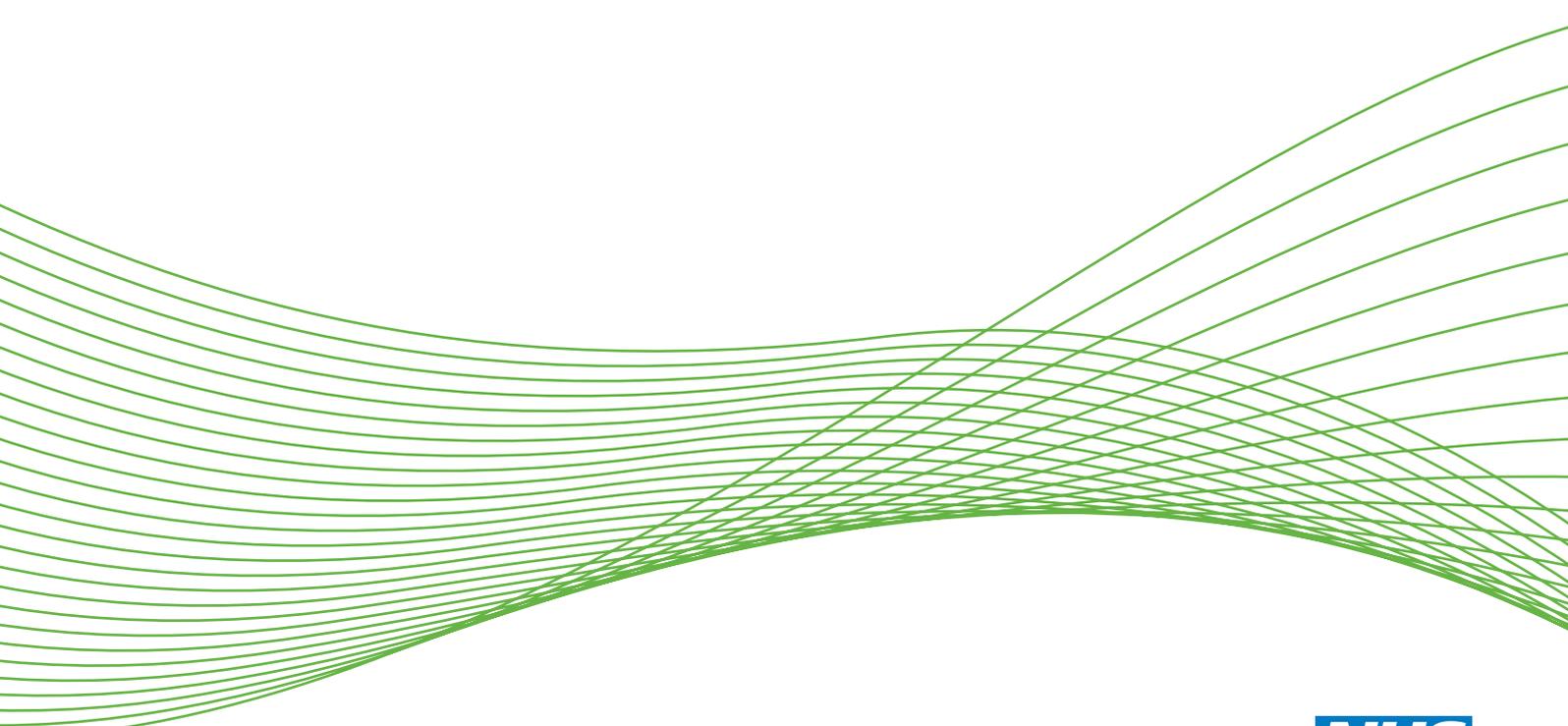


## Refusal and resistance to care by people living with dementia being cared for within acute hospital wards: an ethnographic study

*Katie Featherstone, Andy Northcott, Jane Harden,  
Karen Harrison Denning, Rosie Tope, Sue Bale and Jackie Bridges*



***National Institute for  
Health Research***



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# Abstract

## Refusal and resistance to care by people living with dementia being cared for within acute hospital wards: an ethnographic study

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**Background:** The acute hospital setting has become a key site of care for people living with dementia. The Department of Health and Social Care recognises that as many as one in four acute hospital beds in the UK will be occupied by a person living with dementia at any given time. However, people living with dementia are a highly vulnerable group within the hospital setting. Following an acute admission, their functional abilities can deteriorate quickly and significantly. Detailed research is required to understand the role and needs of health-care staff caring for this patient population and to explore what constitutes 'good care' for people living with dementia within the acute setting.

**Objectives:** The focus of this study was a common but poorly understood phenomenon within the acute setting: refusal and resistance to care. Our research questions were 'How do ward staff respond to resistance to everyday care by people living with dementia being cared for on acute hospital wards?' and 'What is the perspective of patients and their carers?'

**Design:** This ethnography was informed by the symbolic interactionist research tradition, focusing on understanding how action and meaning are constructed within a setting. In-depth evidence-based analysis of everyday care enabled us to understand how ward staff responded to the care needs of people living with dementia and to follow the consequences of their actions.

**Setting:** This ethnography was carried out on 155 days (over 18 months) in 10 wards within five hospitals across England and Wales, which were purposefully selected to represent a range of hospital types, geographies and socioeconomic catchments.

**Participants:** In addition to general observations, 155 participants took part directly in this study, contributing to 436 ethnographic interviews. Ten detailed case studies were also undertaken with people living with dementia.

**Results:** We identified high levels of resistance to care among people living with dementia within acute hospital wards. Every person living with dementia observed within an acute hospital ward resisted care at some point during their admission.

**Limitations:** Limitations identified included the potential for the Hawthorne or researcher effect to influence data collection and establishing the generalisability of findings.

**Conclusions:** Ward staff typically interpreted resistance as a feature of a dementia diagnosis, which overshadowed the person. However, resistance to care was typically a response to ward organisation and delivery of care and was typically rational to that person's present ontology and perceptions. In response, nurses and health-care assistants used multiple interactional approaches that combined highly repetitive language with a focus on completing essential care on the body, which itself had a focus on the containment and restraint of the person in their bed or at their bedside. These approaches to patient care were a response to resistance but also a trigger for resistance, creating cycles of stress for patients, families and ward staff. The findings have informed the development of simple, no-cost innovations at the interactional and organisational level. A further study is examining continence care for people living with dementia in acute hospital settings.

**Funding:** The National Institute for Health Research Health Services and Delivery Research programme.

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## List of abbreviations

A&E	accident and emergency	NIHR	National Institute for Health Research
AHP	allied health professional		
CQC	Care Quality Commission	POVA	Protection of Vulnerable Adults
DoLS	Deprivation of Liberty Safeguard	REC	Research Ethics Committee
HCA	health-care assistant	SDO	Service Delivery Organisation
i.v.	intravenous	SPR	specialist registrar
MAU	medical assessment unit	T&O	trauma and orthopaedic
MOOC	massive open online course		



## Plain English summary

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

This study aimed to find ways in which the delivery of nursing care could be adapted to improve the quality of care received by people living with dementia. To do this, the study focused on a common but poorly understood feature of caring for people living with dementia, namely refusal and resistance to care. For 155 days, over 18 months, care was observed within 10 wards across five hospitals (two wards at each hospital) in England and Wales.

It was found that people living with dementia resisted or refused care frequently while admitted to a hospital ward. Every person living with dementia who was observed resisted care to some degree at some point of their hospital stay. This resistance was typically a response to ward organisation and occurred in direct response to the ways in which care was being delivered at the bedside. However, ward staff typically interpreted resistance as a sign that the person lacked capacity to make decisions, with the dementia diagnosis overshadowing care. By responding to assumptions about dementia, rather than the causes of a person's behaviour, ward staff could inadvertently exacerbate resistance. Common responses included repeated instructions, raised voices, containment of patients to beds and continued attempts to complete a task that a patient had rejected. These responses could trigger further resistance, outright refusal of care and escalating cycles of resistance that caused stress and anxiety for the patient, their families and carers, and staff.



## Scientific summary

The goal of this in-depth ethnographic study was to identify ways in which the social organisation of nursing care and the interactional care processes at the hospital bedside can be structured to improve the quality and humanity of care for people living with dementia who have been admitted to an acute hospital with a comorbid condition.

### Background

The acute hospital setting has become a key site of care for people living with dementia. The Department of Health and Social Care recognises that as many as one in four acute hospital beds in the UK will be occupied by a person living with dementia at any given time. In some areas, these figures may be underestimates, with some hospitals reporting that up to 50% of acute admissions may also have a diagnosis of dementia, and a significant number of other patients may be living with dementia but are yet to receive a formal diagnosis. Dementia as a condition is often thought of as something cared for first in the community, then later in specialist settings and long-term care, but the prominence of the acute hospital setting and its impact on people living with dementia cannot be ignored.

People living with dementia are a highly vulnerable group within the hospital setting and after an acute admission their functional abilities can deteriorate quickly and significantly. People living with dementia are more likely to experience a delayed discharge, are more likely to be readmitted and are at much higher risk of dying during an admission and in the months immediately after discharge than people without a diagnosis of dementia or another cognitive impairment.

Although there is a recognition that many hospitals have initiatives to improve the environment and support for people living with dementia, there is an acknowledgement that hospitals are struggling to respond to the needs of such patients. However, prior to developing interventions and implementing policy solutions, detailed research is required to understand the role and needs of health-care staff caring for this patient population and to explore what constitutes 'good care' for people living with dementia within the acute setting.

### Objectives

The focus of this study was to examine a common but poorly understood phenomenon within the acute setting: refusal and resistance to care. Refusal of care (also labelled in the literature as resistance, resistive behaviours or rejection of care) is characterised as non-compliant behaviour in response to health-care staff. People living with dementia may refuse medications, food and personal care, as well as diagnostic or therapeutic procedures. Although there is already a large body of literature examining refusal of care within primary and long-term service provision, little is known about the social and organisational context of refusal of care and how clinical teams in acute hospitals respond when they believe a person living with dementia is refusing care.

