MemoryCare: The management of refusal of food, drink and medications by people with dementia admitted to hospital with an acute condition

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Summary

Little is known about how clinical teams in acute hospitals respond when they believe a patient with dementia is refusing care. Recent reviews (Elliott et al, 2012; Moyle et al, 2008) suggest that, prior to developing interventions, detailed research is required to understand the role and needs of healthcare workers caring for this patient population and to explore what constitutes 'good care' within the acute setting. In response, this ethnography examines (1) medication and mealtimes within wards; (2) the care of patients within the wards who refuse or resist care; and (3) focus on the experiences of patients with dementia (a group known to refuse care) and their families.

Fieldwork will take place in 5 hospitals (across Wales and England). Observation in each hospital (30 days) will be carried out within two acute hospital wards (MAU and orthopaedic) known to have high admission rates of people with dementia (approximately 15 days per ward). It will involve observation, interviews, case studies and routine ward data:

- Observations within the ward will concentrate on the everyday work of nurses, Health Care Assistants and other ward staff as they are involved in medication rounds and meal times, ward routines and handover and admissions.
- Carry out (where possible) short ethnographic (within observation) interviews (<15 minutes each, 3-6 per shift) with a sub-sample of patients who refuse: patients with dementia who refuse. Short interviews will also be carried out with their carers and the staff caring for them. **Informed written consent will be required before interviews take place.**

- A detailed case study of one patient with dementia (identified as refusing or resisting care) and the care they receive throughout their admission in each hospital (identified in the MAU or the orthopaedic ward). This will involve regular periods of observation and a series of in-depth interviews (<30 minutes each) with the patient with dementia, staff caring for them and their carer/family members (n= 6-8) during their hospital admission. Interviews will be carried out with the patient and carer following discharge (n=2).
- Routine ward data (from ward managers) will be collected (ward staffing levels, bed occupancy, turnover etc), recorded levels of resistance and refusal, and the number of patients with dementia (from patient records) admitted to the ward during the fieldwork period.

The study will provide a detailed understanding of the organizational, clinical and interactional processes that influence responses to 'refusal of care'. This will be used to identify ways in which the social organisation of nursing care and care processes can be structured to improve the nursing and clinical management of resistance and refusal in acute hospital ward and patient and family experiences of care.

Background

Refusal of care during hospital admissions can be distressing, time consuming and difficult to manage for both professional and family carers. It has important implications for morbidity, mortality and quality of life for patients.

There is already a large body of literature examining how refusal of care is managed within primary and long-term service provision, but little is known about how clinical teams in acute hospitals respond when they believe a patient is refusing care. Recent reviews (Elliott et al, 2012; Moyle et al, 2008) suggest that, prior to developing interventions, detailed research is required to understand the role and needs of healthcare workers with this patient population and to explore what constitutes 'good care' within the acute setting.

Patients with dementia are one of the largest populations cared for within the acute setting and currently occupy one in four acute hospital beds at any one time (Alzheimer's Society, 2009). They are a highly vulnerable group in this setting. Following admission their functional abilities can deteriorate significantly (Goldberg et al, 2012). They are also the group most at risk of delayed discharge (Barker and Halliday, 2005), with the complexities involved in diagnosing and treating patients with dementia extending their hospital stay (Barker Halliday, 2005).

In response, this qualitative study uses an ethnographic approach to examine medication and meal times within acute hospital wards, with a focus on identifying clinical responses to refusal and resistance to food, drink and medicines (to safeguard patient dignity, we will not observe personal care)

and the experiences of both patients who refuse and their carers. In addition, we will focus on the experiences of patients with dementia who refuse by carrying out interviews and a series of detailed case studies to examine the experiences of patients with dementia (identified as refusing or resisting care) and their carers.

Research questions

How do ward staff respond to refusal and resistance to food, drink and medicines by people with dementia being cared for on acute hospital wards, and what is the experiences of refusal of care from the perspective of patients and their carers?

Aims and objectives

The aim of our study is to establish an empirically based conceptual and theoretical foundation that can inform the development of innovations in service organisation and delivery that will improve the nursing and clinical management of resistance and refusal in acute hospital wards. To achieve our aim the study objectives are:

- To provide a detailed understanding of the clinical and interactional processes that influence responses to 'refusal of care' by ward staff, with a focus on medication rounds and meal times (not personal care). Specifically, what they are doing and why, how staff respond to and manage refusal and what influences these approaches.
- To provide a detailed understanding of the hospital organisational processes that impact on the care of patients who refuse. Specifically, map the response and management of this patient group and the incidents of refusal and resistance of care within wards.
- To examine in-depth, the experience of refusal of care within the acute hospital setting from the perspective of people with dementia, a group known to refuse care within an acute ward setting and the perspective of 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.

