these clinical settings and how prevalent the issue of refusal and resistance is in their recorded medical records and the challenges that staff face. We will use this to guide our initial entry into fieldwork. (2) Because we recognise that there will be patients refusing or resisting care within these ward settings who display behavioural features associated with dementia but do not have a formal diagnosis in their medical records or may have different underlying causes of cognitive decline, we will gather data on any resistance or refusal management we observe within the settings. Importantly, we will record within fieldnotes and interview data, the diagnosis provided within the patients medical records and thus the potential underlying causes of that behaviour. In cases where there is a definitive diagnosis of dementia provided by a memory clinic, we will record details of the dementia diagnosis, to reflect and represent the wide range of major sub-types and prodromal categories of dementia.

Dissemination and projected outputs

The analytic outputs will provide a theoretically informed, evidenced based understanding grounded in clinical practice and service user experience to enable the development of:

- Tools to improve the identification of patients within the acute setting who require support with feeding and medications;
- Recommendations for the organisation of nursing and HCAS work at ward level that supports and facilitates adequate nutritional intake and drug concordance;
- Training to promote interactional styles and techniques that de-escalate common resistance and refusal behaviours in the ward setting;
- Models of care that aid the identification of key communication opportunities for involving carers in supporting medication and feeding.
- Identification of factors in hospital organisation and ward culture that can improve or worsen the experiences and outcomes of patients who refuse.

NHS health service managers 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 patients who refuse. Our aim is to provide in-depth evidence based knowledge about the management of refusal and resistance to care to inform the development of evidence based training and organisation of nursing and HCAS that will lead to shorter 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 other populations; refusal of care is a significant issue for patients in acute hospital settings with many other conditions e.g. mental health problems and learning disabilities. We anticipate building a future programme of work examining transferability to other contexts and people with an acute condition and comorbidity other than dementia.

Plan of investigation and timetable
Total 30 months: 1st February 2015 - 30th July 2017. 1-6 months: Draft narrative synthesis, recruit Research Fellow, and confirm advisory board membership; finalise Trusts/LHBs, R&D and NHS REC approvals and negotiate ward access. 7-20 months: Data collection; six weeks in each acute hospital setting, divided into three weeks within each ward. Writing up fieldnotes and analysis of data from each setting prior to entering the next research site. Based on prior fieldwork, the ratio is 1:1 for every 6 weeks of fieldwork, 6 weeks is needed to write up detailed field notes and complete preliminary analysis. Thus 15 months is requested for this stage. 21- 30 months: Report and publication writing, drafting of impact and dissemination materials including workshops, symposium, and on-line materials.

	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		**	**	**	**	**	*			
Writing up and analysis			_**	_**	_**	_**	***	***		
Report and publication writing		__*				__*	***	***	***	***
Drafting of dissemination materials							*	***	***	***
Workshops and									*	*

symposium										
Ongoing impact and on-line materials		*	*	*	*	*	*	*	*	*
Project Advisory Group and Carer Steering Group	*		*		*		*		*	
Public engagement events	*	*	*	*	*	*	*	*	*	*

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