In light of this, this in-depth ethnographic study examined the everyday work of nurses and health-care assistants (HCAs) caring for people living with dementia within acute hospital wards. Our research questions were 'How do ward staff respond to refusal and resistance to food, drink and medicines by people living with dementia being cared for on acute hospital wards?' and 'What are the experiences of refusal of care from the perspective of patients and their carers?'

## Methods

Our approach to ethnography was informed by the symbolic interactionist research tradition, which aims to provide an interpretive understanding of the social world, with an emphasis on interaction, which in turn focuses on understanding how action and meaning are constructed within a setting. This ethnographic approach enabled an in-depth, evidence-based analysis of everyday care, as well as an understanding of how ward staff responded to the care needs of people living with dementia, and enables us to follow the consequences of their actions over time. Importantly, the study also examined how ward staff accounted for and made sense of their responses to the care needs of people living with dementia in these contexts. Ethnography allowed us to examine these elements and, importantly, the interplay between them. This understanding was examined in the context of a narrative synthesis of the existing literature about refusal of care more widely.

This ethnography was carried out in 10 wards within five hospitals across England and Wales, which were purposefully selected to represent a range of hospital types, geographies and socioeconomic catchments. Across these sites, 155 days of observational ethnographic fieldwork were carried out in areas of acute hospitals known to admit large numbers of people with dementia for acute conditions: trauma and orthopaedic (T&O) wards and medical assessment units (MAUs) or variants thereof. Approximately 600,000 words of observational fieldnotes were collected, written up, transcribed, cleaned and anonymised by the ethnographers (KF and AN). To provide a detailed contextual analysis of the events observed, the expertise involved and the wider conditions of patient care, ethnographic (during observation) interviews with ward staff ( $n = 414$ ) were also carried out. Ethnographic interviews ( $n = 71$ ) were also conducted with case study participants ( $n = 10$ ) and their family members ( $n = 37$ ), with care at the bedside being observed throughout a patient's admission.

Ethics Committee approval for the study was granted by the NHS Research Ethics Service via the Wales Research Ethics Committee (REC) 3 on 24 June 2015 (reference number 15/WA/0191). Substantial amendments to the study protocol were approved at a meeting of the Wales REC 3 committee on 10 December 2015.

## Results

In the course of the analysis, the concept of resistance has been treated as emergent and 'in the making', and this surfaced in the ways ward staff interpreted and responded to behaviours during the mundane encounters, interactions and the everyday routine work of the ward. The actual act (of refusal, resistance or rejection) is always context bound and involves many factors (which we have tried to capture in the analysis) and should not be seen as an isolated feature of a dementia diagnosis. Thus, rather than classifying these behaviours as distinct entities, the term 'resistance' is used to represent the range of responses people living with dementia have to the ways in which their care is delivered at the bedside and their wider experiences of their admission to an acute hospital ward. In turn, these responses were viewed by staff as problematic, difficult, signifying a lack of capacity, and, because they do not 'fit' the organisation and timetabled routines of the ward, as something that must be overcome or managed. Specifically, our analysis identified:

- High levels of resistance, refusal and rejection of care among people living with dementia within acute hospital wards. In total, we identified 1052 (T&O,  $n = 523$ ; MAU,  $n = 529$ ) incidents or episodes of resistance to care. We identified that every person living with dementia observed within an acute hospital ward resisted care at some point during their admission.
- Resistance could manifest in a number of ways (in order of prominence): (1) a person attempting to get out (and getting out) of bed, standing and walking around (this includes wanting to go home, trying to leave the bay, ward or hospital; going to other rooms or areas of the ward/unit; pulling at the bed rail; and approaching the nursing station); (2) verbal and physical cues (these include shouting, being angry

- or agitated; crying, screaming or sounding distressed; asking to go home, to see family or to be taken somewhere; biting, pushing, pulling, spitting at or holding on to staff; and refusing to leave the ward); (3) not submitting to the timetabled rounds of the ward (in terms of mealtimes, medication, personal care, observation rounds and examinations); and (4) the removal of equipment (this includes pulling or removing intravenous and/or gastric tubes, dressings, catheters, nebulisers, cannulas, oxygen masks and other medical equipment crucial to care; and pulling sheets off the bed or removing clothing).
- The subsequent patterns of responses and interventions typically involved nurses and HCAs using multiple interactional approaches that combined highly repetitive language (orienting the person to reality, providing instructions to be obeyed, emphasising the necessity and requirements of the institution, negotiation and bargaining) with the performative (a focus on carrying out work on the body, completing essential care, and containment of the person at the bedside). These approaches created damaging cycles of stress for patients, families and ward staff.
  - Ward staff typically interpreted resistance as a feature of a dementia diagnosis, which overshadowed the person, with longer-term, chronic and disruptive resistance viewed as a feature of their identity, which could become their principal identity in the context of the ward. However, resistance to care was typically a response to ward organisation and delivery of care and typically rational to that person's present ontology and perceptions.
  - Resistance appeared to be a response and reaction to the impact of admission on individuals. These were both emotional and somatic and included difficulties in communicating need, high levels of anxiety and the unfamiliar environment of the ward, which could lead to disorientation, and, in turn, were associated with the fixed routines, timetables and organisation and delivery of care. A key impact of this was the person becoming viewed within the ward as having increased dependency, which, in turn, resulted in them losing skills and independence.
  - The completion of ward routines and timetables dominated shifts, which meant that staff did not consider it possible to focus on what appeared to be low-level resistance that was not an immediate priority or risk, particularly in the context of the pressing demands of the ward routines of personal care, bed making, observation and medication rounds. Often, subtle signs could be identified in a patient's body language and changes in their behaviour that indicated resistance or the potential for resistance. However, it was unusual for ward teams to recognise these early signs or feel able to prioritise responses to them.
  - At the bedside, the staff response to resistance to care was one of containment and restraint. Raising the side rails of the bed or tucking bed sheets in tightly around the patient were both common means of containing a patient within the bed. For those patients sitting at the bedside, the close placement of the mobile tray table or unreachable walking frames and technologies such as chair alarms were used to contain people and keep them sitting in their bedside chair. Clinical technologies, including continence technologies (particularly full continence pads, and using bed pans and commodes at the bedside), medication and sedation, and tightly secured medical equipment also limited or restrained movement from the bedside. Importantly, these approaches to patient care and patient containment at the bedside were a response to resistance but also frequently the trigger for resistance or patient anxiety.

## Conclusions

This in-depth ethnographic study has examined the everyday work of nurses and HCAs caring for people living with dementia within acute hospital wards. We identified key responses to resistance to care at the organisational and interactional levels of care delivery at the bedside that had significant consequences for people living with dementia, their family carers and ward staff. Our analysis was drawn from observations that allowed the ethnographers to spend extended time within and across shifts observing specific ward bays and the people within them. This observational approach revealed the potential underlying reasons or triggers for a person's resistance to care. In response to resistance, we identified powerful cultures of containment and restraint, with the interactional care work in the ward driven by the organisational demands of delivering care within fixed routines and timetables that do not meet the needs of people living with dementia. A key impact was the invisibility of people living with dementia and their care needs within acute wards.

At the bedside, staff management of and responses to resistance to care by people living with dementia were focused on containment and restraint. Although specific techniques had some variance between wards, the overall strategy was always to keep the person living with dementia within their bed or sitting at the bedside. Across all sites, staff expressed high levels of concern and anxiety about people attempting to or leaving the bed or bedside, and this increased exponentially if they were walking in the bay, the wider ward and corridor or close to the ward entrance. Importantly, these approaches to patient care and their containment at the bedside were both a response to resistance and also frequently the trigger for resistance or cause of patient anxiety.

We identified that, at an organisational level, a key response to resistance by people living with dementia within wards was to assign one-to-one agency HCA staff to care for them. This was a policy within almost all hospitals and wards. The outsourcing of dementia care and expertise via 'dementia workers' and one-to-one agency care meant that the care of people living with dementia was typically seen as other people's work; this could have a powerful impact on the wider ward culture. Ward staff typically interpreted resistance as a feature of a dementia diagnosis, which overshadowed the person and could become their principal identity in the context of the ward. A key impact of this was the person becoming viewed within the ward as having increased dependency, which, in turn, resulted in individuals losing further skills and independence.

Importantly, our analysis has identified ways in which the social organisation of nursing care and the interactional care processes at the bedside can be structured to improve the patient and family care experience and the effectiveness of treatments. In response, we are currently using our findings to develop simple, no-cost innovations at the interactional and organisational level within wards that can be introduced and used by nurses and HCAs. We are also developing online awareness raising resources and training films tailored for staff within the acute setting in collaboration with one health board, Admiral Nurses (London, UK) and Dementia UK (London, UK). We are currently developing and testing the feasibility of these interventions within one acute 'laboratory' ward.

## Funding

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

## Chapter 1 Context

The quality of care delivered to vulnerable older people admitted to acute hospital settings in England and Wales has been under the spotlight following the publication of both the Francis report<sup>1</sup> and the Andrews report.<sup>2</sup> These enquiries identified an unacceptable quality of care, including the systemic deprivation of dignity and respect<sup>1</sup> and serious concerns about the culture of care.<sup>2</sup> Such findings were not new, with a 2006 Joint Committee report concluding that, 'an entire culture change is needed'<sup>3</sup> (p. 3) to improve the care people living with dementia receive in hospital, and that, 'We believe that this question of the culture in a hospital is absolutely crucial'<sup>3</sup> (p. 6). Both the Joint Committee and the Andrews report gave a particular focus to the poor support with medication, dehydration and malnutrition that older people experience in hospital.