Secondary objectives:

- 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.
- To identify 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 support adequate nutritional intake and drug concordance to improve patient and family care experience and the effectiveness of treatments.

Methodology

Ethnography 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 ethnography can take into account the perspectives of patients, carers, clinical staff and hospital staff (Caracelli, 2006). 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 everyday: medication rounds, meal times, food and drink that are part of the routine care carried out by nurses and healthcare assistants in acute wards.

Study population

Fieldwork will take place in 5 hospitals (across Wales and England) and observation in each hospital (30 days) will be carried out within two acute hospital wards (MAU and orthopaedic) known to have high admission rates of people with dementia. It is not possible to predict the number of patients with dementia or the number of patients who will refuse or resist food, medication or both on each hospital ward during the fieldwork period. We are confident that this will be a significant proportion of the ward population during observations, with people with dementia occupying a quarter of acute hospital beds at any one time (Alzheimer's Society, 2009).

1 in 4 admissions to our hospital wards will have a diagnosis of dementia (a group known to refuse care. However, prevalence rates will differ by hospital and be dependent on their specific population, and current estimates are likely to be low due to underreporting or late diagnosis of this population (NAO, 2007). Our pilot audit of one ward suggests that half of patients with a diagnosis of dementia will also have an episode of refusal during their admission that was recorded in their medical records. By taking a conservative estimate, we expect to be potentially observing and speaking to 5 patients who refuse care with dementia at any one point in time. We estimate that across the 15 days of fieldwork within each ward we will identify >15 potential participants per ward. This means that in each hospital site we expect to identify >30 patients, and 150 across our 5 hospital sites.

Data collection

Our focused ethnographic strategy will involve one researcher based within each ward for approximately 15 days (the Lead Project Nurse will work across the two wards during the observation periods). It will involve observation, interviews, case studies and routine ward data. Within each ward the researcher will:

Observations of staff and ward routines:

- **Observe medication rounds and meal times, concentrating on the everyday work of nurses and Health Care Assistants. Clinical staff from a range of other disciplines and roles (this may include, feeding**

assistants, SPRs, consultants, AHPs, and staff with managerial responsibilities) will also be observed if and when they are involved with medications and meal times.

- **Observe medication rounds and meal times of patients who have been identified through the screening of medical records (carried out by the Lead Project Nurse) as resisting or refusing care.**
- **The periods of observation will also include the everyday work of staff by examining ward routines that inform medication and meal time practices and responses to refusal, and handover and admissions, opportunities for sharing information about refusal and how these might best be managed.**

Sub-sample of patients who refuse care who also have a diagnosis of dementia:

- **Carry out (where possible), short ethnographic (within observation) interviews (<15 minutes each, 3-6 per shift) with patients with dementia who refuse, their carers and the staff caring for them. Informed written consent will be taken before any interviews take place.**
- One detailed case study in each hospital (identified in the MAU or the orthopaedic ward) will involve regular periods of observation of one patient with dementia (identified as refusing or resisting care) and the care they receive throughout their admission (2-4 short visits per day to coincide with meal times and medication rounds) and a series of in-depth interviews (<30 minutes each) with the patient with dementia, staff caring for them and their carer/family members (n=6-8) during their admission. Follow-up interviews will be carried out with the patient and carer following discharge (n=2).

Ward data:

- Routine ward data (from ward managers) will be collected (ward staffing levels, bed occupancy, turnover etc).
- Recorded levels (patient records) of resistance and refusal and the number of patients with dementia admitted to the ward during the fieldwork period (accessed by the Lead Project Nurse) will be collected.

Observation

Observations will require the researchers (and the Lead Project Nurse) to be present for long stretches of time at regular intervals observing across shifts, including night shifts and weekends. We will observe the everyday work of staff, ward routines with a focus on feeding and medication rounds. Observations will be recorded in a notebook and written up as fieldnotes that describe the researcher's observations as straightforwardly as possible. Fieldnotes will provide details of the setting, what happens, the people we meet and interact with, the routine work and how it is organised and what people do. We will describe the interactions and conversations we observe and participate in. We will also record some brief direct quotes from conversations. No identifiable information about individuals will be recorded.