The Care Quality Commission (CQC) has repeatedly identified systemic failures in the care of older people<sup>4</sup> and has concluded that the variation in care in hospitals experienced by people with dementia means that they are 'likely to experience poor care at some point along their care pathway'<sup>5</sup> (p. 9). A number of national audits have also been critical of the systematic failings in the quality of care people living with dementia receive in hospital,<sup>6</sup> and of particular concern was the failure to safeguard people living with dementia from avoidable and protracted hospital stays.<sup>7</sup> These findings were supported by the more recent national Adult Inpatient Survey, which concluded that older people experienced inconsistent or poor standards of dignity and respect and emphasised that this was 'a significant general problem affecting inpatients in the vast majority of NHS acute hospital trusts'<sup>8</sup> (p. 3). Variable or poor practice in the care of people living with dementia was identified within 56% of hospitals inspected.<sup>5</sup>

There are corresponding widespread concerns among carers and families about the quality of hospital care that people living with dementia experience,<sup>9</sup> with the Carers Trust reporting that hospitalisation may lead to dehydration, bedsores and a lack of nutrition.<sup>10</sup> The 2010 Nottingham City and Nottinghamshire County Joint Health Scrutiny Committee<sup>11</sup> review identified carers' concerns about mealtime support, medications, poor management of behaviours arising from anxiety, and low levels of staff awareness and understanding of how to care for people living with dementia.

In response to this body of evidence, there has long been a recognition by policy-makers of the potential for the improvement of care for people living with dementia in hospitals, particularly when they are admitted to general hospital for a condition unrelated to their dementia. A 'transformation of dementia services'<sup>12</sup> (p. 14) has been called for within the Department of Health and Social Care's national strategy, *Living Well with Dementia*,<sup>12</sup> and by the Dementia Action Alliance.<sup>13</sup> In partnership with the NHS Institute for Innovation and Improvement, a key objective within their call to action<sup>13</sup> is for services to be designed around the person with dementia through the creation of dementia-friendly hospitals. This focuses on five key areas: (1) the care environment, (2) the knowledge, skills and attitudes of the workforce, (3) the ability to identify and assess cognitive impairment, (4) supportive discharge home and (5) person-centred care plans involving families and carers. The Alzheimer's Society<sup>14</sup> recommends that hospitals endorse and implement these objectives.

The National Institute for Health and Care Excellence has previously recommended<sup>15</sup> that acute and general hospital trusts should plan and provide services that address the specific personal and social care needs and the mental and physical health of people living with dementia who use acute hospital facilities. Improved screening, management and discharge processes are key to improving outcomes in the acute hospital.<sup>6</sup> The Department of Health and Social Care has highlighted the need for individuals with direct responsibility for dementia care within the acute setting and has suggested that these individuals should work closely with specialist older people's mental health teams.<sup>16</sup> More recently, the Prime Minister's *Challenge on Dementia 2020*<sup>17</sup> renewed the focus on creating dementia-friendly health and care, with the goal of every person with dementia obtaining the safest, best-quality care in our acute hospitals.

A large number of reports highlight that, to deliver these significant improvements in care, there is a need for specialist training for staff to improve their knowledge, skills and attitudes within the acute setting.<sup>12,15,16,18–21</sup> Importantly, the majority of nursing staff (89%)<sup>22</sup> have identified working with people living with dementia as challenging, with health-care professionals within the acute setting reporting that they lack the necessary skills and knowledge to care for this patient population.<sup>12,23,24</sup> Without the appropriate training and support, there is a recognition that health-care staff will become resentful and demoralised and cut themselves off from patients, all things that can lead to the depersonalisation and dehumanisation of the people in their care.<sup>25</sup>

The failure to provide appropriate training for hospital staff in caring for people living with dementia has been identified as a key contributor to their poor outcomes and long inpatient stays.<sup>26</sup> Training in the care and support of people living with dementia should be part of the core curriculum for nurses, and such training must also be part of their continuous professional development,<sup>12</sup> with there being a further emphasis on training required for all staff working in health or social care.<sup>14,21</sup> Training is recognised as key to reducing stigma<sup>12</sup> and delivering dignity in care.<sup>17</sup> The House of Lords/House of Commons Joint Committee on Human Rights advocates training for hospital staff that utilises a human rights framework to improve the culture of dignity and respect for older people in hospital.<sup>3</sup>

However, there is still a disparity between these recommendations and their implementation within the acute setting. Many hospitals now have initiatives to improve the environment and support they provide for people living with dementia,<sup>27</sup> and there are examples of innovative practice.<sup>17</sup> However, even within institutions in which high-quality acute care for people living with dementia is identified, this may be limited to specific wards and may fail to reach across an organisation.<sup>27</sup> Overall, there is an acknowledgement that hospitals are struggling to cope with the challenge of an ageing population in the context of increasing hospital admissions for this group.<sup>28</sup> Hospital doctors report high levels of concern about the lack of continuity of care for older patients.<sup>28</sup>

However, despite calls for a culture change across the NHS,<sup>3,17</sup> and key national objectives and strategies to reduce variability and improve care, the detrimental impact of a hospital admission on the long-term independence of people living with dementia has been consistently documented. There is still unacceptable variation in the quality of care for people living with dementia in hospital and at discharge.<sup>27</sup> The CQC's most recent report<sup>29</sup> suggests that, although the provision of health and social care for people living with dementia in some areas of England has moved away from a 'tipping point'<sup>29</sup> (p. 3), services within other geographic areas have moved closer to that point of crisis.

## Acute hospital care

There is an increasing recognition that a key aspect of care for people living with dementia that needs immediate action is improving their experiences and outcomes following an admission to hospital for a condition unrelated to their dementia.<sup>7,12,30,31</sup> The National Audit Office similarly advocates increased investment to improve care for people living with dementia within general hospitals to enable long-term savings and shorter hospital admissions.<sup>6</sup> The Alzheimer's Society's most recent report<sup>32</sup> has found that poor care for people living with dementia is still widespread and that the quality of care varies widely between hospitals, with the admission for a person living with dementia being up to five to seven times longer than for other patients over the age of 65 years in the worst-performing hospitals.<sup>33</sup>

UK health policy emphasises the importance of keeping people living with dementia out of hospital, minimising the duration of any necessary hospital admission and supporting people living with dementia in the community.<sup>31</sup> However, although health and well-being outcomes for people living with dementia are better when they are supported within the community, there is also an acknowledgement that, in reality, many people living with dementia also need to be cared for in hospitals and other institutions.

Hospitals are not designed to care for this group of patients.<sup>34</sup> Evidence suggests that the structural conditions and standardised care plans within the acute setting often do not fit the needs of people living with dementia and their families,<sup>35</sup> with one ethnographic study identifying systemic and organisational factors within the hospital setting that compromised the ability of clinical staff to provide dignified care.<sup>24</sup> Hospital systems are designed to care for patients with one clinical problem but are settings ‘which [are] chiefly subscribed by people who have many things wrong’; these people are thus deemed to be ‘inappropriate’<sup>36</sup> patients. This leads to the treatment of the acute clinical problem for patient admission being prioritised, with the care of their additional dementia not being recognised by clinical staff as a priority.<sup>34</sup> However, older patients commonly have more than one chronic condition in addition to their acute illness,<sup>24</sup> and, for people living with dementia, there is a need for specific care practices that bring together care of dementia and their acute clinical problem with the acute care setting and its practices.<sup>37</sup>

Within the acute setting, there is often the perception that the person living with dementia is at fault rather than the environment.<sup>38</sup> Clinical staff often hold negative stereotypical attitudes towards older patients in their care,<sup>39</sup> with clinical features of dementia such as ‘wandering’ perceived by clinical staff as deviant behaviours.<sup>40,41</sup> This lack of understanding of the needs of people living with dementia often results in this group being labelled ‘difficult’.<sup>42</sup>

The care of patients living with dementia within hospitals is not only a welfare issue but also a human rights issue. The House of Lords/House of Commons Joint Committee on Human Rights highlights concerns about poor treatment, neglect, abuse, discrimination<sup>3</sup> and the lack of dignity, especially with regard to personal care needs.<sup>3</sup> The *Counting the Cost of Care* report<sup>43</sup> identified persons with dementia being treated with a lack of dignity and respect as a key area of concern. An Alzheimer’s Society survey<sup>43</sup> found that more than one-third (36%) of carers said that the person living with dementia was never treated with respect and dignity. A more recent Alzheimer’s Society report stated that 60% of carers reported experiencing a lack of dignity or understanding.<sup>44</sup>

The undignified care that people living with dementia experience in hospital does not happen in a vacuum; it is rooted in the wider social discrimination that older people experience within our society.<sup>45</sup> The House of Lords/House of Commons Joint Committee on Human Rights identified the powerful impacts of historic and embedded ageism that have contributed to the systematic failures to respect and protect the human rights of older people within the health-care system.<sup>3</sup> This seems particularly notable in the acute setting, where discrimination in the provision of services and quality of care has been acknowledged as ‘an ageist policy’ (p. 5).<sup>18</sup> The Department of Health and Social Care implementation plan for the older people’s National Service Framework<sup>46</sup> singled out the deep-rooted negative attitudes and behaviours towards older people in acute care.

This stigmatisation of older people in hospitals is particularly acute for people living with dementia.<sup>47</sup> The poor recognition and systematic undertreatment of post-operative pain among people living with dementia:<sup>48,49</sup>

*illustrates the discriminatory care provided for people with dementia.*

*p. 62.<sup>12</sup> © Crown copyright. Contains public sector information licensed under the Open Government Licence v3.0*

In addition, people living with dementia from black, Asian and minority ethnic communities are more likely to experience stigma and poor care,<sup>50</sup> and women with dementia are exposed to a ‘triple jeopardy’<sup>51,52</sup> of discrimination because of their age, sex and condition.