Interviews

We will invite individuals (patients with dementia who refuse, their carers and the staff caring for them) to take part in ethnographic (within observation) interviews (<15 minutes each). Participants identified for the case study will be asked to take part in in-depth interviews (<30 minutes each). Interviews will explore experiences of the ward, meal times and medications. The interviews will be arranged to suit the individual and will be audio-recorded. Staff interviews will be carried out during lunchtime or scheduled breaks in the work flow. **Informed written consent will be taken before any interviews take place.**

Data set

Overall the two researchers will carry out 30 days of observation in each of the 5 hospital sites. Each researcher will carry out 12 hour shifts of observation during each day of study in the field (15 days in each ward, total= 180 hours of observation). A median of 50 ethnographic (within observation) interviews (<15 minutes each, 3-6 per shift) will be conducted during the observation periods with staff, patients and their carers. The case study will involve regular observation (2-4 short visits per day to coincide with meal times and medication rounds) of a single patient with dementia who refuses care (identified by the Lead Project Nurse in discussion with the clinical and research teams), throughout their admission. A series of interviews (total= 10 interviews) will be conducted (<30 minutes each) as part of the case study with the patient with dementia, staff caring for them and their carer/family members during their admission (n=6-8). Follow up interviews will be conducted with the patient and their carer following discharge (n=2).

Analysis

Data collection (observations and interviews) and analysis will be informed by the analytic tradition of grounded theory (Glaser and Strauss, 1967). This uses the constant comparative method; 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.

Field notes of observation, experience, and near verbatim text will be written up into word files and all audio recordings of interviews (short and in-depth) will be transcribed verbatim by a professional transcription service. 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.

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.

Access
Using purposive and maximum variation sampling we have included 5 hospitals that represent hospitals types, geographical location, expertise, interventions and quality (as identified by the Quality Care Commission) across Wales and England to represent the range of variables that may influence the phenomena.

There will be a phased consultation approach to obtaining consent to observe in each hospital ward. We recognise that observations may be perceived as intrusive by individual staff members and initial meetings will be made at least four weeks in advance to discuss the study and its implications, with a further opportunity to meet with the research team at least seven days prior to observations.

Eligibility
Staff
All ward staff involved in medication rounds and mealtimes will be invited to participate.

Patients who refuse care within the ward
We will include patients within the ward who refuse care and this will include patients with dementia, a group that may have some communication difficulties. We need to study refusal by including the patients who display these behaviours. This sample will include patients (1) refusing or resisting care within these ward settings (2) may have a range of underlying causes of cognitive decline, (3) patients with a diagnosis of dementia or probable dementia recorded in their medical records.

To identify this group, the medical records of all patients within the ward will be reviewed (by the Lead Project Nurse employed by the project employed via the local hospital trust) prior to the start of fieldwork using a screening tool. This review process will be ongoing, with new admissions reviewed prior to every fieldwork period to identify individuals (newly admitted or newly identified) who are part of this patient group.

The sub-group of patients who refuse care who also have a diagnosis of dementia will be approached to take part in short interviews (and the case studies) will be identified from this sample.

Exclusion criteria
We will exclude patients who do not speak fluent English, we do not have translators available to this study and this is not the focus of our research.

Recruitment and consent to participate
To ensure that hospital staff, patients, family members and all entering the ward are aware of the ongoing research and that there may be a researcher present, the research team will:

- Display posters providing general information about the observations on the ward in staff coffee rooms, family rooms and other ward areas.
- Provide study information, links for further information and contact details.
- Wear badges giving their name and stating their role.

Observations and Interviews

Staff within the ward: Observation and interviews

We will publicise the study via leaflets and posters and by meeting ward staff in advance. Staff within the wards will be approached directly by a senior nurse within the ward, emphasizing that they are not obliged to participate. This will be carried out prior to the research team entering the wards and at ward handovers during the period of fieldwork. Staff will not be approached directly by members of the research team. All staff who will be working within the ward settings during the fieldwork period will be informed about the project and asked confidentially if they are willing to consent to participate in the study. **Those staff that verbally consent to observations will be asked to complete informed written consent at a time convenient to them, their patients and the ward. This may be before, during or after the research.**

Data collected from observations will be destroyed if a member of staff verbally consents to observations but later changes their mind when asked to give informed written consent.

The consent process will be ongoing within the ward settings. Staff from other wards and specialisms (this may include, feeding assistants, SPRs, consultants, AHPs, and staff with managerial responsibilities) who will not have been part of the initial informed consent process are likely be present during points of the observation period. These individuals will be provided with study information describing the research and given the opportunity to 'opt out' of observations. Informed consent will be taken prior to conducting any interviews with staff within this group.

Staff within the wards will not be approached directly by the researchers. The researchers will not carry out observations when staff who 'opt out', decline or withdraw their consent are present.

Patients within the ward: Observation of ward routines

During the period of observation, information about the research will be provided by ward staff (or the Lead Project Nurse) to all patients and their carers/family members within the ward, and to all patients joining the ward as part of their admission process. The researchers will *not* directly approach patients.

Project information will state that the researchers are observing ward staff, as they conduct everyday care such as medication rounds and mealtimes. It will clarify that the researchers will only record non-identifiable information. All

patients will have the opportunity to 'opt out' of the study. The researchers will not carry out observations when patients who decline to participate are present.

Patients will be informed that some patients on the ward may be asked to take part in interviews or have their meal times and medication observed more closely than others. If they are asked to take part in this additional research, they will be provided with more information about the study and they will be asked to give specific written consent to agree to take part.

[Consent sub-group 'Patients who refuse care: observation of medication and mealtimes' removed.]

Patients who refuse with dementia and their carer: observation and interviews
There will be an informed written consenting process for some participants (patient and their carer), who will be asked if they are willing to take part in additional research that will examine their care and experiences in more detail. This will involve observing their care (not personal care) and talking to them (short interviews) during their stay within the ward.

Carers are expected to take part in the study throughout their partners stay within the ward. It will be explained to participants that they have the right to withdraw from the study, and this won't affect their partners care in any way. Their confidentiality and anonymity will be respected.

It is considered good practice to involve carers in studies in which people with dementia are participants (Alzheimers Europe). McKillop (2002) suggest that whilst it is not necessary to ask the permission of carers, they should discuss the research and what it involves with them. If the carer does not support the participation of the patient with dementia then McKillop (2002) suggest that the person should be withdrawn from the study. We are aware that not all patients in this group will have a carer or next of kin.

Case Study
Patients with dementia who refuse and their carers identified for the case study
During the period of observation in each hospital, one patient with dementia and their carer will be asked to take part in additional observation of their care (not personal care) and interviews throughout their hospital admission and include a visit to them once they have been discharged.

The researchers will *not* directly approach patients or carers. This patient and carer will be provided with information about this additional research at the initial meeting with the ward staff. If they are willing to consider participation the Lead Project Nurse will provide study information and discuss what participation will involve and they will be asked to give specific written consent to agree to take part in this additional research.

Informed consent will be taken by the Lead Project Nurse. Carers are expected to be in the study throughout their partners stay within the hospital. It will be explained to participants that they have the right to withdraw from the study, and this won't affect their partners care in any way. Their confidentiality and anonymity will be respected.

Capacity to consent
Many of the patients recruited to this study will lack capacity to give informed consent. The research is about refusal of care within wards and people with dementia who refuse care, and could not be validly undertaken if we exclude people who lack capacity. As a team we have extensive experience in training researchers to recruit such patients and the requirements of the Mental Capacity Act 2005 and have successfully recruited and collected data from people with dementia and the healthcare professionals working with them. Agreement to participate in research is an on-going process and it is important to confirm that the person with dementia agrees to continue with research irrespective of consent in place. In addition to informed consent and consultee agreement (where the patient does not have capacity), we will use a form of 'process consent' (Dewing 2007) and, irrespective of patients' mental capacity at the time of recruitment, verbal agreement to undertake the observations will always be sought from the patient prior to the period of observation.