There is evidence to suggest that clinical staff routinely believe that people living with dementia do not belong within the acute setting, which is seen as an inappropriate place for older people more generally to receive care.<sup>24</sup> However, there was little exploration by staff of where a more appropriate place for older people would be. Tadd *et al.*<sup>24</sup> suggest that this may indicate an underlying ageism, but it can also be seen

as an example of 'specialism hegemony': acute staff tend to dismiss conditions they see as belonging to the specialism of mental health.

A report by The King's Fund<sup>25</sup> highlights that 'the work of caring for older patients with complex needs is hard and testing – physically, psychologically and emotionally'.<sup>25</sup> This work, carried out by nurses and health-care assistants (HCAs), is often described as 'basic' rather than 'essential' care, implying that it is unskilled work, and the report acknowledges the physical and emotional impact of this work:

*In hospital, patients with dementia and delirium may disturb other patients, or may be challenging and difficult to keep calm and safe . . . changing a doubly incontinent patient and remaking the whole bed requires the effort of two people. Sometimes patients are unresponsive, and beds need to be changed again almost immediately.*

*Cornwell J. The Care of Frail Older People with Complex Needs: Time for a Revolution. London: The King's Fund; 2012 (p. 4).*<sup>25</sup> This is an Open Access article distributed in accordance with the terms of the Creative Commons Attribution-NonCommercial-NoDerivs 4.0 licence, which permits others to share the work, provided the original work is properly cited. See <https://creativecommons.org/licenses/by-nc-nd/4.0/>

This presents a significant challenge to the NHS,<sup>20</sup> and new approaches are needed to improve what happens to older people, and, more specifically, people living with dementia, when they are admitted to hospital. Consumer groups have lobbied to improve the experiences of elderly patients,<sup>9,22</sup> a need also recognised by several government enquiries.<sup>53,54</sup> However, the research agenda has lagged behind<sup>20</sup> and there is an evidence vacuum in understanding the experience of elderly patients with dementia and how their care can be improved within the acute setting.

## Dementia and hospitalisation

The acute hospital setting has become a key site of care for people living with dementia. The Department of Health and Social Care recognises that as many as one in four acute hospital beds in the UK will be occupied by a person living with dementia at any given time,<sup>33,43</sup> the equivalent of 3.2 million bed-days per year. In some areas, these figures may be underestimates, with some hospitals reporting that up to 50% of their acute admissions may also have dementia.<sup>43</sup> A systematic review has identified that, internationally, the prevalence estimates for people living with dementia within acute hospitals range between 12.9% and 63.0% across studies.<sup>55</sup> Dementia as a condition is often thought of as something cared for first in the community, then later in specialist settings and long-term care, but the prominence of people living with dementia in the acute hospital setting and the impact that admissions have on these patients cannot be ignored.

A diagnosis of dementia is associated with an increased risk of hospitalisation.<sup>56</sup> Russ *et al.*<sup>57</sup> estimate that approximately 6% of all people living with dementia in the UK are inpatients in acute hospitals at any one time, in comparison to only 0.6% of people aged > 65 years without a diagnosis of dementia. A hip fracture,<sup>35,58</sup> urinary tract infection,<sup>59</sup> pneumonia<sup>59</sup> and nutritional disorders<sup>35</sup> are among the common causes of admission among people living with dementia. A national review of case notes ( $n = 7987$ ) for people living with dementia found that the majority were admitted within care of the elderly (40%), general medical (25%) and orthopaedic (11%) acute care wards.<sup>20</sup>

Although prevalence rates differ by hospital and are dependent on their specific population, current estimates of prevalence rates are believed to be low owing to under-reporting or late diagnosis of this population.<sup>6</sup> Estimates suggest that, within the acute setting, approximately 50% of those affected by dementia do not yet have a formal diagnosis in their medical records.<sup>57,59,60</sup> There are a range of potential reasons for this potential underdiagnosis<sup>61</sup> or delayed diagnosis of dementia, with much of this attributable to clinical teams not having the appropriate expertise.<sup>61</sup> A significant number of people living with

dementia may have their first assessment when they are admitted with an acute condition.<sup>58</sup> For example, among older people admitted to hospital following a hip fracture, of those living with dementia (40%), just over one-quarter (27%) received their diagnosis during their admission.<sup>58</sup>

However, there are also likely to be many older people within the acute setting who may appear to have features of dementia, but who may have different underlying causes of cognitive decline, including delirium or subsyndromal delirium. One screening study of a large cohort of older patients following an unplanned admission to an acute hospital setting such as a medical assessment unit (MAU) found a high prevalence of delirium (15.5%), and a high rate of undiagnosed (72%) delirium among this population.<sup>62</sup> Other studies have identified similarly high levels of comorbid mental health in this group.<sup>60</sup> Medication and comorbid chronic conditions such as diabetes mellitus can also have an impact on cognitive function<sup>57</sup> within the acute setting.

## Impact on patient outcomes

People living with dementia are a highly vulnerable group within the hospital setting, and, following an acute admission, the functional abilities of this population can deteriorate significantly.<sup>60</sup> A systematic review has identified that people living with dementia in the acute hospital are older, require more hours of nursing care, have longer admissions, are at higher risk of delayed discharge and are likely to experience functional decline during their admission.<sup>55</sup> Similarly, a screening study of emergency admissions of patients aged > 70 years with cognitive decline showed that the majority were at risk of malnutrition (80%) and just under half (47%) were classified as incontinent and as needing help at mealtimes (49%).<sup>56</sup> An acute hospital admission for people living with dementia is associated with an increased risk of functional decline<sup>63,64</sup> and with experiencing adverse events.<sup>63,65</sup> A longitudinal cohort study of acute emergency admissions found that patients aged > 70 years with cognitive impairment had markedly higher short-term mortality, with 24% dying during admission,<sup>59</sup> and this group of patients being more likely to be readmitted and also more likely to die post admission than patients without cognitive impairment admitted for the same reason.<sup>5</sup> Similarly, a prospective cohort study found that people living with dementia who have an unplanned acute hospital admission had half the survival time of similar inpatients without a diagnosis of dementia.<sup>66</sup>

The poor recognition and systematic undertreatment of pain among people living with dementia<sup>48,49</sup> illustrates the inequity in care experienced by people living with dementia in the acute setting.<sup>12</sup> People living with dementia receive poor end-of-life care, fewer palliative medications<sup>67</sup> and only one-third the level of painkilling opioid medication<sup>48</sup> compared with patients without a diagnosis of dementia, with one study concluding that the majority of people living with dementia were in severe pain post operatively.<sup>48,68</sup> People living with dementia find it difficult to articulate their pain,<sup>49</sup> and pain is poorly identified and undertreated in people living with dementia.<sup>68</sup>

People living with dementia in the acute setting are also at risk of 'cascade iatrogenesis', whereby the treatment or intervention used to treat the initial acute admitting condition leads to an unintended sequence of multiple medical complications and a cascade of decline in the person,<sup>69</sup> which can result in further dependency, institutionalisation and, potentially, death during their acute admission.<sup>70</sup> Adverse events are common for people living with dementia during an acute admission and, importantly, these are typically associated with identifiable risk factors, with staff failing to understand and recognise the impact of a diagnosis of dementia on patient outcomes.<sup>65</sup>

George *et al.*<sup>70</sup> in their review of challenges and solutions to the care of people living with dementia in the acute setting concluded that there is a need to increase awareness and understandings of the way health-care-related harm manifests in patients admitted to hospital with a diagnosis of dementia, given that they can often present as common geriatric syndromes. The subtlety of adverse events in patients with dementia is said to be overlooked and compounded by a culture of low expectation running counter to a dominant safety culture.<sup>70</sup>

## Examining culture and organisation

The House of Lords concluded that ‘an entire culture change is needed’<sup>3</sup> to improve the care people living with dementia receive in hospital, stating:

*We believe that this question of the culture in a hospital is absolutely crucial.*

*p. 44.<sup>3</sup> © Parliamentary Copyright. Contains Parliamentary information licensed under the Open Parliament Licence v3.0*

Research highlights the importance of the culture of care in influencing front-line delivery. Meta-ethnography findings<sup>71</sup> reflect that, in spite of acute care nurses’ aspirations to deliver a high standard of psychosocial care, standards of care are largely dependent on ward-level social and organisational conditions. National Institute for Health Research (NIHR) studies of acute settings report a strong association between ward climate and quality of care. Patterson *et al.*<sup>72</sup> found that more positive patient and carer assessments of acute care for older patients was correlated with higher staff ratings of team climate in terms of ‘supporting each other’, highlighting the vital role of the ward manager in shaping a positive climate for care. Such findings were mirrored in a second Service Delivery Organisation (SDO) study<sup>73</sup> highlighting that the experiences of working in wards directly affects patient experiences of care and that complex or demanding patients received less personalised care from staff.<sup>73</sup>

Ward nurses play a key part in facilitating the flexibility needed for hospital systems and processes to function effectively.<sup>74</sup> SDO studies have examined the role and impact of allied health professionals (AHPs)<sup>75</sup> and Advanced Nursing Practitioners<sup>76</sup> in ward leadership. Studies highlight the importance of focusing on the relationships between nurses and less privileged groups, which influences how care is organised, supervised and delivered,<sup>77</sup> given the increasing delegation of ‘hands-on’ care to HCAs.<sup>77</sup>

An ethnography of HCAs identified that they are typically a close-knit, marginalised group with a strong identity, which could negatively affect the organisation of wards; this has implications for multidisciplinary teamworking and the provision of care.<sup>78</sup> The impact of different shifts on work goals and priorities,<sup>79</sup> a culture of reactivity that responds to immediate problems,<sup>80</sup> ward environments characterised as austere and as emphasising routines, plus the lack of communication opportunities, combined to restrict patients and staff, thus contributing to moral distress and burnout among ward nurses.<sup>81</sup>

Ethnography has also examined the ways in which information about patients and the delivery of care is defined and communicated within wards, with nurses often using ‘scraps’ as a form of invisible documentation that they had ownership of.<sup>82</sup> In contrast, the formal nursing record had limited relevance to informing practice and supporting the delivery of care,<sup>74</sup> with ward structures further hindering the development of nurses’ practice.<sup>83</sup>