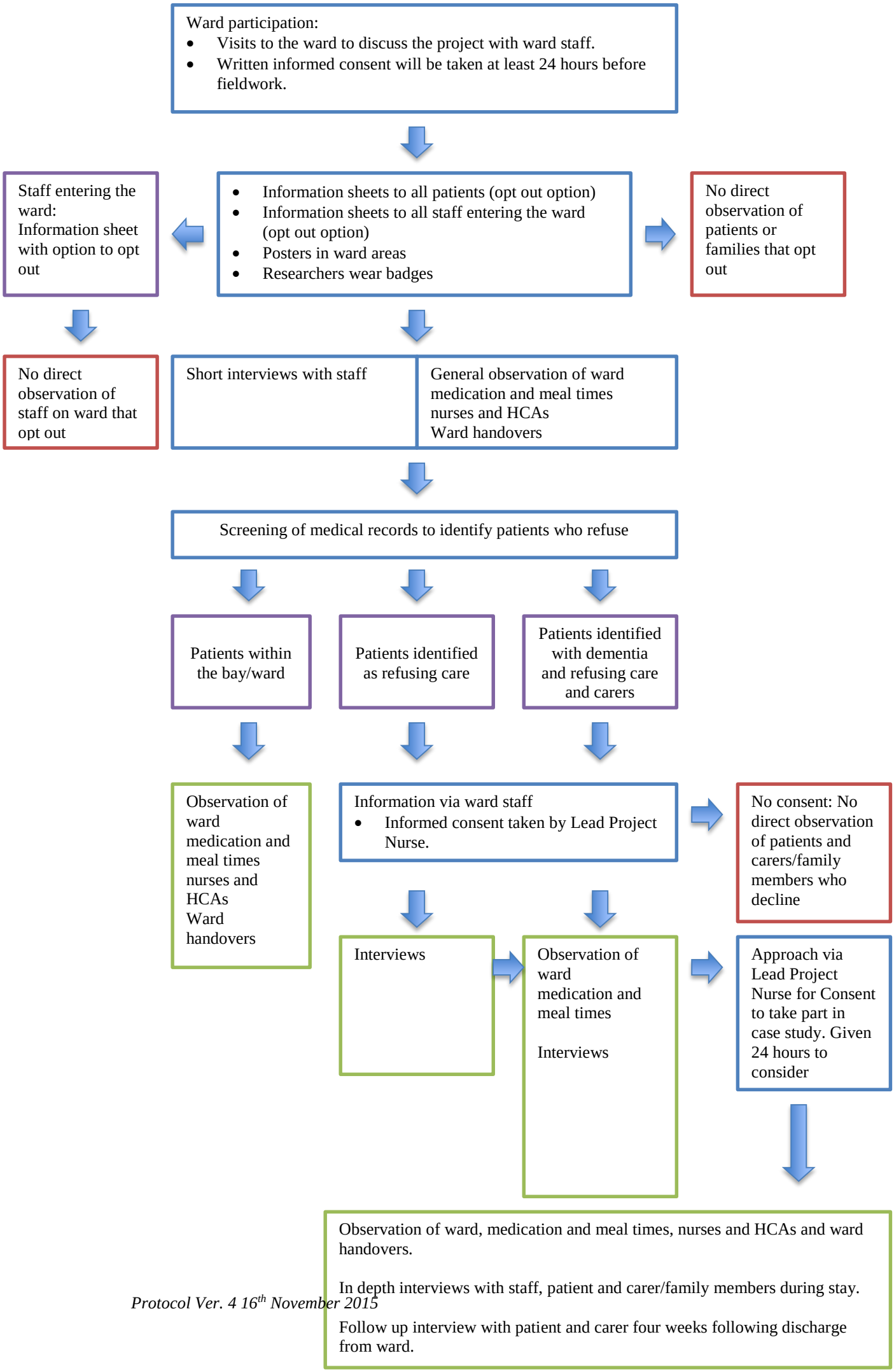
Outputs
The study analysis will provide:
- Tools to improve the identification of patients within the acute setting who require support with feeding and medications;
- Recommendations for the organisation of nursing and HCAS work at ward level that supports and facilitates adequate nutritional intake 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.

Timetable
1-6 months: Draft narrative synthesis, recruit acute sites and negotiate ward access. 7-20 months: Data collection, writing up fieldnotes and analysis of data. 21- 30 months: Report and publication writing, drafting of impact and dissemination materials including workshops, symposium, and on-line materials.

Management of the project
Project Advisory Group: Already established and includes researchers with experience of working within NHS settings, service manager, service users,

carers and people with dementia. It will meet at least 3 times during the study to ensure key components and milestones are achieved.
Carers Steering Group: Already established and includes carers and patients at different stages in the journey. It will meet at least 10 times during the study to ensure key components and milestones are achieved.

Design
See overleaf ***[modified]***


Ward participation:
Visits to the ward to discuss the project with ward staff.
Written informed consent will be taken at least 24 hours before fieldwork.
Staff entering the ward: Information sheet with option to opt out
Information sheets to all patients (opt out option)
Information sheets to all staff entering the ward (opt out option)
Posters in ward areas
Researchers wear badges
No direct observation of patients or families that opt out
No direct observation of staff on ward that opt out
Short interviews with staff
General observation of ward medication and meal times nurses and HCAs
Ward handovers
Screening of medical records to identify patients who refuse
Patients within the bay/ward
Patients identified as refusing care
Patients identified with dementia and refusing care and carers
Observation of ward medication and meal times nurses and HCAs
Ward handovers
Information via ward staff
Informed consent taken by Lead Project Nurse.
No consent: No direct observation of patients and carers/family members who decline
Interviews
Observation of ward medication and meal times
Interviews
Approach via Lead Project Nurse for Consent to take part in case study. Given 24 hours to consider
Observation of ward, medication and meal times, nurses and HCAs and ward handovers.
In depth interviews with staff, patient and carer/family members during stay.
Follow up interview with patient and carer four weeks following discharge from ward.