A systematic review of qualitative studies highlighted the importance of the relational work in the quality of care that patients receive within acute wards<sup>84</sup> and the significance of the nursing role in identifying and promoting dignity for older people living with dementia.<sup>85</sup> Meta-ethnography concludes that service improvements need to focus on how to optimise the organisational conditions that support nurses in their relational work with patients<sup>71</sup> and that take into account the challenges of implementing innovations and embedding change.<sup>86</sup>

National Institute for Health Research ethnographic studies have examined the complexity of hospital discharge<sup>87</sup> and transitions in care,<sup>88</sup> with a Research for Patient Benefit ethnographic study of hospital discharge identifying the complexity of judgements about a person’s capacity, best interests and decision-making for people living with dementia,<sup>89</sup> emphasising the importance of communication and collaboration during transitions in care.<sup>88</sup>

## Ethnographic studies

There are a small number of ethnographic studies exploring the experiences and care of older people in acute settings,<sup>90–96</sup> which have a focus on dignity in older patients<sup>24</sup> with and without<sup>97</sup> a diagnosis of dementia. Ethnographies have explored dementia in the context of long-term care settings,<sup>98–101</sup> with only a small number of studies examining people living with dementia in acute settings;<sup>97,102,103</sup> importantly, both sets of studies highlight the failure of acute settings to respond to the needs of this patient population.

Norman's observation of wards within a general hospital found that people living with dementia were viewed by the health-care professionals caring for them as belonging to one of two groups, either 'positive and acceptable patients' or 'negative and unacceptable patients'.<sup>102</sup> Similarly, the Tadd *et al.*<sup>24</sup> ethnography of four acute care settings identified ageist attitudes among ward staff. In examining the occupational, organisational and cultural factors that affect care, the authors found a failure to provide dignified care and assessed the impact of this on both the quality of care and patient outcomes.<sup>24</sup> Both Tadd *et al.*<sup>24</sup> and The *et al.*<sup>96</sup> found that staff believed that the acute hospital was not an appropriate setting for older people to receive care and also found that this patient population was perpetually moved both between and within hospital wards.

## Do we know anything about best practice in acute settings?

Few studies have explored what constitutes 'good care' for people living with dementia within the acute setting, with studies developing models of care for this patient group typically assuming that the principles of good care that have been integrated into long-term facilities can transfer unproblematically into other settings.<sup>42</sup> Only a small number of studies have evaluated proposed models of care to improve patient outcomes within acute settings for dementia; however, the focus of these interventions has been to address 'chronic confusion'<sup>104,105</sup> rather than dementia. There is little evidence that training interventions to enhance health-care workers' expertise and capacity in working specifically with patients with dementia are effective. Recent reviews<sup>42,106</sup> suggest that, prior to developing interventions, further detailed research to understand the role and needs of health-care workers with this patient population<sup>106</sup> and an exploration of what constitutes 'good care' within the acute setting<sup>42</sup> are needed.

In their review identifying best practice for caring for this patient population within the acute setting, Moyle *et al.*<sup>42</sup> identified a number of key features: the early identification of dementia and assessment of the patient, the knowledge and attitudes of nursing staff, a multidisciplinary approach to care, providing focused communication, a reduction in stressors, and carer and family involvement. Staff within an Australian hospital reported that the main constraints to being able to provide best practice were environmental, sociocultural and economic, concluding that the acute setting was not appropriate for this patient group.<sup>107</sup>



## Chapter 2 Research objectives

This study used an in-depth ethnographic approach to examine the work of nurses and HCAs who are responsible for refusal of care, with a focus on mealtimes and medications within wards to explore how staff respond when people living with dementia refuse care. We have focused on wards known to have a large number of people with cognitive impairment [MAUs and trauma and orthopaedic (T&O) wards] within a purposive sample of five hospitals in England and Wales. Ethnography is particularly useful when exploring complex and sensitive topics in health care. Our analysis has focused on identifying ways in which the social organisation of nursing care and care processes can be structured to support care to improve patient and family care experience, as well as the effectiveness of treatments.

In response to the limited body of literature examining refusal of care and what constitutes 'good care' for people living with dementia within the acute setting, the aims of this study were to provide an empirically informed theoretical underpinning to inform the development of a follow-up programme of work to develop and test innovation in service organisation and clinical interventions to improve the care and support of people living with dementia who refuse care within the acute hospital setting. To achieve our aims, the study objectives were to:

- Provide a detailed understanding and concrete examples of the clinical and interactional processes that influence nurses' and HCAs' response to 'refusal of care'. What they are doing and why: what are their caring practices when interacting with people living with dementia and their family carers, how do they respond to and manage refusal and what influences these approaches?
- Provide a detailed understanding of the context of care and concrete examples of the hospital organisational processes that affect the care of this group. Specifically, the study aimed to map the response and management of this patient group and incidents of refusal and resistance to care within wards known to have a large number of people living with cognitive impairment and dementia.
- Examine the experience of refusal of care within the acute hospital setting from the perspectives of people living with dementia and their family carers. What is the impact of refusal of care and clinical responses to it on patients' care and experience of an acute admission?
- Identify markers of good care and understand the enablers of and barriers to good care in response to refusal and to identify how, where and why individual and organisational expertise or ineffective care exists.
- 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.
- 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.



## Chapter 3 Literature search

### Conceptualising refusal and resistance to care

Refusal and resistance to care by people living with dementia is not a clearly defined concept within the wider research literature. The terms 'resistance' and 'refusal' are used interchangeably, both clinically and in the literature, to cover both the range and extent of this behaviour or phenomenon.<sup>108</sup> Other terms used in the literature include 'non-compliant behaviour',<sup>109</sup> 'challenging behaviours',<sup>110</sup> 'behaviours that challenge'<sup>111</sup> and 'agitated'<sup>112</sup> and 'aggressive'<sup>113</sup> behaviours. At their core, refusal and resistance to care remain something of umbrella terms and cover behaviour(s) characterised as non-compliant in response to health care.<sup>109</sup>

Within the research, examining what Ishii *et al.*<sup>108</sup> conceptualise in their review under the umbrella term 'rejection of care', there is a significant focus on long-term settings, including community care, home care, care home and nursing home settings, psychiatric wards, and specialist mental health settings. Within these settings there has been sufficient research to support systematic reviews that examine how dementia and associated behaviours, including rejection of care, affect friendship,<sup>114</sup> marriage,<sup>115</sup> caregivers,<sup>116–119</sup> the person as patient,<sup>119,120</sup> self and identity,<sup>121</sup> quality of life,<sup>122</sup> costs of care,<sup>123–125</sup> access to care,<sup>55,126</sup> care staff resilience,<sup>106</sup> care staff stress,<sup>127</sup> care staff competence,<sup>128</sup> care staff communication skills<sup>129,130</sup> and care staff retention.<sup>131</sup> The impact of behaviours relating to a dementia diagnosis, including rejection of care, has been explored extensively within long-term and specialist settings.

### Locating refusal and resistance to care in the acute setting

Thus, although there is considerable evidence exploring the long-term settings in which one would expect to find people living with dementia being cared for, research examining the impact of other settings in which people living with dementia are also found is scarce. A notable setting in which there is little research is the acute care setting, in which people living with dementia form a significant population. Acute care nurses in the UK have reported that they are 'always' responsible for caring for at least one patient with a diagnosis of dementia<sup>132</sup> and almost all find such care a 'challenging' part of their work.<sup>22</sup> 'Rejection of care' is a recognised feature of these admissions,<sup>24,42,132,133</sup> yet, unlike in other long-term and specialist settings, few studies have examined the prevalence, causes, experiences and impacts of this phenomenon within the acute ward.

This disparity within the research literature is reflected at the organisational level of care delivery. Despite the number of admissions of people living with dementia to the acute setting, only 36% of hospitals have a fully developed dementia care pathway in place.<sup>20</sup> A large number of reports highlight the need for specialist dementia training for all clinical staff within the acute setting,<sup>18,19,31,58,134</sup> but health-care professionals working on acute wards continue to lack the necessary skills, competencies and knowledge to care for this group of patients.<sup>12,23,24</sup>

Within the hospital setting, refusal of care typically refers to non-compliance towards staff-led provision of care, which ranges from essential treatments to the more everyday, mundane but still vital elements of care, including, but not limited to, food, hydration, medication, personal care and toileting.<sup>40</sup> This characterisation and conceptualisation of refusal and resistance as non-compliance means that it is commonly perceived by clinical staff as deviant behaviour, leading to patients admitted with a diagnosis of dementia being labelled, and conceived of by acute care staff, as a 'difficult' patient group to care for.<sup>42</sup> Although the literature examining the refusal of care of people living with dementia in the acute setting is scarcer than for other settings, there is still a small body of work that raises crucial issues for consideration.

Importantly, this literature emphasises the importance of recognising both that people living with dementia are to be found and belong within acute care wards and that, in their current form, acute care wards are an inappropriate place for people living with dementia to be.<sup>42,132</sup> Although an admission to an acute ward is associated with poor care outcomes for people living with dementia,<sup>48,49,56,59,60,135</sup> the reviews by Moyle *et al.*<sup>42</sup> and Dewing and Dijk<sup>132</sup> suggest a major factor for this could be the acute ward itself. The built environment of acute care is unfamiliar, frustrating and threatening for people living with dementia. Acute wards are busy, with a constantly changing number of unfamiliar people doing unfamiliar things against a backdrop of unfamiliar and irregular noises from alarms and machines, with artificial bright lighting, in a space that is disorientating. All of these factors can be disorientating, distressing or agitating for the admitted patient with a diagnosis of dementia and may lead to behaviours that Ishii *et al.*<sup>108</sup> conceptualise as 'rejection of care'.<sup>136</sup>

This literature confirms that people living with dementia can be found in the acute setting, are likely to refuse care while accommodated within it, and that this both poses challenges for ward staff and has negative outcomes for patients. However, what is unusual is for such well-documented phenomena to remain so under-researched. Within the acute setting, refusal of care is often considered in detail within the literature only when it is associated with another well-researched phenomenon. The refusal of food, for instance, is discussed in the literature but is typically examined as one feature of other phenomena, such as the ethics of artificial feeding<sup>137–139</sup> or the efficacy of food supplements for patients presenting with reduced nutritional intake.<sup>139</sup> Refusal of treatments and medications may also seem, at a first glance, to be well examined, but too often terms such as rejection, refusal and resistance are used as synonyms for non-compliance or non-adherence with a long-term or new drug regime. Rather than exploring the behavioural aspects of the rejection of medication, this literature is concerned with an examination of the potential biomedical and technical solutions, such as the assessment of the efficacy of non-oral administration.<sup>140,141</sup> At present, although the gaps in our understanding of the behavioural features of refusal and resistance to essential everyday care in the acute setting have been remarked on,<sup>138,142</sup> little has been done to address them.

With little research evidence or best practice that can be implemented in the acute care ward, key responses to refusal of care are its management through restraint, sedation or Deprivation of Liberty Safeguard (DoLS) applications.<sup>136,143,144</sup> A retrospective review of DoLS applications (in the UK, this is an application of 'deprivation of liberty' to protect a vulnerable person who is judged to lack the capacity to consent to the care or treatment they need) identified that 22.5% of all DoLS applications were for patients with a dementia diagnosis and that 23.6% of all applications were directly related to refusal of care, with the person attempting to leave their ward a key trigger for a DoLS application for a further 21.3%.<sup>143</sup> However, the overall evidence base for why restraint is used, and in what circumstances, is limited, emerging briefly as a discussion point within a small number of quantitative studies piloting therapeutic interventions,<sup>136,144</sup> with few studies examining the use of restraint in response to resistance to care.

A small body of research has identified that these techniques and approaches in response to resistance continue and are embedded within hospital nursing culture,<sup>111,136</sup> despite recognition that they are undesirable and contribute to missed diagnosis, poor care experiences, poor outcomes and functional decline in the person.<sup>111,133,136,144–146</sup> However, although the evidence around the embedded use of restraint, and the lack of alternative methods of recognising and managing the refusal of everyday care, is consistent, it is limited. It includes a single case study,<sup>111</sup> limited case studies ( $n = 4$ ) derived from larger randomised controlled trials,<sup>145</sup> small- $n$  quantitative studies ( $n = 36$ )<sup>133</sup> or studies focused on topics tangential to rejection of care (barriers to post-operative pain-management).<sup>146</sup>

Although this evidence is consistent with studies that suggest that people living with dementia respond more positively to autonomous cultures of care than to restrictive ones,<sup>85</sup> there remains a significant gap in the literature that provides systematic evidence of the extent of refusal and resistance to care, how it manifests, the ways in which ward staff respond, and whether or not cultures of restraint continue to exist in acute settings in response to rejection of care behaviours, and, if so, why. The limited body of literature

examining the rejection of care in the acute hospital setting acknowledges this, highlighting the scarcity of high-quality studies examining this phenomenon within the acute environment.<sup>133,136,144,146,147</sup>

## Refusal and resistance towards food

What research we do have is useful for examining the ways in which resistance to everyday care is currently conceptualised and managed. Archibald<sup>148</sup> suggests that resistance towards or refusal of food is one of the most common manifestations of rejection of care across all settings. Archibald<sup>148</sup> argues that although it is known that as many as half of people living with dementia in long-term settings regularly refuse food, there are few data to illustrate how common a phenomenon this is in a short-term acute hospital setting, although it is likely to be significantly higher. The lack of data is arguably symptomatic of how a behaviour or response can become a mundane and even accepted behaviour during an admission, as demonstrated by the scarcity of research around it.<sup>147</sup> Importantly, it means that many of the recommendations from the literature to improve or manage the rejection of food are drawn from data and research within long-term settings.

The recommendations of this literature in managing the refusal of food are relatively straightforward. Many of them could be described as 'common-sense'. Examples include serving only easily manipulated and easily swallowed food to people living with dementia,<sup>148,149</sup> flexibility in mealtimes (both in terms of when they are served and their duration) and flexibility around sleeping routines and daytime rhythms,<sup>150</sup> serving meals in preferred or recognisable dining settings and using recognisable plates and cutlery,<sup>151</sup> and spending time familiarising patients with both their meal and the associated technologies.<sup>142</sup> The key theme running through this literature is of making meals as normal as possible, making them social and triggering memories of an archetypal 'normal' meal, sitting around a dining table at home with family. However, there is little within these recommendations to address the extraordinary environment of the acute ward. In addition, these recommendations also remove the agency of the person living with dementia, suggesting that if the person responsible for care serves the meal in the correct way, then refusal of care can be managed. That the person living with dementia may have agency or rationality in their refusal, beyond unfamiliarity with the meal or their surroundings, is completely overlooked.

This literature providing recommendations that focus on the presentation of the meal rather than the needs of the person is reflected within acute wards. The potential underlying causes of resistance to food are rarely investigated by nursing staff.<sup>147</sup> Byron *et al.*<sup>138</sup> criticise a lack of any primary research examining nurse decision-making around mealtimes and food-related issues in the hospital setting. However, it has been shown that ward staff are rarely trained to recognise or investigate factors underlying the rejection of food, instead viewing rejection as a feature of the dementia diagnosis.<sup>137</sup> As a result, the consistent or consecutive refusal of meals is likely to be responded to by altering the meal or method of intake, for example by giving pureed meals, thickened fluids, nutritional drinks or intravenous (i.v.) drips or, in extreme cases, by undertaking artificial feeding.<sup>137,138,149,151</sup> The person refusing food may be labelled as difficult,<sup>42</sup> be infantilised by their rejection of the meal or be seen as ungrateful by staff.<sup>148</sup> The literature suggests that it is rarer for the refusal behaviour to be perceived as a responsive behaviour expressing something about the person and their feelings in that moment to their condition, their comfort or the environment and surroundings, which would be in line with current recommendations.<sup>32</sup>

## Refusal and resistance towards medication

The literature examining medication is clearer in identifying that the underlying causes of resistance, refusal and rejection need to be investigated rather than simply responded and reacted to. While acknowledging the difficulties in doing so, the literature suggests that staff must take on the role of a detective to identify the underlying cause at the root of a patient's behaviour,<sup>111</sup> which, it is suggested, may often be pain or discomfort that the patient is unaware of or is unable to communicate.<sup>146</sup> However, nurses working in the

acute setting may lack the training to do this kind of detective work<sup>111</sup> or believe that such a role is for specialist pain management staff<sup>146</sup> rather than for general acute nurses. Rantala *et al.*<sup>146</sup> argue that the current lack of investigation of the potential underlying causes of refusal and resistance can be illustrated by the significantly lower prescription rates for post-operative pain-killing medication among people living with dementia than among the general acute patient population. Such findings are repeated in other studies<sup>152,153</sup> and are associated with poor patient outcomes and significantly higher post-operative mortality rates.

At the same time, research focusing on improving how staff care for patients refusing medication in the acute setting is limited, particularly in comparison to studies that focus on food refusal. There is a small body of translatable behavioural work from long-term care settings,<sup>149–151,154</sup> and work examining the use of alternative methods of medication delivery. However, this is often concerned with longer-term adherence to a drug regime, rather than specific interventions,<sup>140,155</sup> or is instead concerned with the covert delivery of medication and the ethics thereof.<sup>156,157</sup>

In contrast, the limited research carried out within the acute setting identifies more challenges than it answers. Rantala *et al.*<sup>146</sup> describe the ways in which aggression can escalate from poor pain management, leading to cycles of aggression that, in turn, create further barriers to future treatment and pain management itself once recognised. Such cycles are often treated with sedation, which calms the observable aggression but not the less visible pain. Similar issues have been observed when clinical investigation fails to differentiate the features of dementia and related symptoms of agitation from a potential diagnosis of delirium and/or confusion superimposed on to the patient's dementia.<sup>158</sup>

There is some research addressing resistance to medication that is not associated with underlying pain. Abetz *et al.*<sup>141</sup> discuss how factors including suspicion of new medication, suspicion of unfamiliar people bringing medications and fear of unpleasant side effects can contribute to or trigger resistive behaviour towards medication. However, these findings come from a body of pharmaceutical research promoting the use of transdermal medication delivery in place of oral medication for people living with dementia. Reviews of such delivery methods suggest some reduction in medications refusal,<sup>140</sup> although these findings do not factor in the suitability or accessibility of these methods within an acute ward environment.

## Implications for our research strategy

This small body of literature highlights that there is a clear need for systematic research exploring the ways in which refusal and resistance manifests in the acute care setting, and what can be done to improve care in response to this to enhance both care experiences and outcomes.

To improve care we must first address the tension that lies in the clear articulation of what we mean and understand by refusal and resistance when observing it. In other words, how do we know it when we see it? Thus, a key aspect of our examination and analysis of resistance, refusal and rejection of care focuses on the ways in which ward staff (nurses and HCAs) interpret, recognise, assess, classify and subsequently respond to these behaviours. Ishii *et al.*<sup>108</sup> give a very helpful definition of 'rejection of care', namely to 'reject evaluation or care [e.g. bloodwork, taking medications, ADL (activities of daily living) assistance] that is necessary to achieve the patient's goals for health and well-being'.<sup>108</sup> Importantly, the authors go on to state that this definition requires a patient's intent to refuse or reject care and does not constitute a rejection if the patient's somnolence renders them unable to swallow medication. This definition also excludes aggressive behaviours. However, as this report shows, a person being non-responsive or aggressive in response to care delivery was a key feature of how ward staff practically recognised and understood dementia, with 'refusal of care' interpreted within the ward as an expected feature or outcome of the behavioural or psychological symptoms of dementia during an admission.

In the course of this analysis, the concept of resistance is treated as emergent and 'in the making', which surfaced in the ways staff interpreted and responded to behaviours during the mundane encounters, interactions and the everyday routine work of the ward. The actual act of refusal, resistance or rejection is always context bound and involves many factors (which we have tried to capture in our analysis) and should not be seen as an isolated element within a wider repertoire of dementia-related behaviours. Thus, rather than classifying these behaviours as distinct entities, the term 'resistance' is used and the ways in which this manifests as part of a continuum of responses that people living with dementia have to the ways in which their care is delivered at the bedside and their wider experiences of their admission to an acute hospital ward are assessed. In turn, these responses are viewed by staff as problematic and difficult, are believed to signify a lack of capacity and, because they do not 'fit' the organisation and timetabled routines of the ward, are viewed as something that must be overcome or managed.



## Chapter 4 Methodology

Ethnography can provide sophisticated tools for understanding the complexities of the everyday and for examining daily meaning-making<sup>159</sup> within an organisational setting. Ethnography allows a detailed understanding of organisational culture, organisational change and the inter-relationships between different elements of an organisation. Importantly, it also takes into account the perspectives of patients, carers, clinical teams and wider hospital staff.<sup>160,161</sup> It is particularly useful to examine research questions and topics for which (1) measurement is either not easy or inappropriate, (2) the aim is to access the unspoken and tacitly understood and (3) the topic is complex and highly sensitive.<sup>162</sup>

Our approach to ethnography is informed by the symbolic interactionist tradition, which aims to provide an interpretive understanding of the social world, with an emphasis on interaction. This approach focuses on understanding how action and meaning are constructed within a specific setting and acknowledges the mutual creation of knowledge by the researchers and the researched.<sup>163</sup> Thus, within this study, the aim of our approach is to uncover the relevant conditions of people living with dementia within the acute hospital setting and to understand how the wide range of social actors within these settings (the large number of ward staff they will come into contact with during their admission) actively respond to these conditions through their actions and the consequences of their actions. Ethnography allows us to examine these elements, and, importantly, the interplay between them. It examines 'up close and in person how work is organized and how the organizing organizes people'<sup>159</sup> (p. 1).

Ethnography is the in-depth study of a small number of cases. Ethnographers study people's actions and accounts within their natural everyday settings and collect relatively 'unstructured' data from a range of sources including observation, informal interviews and documentary evidence.<sup>164</sup> It is also important to consider the articulation work of people within organisational and institutional settings, examining how people within them account for and make sense of their actions. Ethnographers 'hold that an appreciation of the extraordinary-in-the-ordinary may help to understand the ambiguities and obscurities of social life' (p. 2).<sup>159</sup> The value of this approach is the depth of understanding and theory generation it can provide, with a key objective of providing findings that are transferable to other settings.<sup>165</sup>

The aim of ethnography is to explore the details of everyday life that can otherwise go unnoticed, trying to read the tacitly known scripts and schemas that organise ordinary activities. Star notes the importance of examining organisational infrastructure and the 'hidden mechanisms'<sup>166</sup> within them that are constructed and embedded into the technical and procedural work carried out within it. It examines not only the front-line performance but also the backstage work practices.<sup>167</sup> Within any organisation there are always groups whose everyday work is not recognised formally and is often unnoticed and invisible.<sup>166</sup> In the hospital setting this includes carers, nurses, HCAs, cleaners and porters. In the context of understanding how health-care services within hospital settings are delivered and the organisation underlying their delivery, ethnography can examine how the social and institutional forces shape and influence the work of health-care providers<sup>168</sup> and the everyday routine behaviours of individuals, both within and across multidisciplinary teams.<sup>98</sup>

There is a long tradition of using ethnography within health-care settings.<sup>163</sup> There are many examples of studies that provide detailed ethnographic findings that have had a significant impact on policy.<sup>169</sup> The potential of ethnography to inform public debate, policy and practice is increasingly recognised.<sup>170,171</sup> There has also been a growing legitimisation of qualitative evidence as appropriate to health services research and the evidence-based medicine movement.<sup>169,172</sup> In terms of the presentation of findings, ethnographic 'thick description' provides the reader with ways to connect concepts, policies and practice to detailed empirical examples.<sup>173</sup> These details allow the reader to develop not only a strong connection to that social world but also an understanding of the complex social relations in the context of both the personal impact and how it connects with wider public and policy issues.<sup>173</sup>

Thus, this study has focused on the largely invisible routine work of caring for people living with dementia, with significant elements of the everyday routine care carried out by nurses and HCAs in acute hospital wards. The study provides a detailed understanding of the social and institutional forces that shape and influence this work. This ethnographic approach has enabled an understanding of how staff respond to the care needs of people living with dementia and follows the consequences of their actions. Importantly, the study also examines how staff account for and make sense of their responses to the care needs of people living with dementia in these contexts. Ethnography allows an examination of these elements and, importantly, the interplay between them.<sup>174</sup>

## Data collection and analysis

Data collection (observations and interviews) and analysis has been informed by the analytic tradition of grounded theory,<sup>175</sup> a practical and flexible approach for ethnographic research.<sup>176</sup> It uses the constant comparative method and theoretical sampling whereby data collection (observation and interview data) and analysis are inter-related<sup>175,177</sup> and carried out concurrently.<sup>178,179</sup> The flexible nature of this approach is important because it has allowed us to increase the 'analytic incisiveness'<sup>176</sup> of the study; as data were collected at one site, preliminary analysis of the data was able to proceed in parallel, with this preliminary analysis informing the focus of later stages of data collection and analysis.

Although these traditions have developed independently, they are complementary. Grounded theory strengthens the ethnographic aims of achieving a theoretical interpretation of the data, and the ethnographic approach prevents grounded theory from being applied in a mechanistic and rigid way.<sup>176</sup> 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 numbers of unconnected data and producing a heavily descriptive analysis.<sup>180</sup> 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.<sup>176</sup>

## Chapter 5 Data sources

Multisite ethnography is an exercise in ‘mapping terrain’, whereby the goal is not ‘representation’ but the identification of social processes within the data. Although we are interested in speech acts, communication is not always verbal but may also be expressed non-verbally. There are multiple complex and nuanced interactions within 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’.<sup>181</sup> Thus, it was important to observe interaction and performance, namely how care work is organised and delivered and how refusal is responded to and managed, plus the backstage talk and informal conversations within the setting. It remedies a common weakness in many qualitative studies, namely that what people say in interviews may differ from what they do or their private justifications to others.<sup>176</sup> It also allowed us to follow the impact of the organisation and delivery of care on people living with dementia, their family carers and ward staff over time.

### Ethnographic fieldwork

This ethnography was carried out in 10 wards within five hospitals across England and Wales, which were purposefully selected to represent a range of hospital types, geographies and socioeconomic catchments. Across these sites, 155 days of observational ethnographic fieldwork were carried out in areas of acute hospitals known to admit large numbers of people with dementia for acute conditions: T&O wards and MAUs or variants thereof. Approximately 600,000 words of observational fieldnotes were collected, written up, transcribed, cleaned and anonymised by the ethnographers (KF and AN). To provide a detailed contextual analysis of the events observed, the expertise involved and the wider conditions of patient care, we also carried out ethnographic interviews (during observation) with ward staff ( $n = 414$ ). Ethnographic interviews ( $n = 71$ ) were also conducted with case-study participants ( $n = 10$ ) and their family members ( $n = 37$ ), with care being observed at the bedside throughout a patient’s admission. Given the scope of our data set, in this report we focus on presenting our analysis of the observational fieldwork.

Multisite ethnography defines the object of study via a number of techniques or tracking strategies, and within the fieldwork we recognise the importance of focusing on the ‘busy intersections’<sup>182</sup> and of seeking out sites of tension at which 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. The aim of this study was to provide a detailed understanding of the clinical and interactional work and processes that influence nursing, HCA and other clinical staffs’ [this included mealtime assistants, specialist registrars (SPRs), consultants, AHPs and staff with managerial responsibilities] responses to ‘refusal of care’ with a focus on everyday care, medication rounds and mealtimes. We studied actions and accounts within their natural everyday settings to explore how individuals, teams, wards and hospitals respond to and manage refusal and what influences these approaches. Our focused observational strategy within each setting did the following:

- Concentrated on the work of nurses and HCAs and other clinical staff from a range of disciplines and roles when they are involved in the care of people living with dementia, focusing on medication rounds and mealtimes. We mapped the organisation of care, responses to refusal and management and communication of refusal of care with wards.
- Followed nurses and HCAs within each ward setting to explore their everyday work, and what informs this work. The processes of decision-making, the management of uncertainty and treatment procedures in response to refusal of care were identified by examining the everyday routine behaviours of individuals and teams within wards.
- Focused on observing handovers, admissions and conversations with carers, all of which present opportunities for sharing information about refusal behaviours and how these might best be managed.
- Where possible, collected routine data (from ward managers and within patient records) about ward staffing levels, overall work allocation, bed occupancy, patient acuity, turnover and recorded levels of refusal and resistance at the time of fieldwork to provide context and an understanding of the workload of refusal and resistance within this setting.

This has provided a detailed understanding of organisational and care processes that have an impact on the responses to and the management of refusal and resistance within this patient group. We examined the everyday work of staff, their practices and the interactions among staff, and between staff and patients/carers within these wards.

### Ethnographic interviews with patients who refuse care and their carers

We carried out ethnographic interviews to explore the impact of refusal of care on patient and carer experience and the factors that could lead to improved care and support. However, ward staff and the NHS Research Ethics Committee (REC) were concerned that the consent process for interviews was too demanding for patients living with dementia within wards and, in addition, patients who refused within the wards could not be identified as a distinct group (as we had assumed from the available literature) within the wider bay or ward populations. In response, recruitment was informed by the importance of recognising issues of capacity to consent and the impact of an individual's acute admitting condition on their ability to participate in an interview. To comply with our NHS REC approvals, we obtained written consent for interviews and observation at the bedside only when approved and supported by ward staff and patients' families. When the patient instigated a conversation with us, we obtained verbal but not written consent and recorded only the broad themes of the conversation within fieldnotes rather than verbatim quotations.

Where possible, we carried 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. Although we originally proposed to interview patients resisting care, this was ultimately not possible as we underestimated the emotional duress and agitation linked to such experiences. Where possible, we spoke to people living with dementia following a period of resistance, but the prior resistance was not discussed with them, in order to minimise further agitation.

Thus, in response to these limitations, in consultation with ward staff and the NHS REC, we used our case studies to obtain the perspectives of people living with dementia and their families and carers via ethnographic interviews. Ethnographic interviews were carried out with the case study participants throughout their admission, as well as with their family members. Ethnographic interviews ( $n = 71$ ) were conducted with case study participants ( $n = 10$ ) and their family members ( $n = 37$ ) to explore:

- experiences of admission and care, the impact of the physical environment and wider hospital structures
- processes of being listened to, communication and decision-making
- fears and concerns about treatment and management, particularly around refusal and resistive behaviours
- the identification of refusal of care and involvement and recognition of carer expertise.

### Ethnographic interviews with nurses and health-care assistants

The aim of ethnographic interviews was to provide a detailed understanding of the influences on health-care professionals' responses to 'refusal of care'. Ethnographic (during observation) interviews were carried out with nursing staff, HCAs and clinical staff ( $n = 436$ ) from a range of disciplines (including mealtime assistants, SPRs, consultants, AHPs and staff with managerial responsibilities) as they cared for this patient group within each ward and focus on medication rounds and mealtimes. This allowed us to question what staff were doing and why. The following key questions were asked:

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

- What aspects of caring are defined as 'difficult', demanding or rewarding and what is the level of staff confidence in their competence of working with this patient group? What are the barriers to and enablers of supporting this patient group?
- What is the recognition and reward for providing care to this patient group from patients, relatives, colleagues and managers?

## Case studies

Across the hospital sites we carried out detailed case studies ( $n = 10$ ) of patients living with dementia who were identified as refusing or resisting food or medicines ( $n = 5$ ). This allowed us to extend our fieldwork to provide a detailed contextual analysis of the events, the clinical staff and expertise involved in the events, and the wider conditions of care and their impact over time. This provides an understanding of the broader care systems within the acute setting that affect care and enable a multiperspective analyses. Purposive sampling was used, which was informed by our early analysis of observational data within each setting. Each case study involved:

- A detailed systematic observation of patient care during their admission (114 days of observation), interviews with carers and family members ( $n = 37$ ) and, where possible, patients ( $n = 71$ ), to explore the needs of this patient population and issues of refusal (target = 20–40).
- Interviews with nurses, HCAs and other clinical staff (including feeding assistants, SPRs, consultants, AHPs and staff with managerial responsibilities) involved in the care of these patients (see *Ethnographic interviews with patients who refuse and their carers*) to explore their response to refusal or resistive behaviour with a focus on medication rounds and mealtimes.

This allowed 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 to and management of refusal and resistive behaviour for this group of patients and their carers.

Field notes of observation and near verbatim text have been written up as Microsoft Word 2016 (Microsoft Corporation, Redmond, WA, USA) files<sup>183,184</sup> and all audio recordings of observations and interviews (ethnographic and in-depth) have been written up as Word files or transcribed verbatim by a professional transcription service. All site and individual data have been anonymised and organised in accordance with the Data Protection Act 1998<sup>185</sup> and the NHS England Data Protection Policy 2014.<sup>186</sup> Storage of the data is managed by the Cardiff University Information Security Framework Program.

## Sampling

Sampling in ethnography requires a flexible, pragmatic approach, using a range of variables that may influence any phenomena, as well as 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, was used to provide analytically rather than statistically generalisable findings.<sup>187,188</sup> This is the most appropriate means by which 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. Using this approach, the number of sites and participants in the sample is judged appropriate not on the basis of size but on the quality and appropriateness of the sample and when saturation of data has been achieved.<sup>188</sup>

## Setting and access of hospitals

This approach emphasises the importance of comparisons across sites,<sup>189</sup> allowing for and optimising the generalisability of findings<sup>190</sup> and enhancing the ability for the findings to affect policy and practice.<sup>160</sup>

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, which is informed by local dominant cultures and belief systems, which in turn means that care and decision-making can vary widely within institutions.<sup>191,192</sup> Thus, we identified a range of variables that may influence the phenomenon of refusal using purposive and maximum variation sampling to include five hospitals that represent different hospital types, geographical location, expertise, interventions and quality. The five acute hospital settings were identified from across the UK to represent the:

- types of acute hospital [two large university teaching hospitals (Sites B and D), two medium sized general hospitals (Sites A and C) and one smaller general hospital (Site E)]
- geographical locations, to include urban (Site A), inner-city (Sites C and D) and a large rural and urban catchment area (Sites B and E), situated across England and Wales
- range of specialist and non-specialist clinical and non-clinical staff, from staff with no formal expertise to dementia specialist workers (Site B).

### **Sampling within each hospital site**

Although our data collection sites (acute hospitals) were standardised, with sequential and systematic data collection, there was some variation within each site. We used theoretical sampling within sites to ensure that representativeness and consistency of concepts and events, rather than of sites and people, was achieved within the study. Informed by grounded theory, sensitising concepts from the ongoing analysis informed the next stage of data collection to expand the research process and to capture relevant aspects as they emerged into the ongoing analysis. The focus was on 'discovery' to ensure the grounding of emerging concepts within data and the reality of the settings.<sup>175</sup>

### **Sampling of wards for observation**

We observed episodes of care involving patients within MAU and T&O wards, which receive a large population of patients who have dementia and who require acute medical attention:

- MAUs – these are where unscheduled admissions arrive for assessment from accident and emergency (A&E), an outpatient department clinic or a general practitioner. Following assessment, patients are discharged, transferred to a specialist centre or admitted to an inpatient bed (see Collins *et al.*<sup>62</sup>). These are high-turnover settings, which aim to discharge or transfer 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 areas designed for or conducive to patients who have any cognitive deficit or dementia at a critical time where escalation of symptoms may occur. Members of the Carer Steering Group all had poor experiences of this setting and found it a frightening time, when they felt that they were not listened to and were often separated from their partners; we observed 267 patients in this type of setting.
- T&O wards – these settings allowed us to observe routine ward care and those patients who have an unscheduled admission following an accident where there may be no opportunity to provide additional support. The patients within this setting have had an accident or fall that has typically resulted in a fracture; we observed 65 patients in this type of setting.

### **Sampling and recruitment of staff for observation and interviews**

We followed the work of nurses and HCAs. We purposively sampled to ensure that we included 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) across the ward settings as well as other clinical staffs' (mealtime assistants, SPRs, consultants, AHPs and staff with managerial responsibilities) responses to 'refusal of care'. Within each acute setting we worked with our

key contact, who was typically the senior nurse responsible for care of the elderly and people living with dementia within each trust, who facilitated the process of identifying and introducing the team to key informants at hospital and ward levels. These key informants also provided introductions to our wards.

## Sampling and recruitment of patients and carers for interview and observation

Within wards we focused 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'.<sup>177</sup> Importantly, the focus of observation was on the daily practice of nurses and HCAs and other clinical staff during mealtimes and medication. It was not possible to predict the numbers of patients and carers within each hospital ward during the fieldwork period; however, we found that a high number of patients in the wards we observed had a diagnosis of dementia (as identified in ward records).

## Case studies

We carried out a focused series of individual case studies ( $n = 10$ ), identified using purposive sampling, which was informed by our early analysis of our initial observational data. We included a range of subjects (maximum variation sampling) who have had particular types of experiences within the setting (critical case sampling). Thus, sampling included patients who represented a range of presenting, diagnostic and prognostic, and, where possible, sociodemographic factors:

- We expected to identify refusal and resistance via the ward team and ward records; however, although we found high rates of refusal in the wards, we found low rates of identification, recognition and recording.
- Men ( $n = 5$ ) and women ( $n = 5$ ), aged  $> 65$  years (range 70–99 years) with an unplanned admission (fractured hip,  $n = 5$ ; fractured wrist,  $n = 1$ ; high number of falls,  $n = 2$ ; head injury,  $n = 1$ ; gout,  $n = 1$ ) and an accompanying comorbid diagnosis of dementia (dementia,  $n = 6$ ; 'unspecified dementia',  $n = 1$ ; Alzheimer's disease,  $n = 1$ ; vascular dementia,  $n = 2$ ) formally recorded in their medical records were identified.
- Expected length of stay can be highly variable for this group, ranging from days to weeks and months; thus, we followed these patients for up to 6 weeks within each hospital setting.
- Where possible, we carried out follow-up interviews with individuals and families after discharge. Of these patients, two died during their admission, six were medically fit and waiting for a placement in a nursing home and two were medically fit and waiting for a placement in a care home.

## Ethics approvals

The REC approval for the study was granted by the NHS Research Ethics Service via the Wales REC 3 on 24 June 2015 (reference number: 15/WA/0191). Substantial amendments to the study protocol were approved at a meeting of the Wales REC 3 committee on 10 December 2015. The committee has approved this research project for the purposes of the Mental Capacity Act 2005<sup>193</sup> and confirmed that it meets the requirements of Section 31 of the Act in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project. The study was accepted by NHS Research Permissions Wales on 16 July 2015, with permission received from the NIHR Coordinated System for gaining NHS Permission and West Midlands Clinical Research Network on 11 March 2016 and from the Health Research Authority on 27 May 2016. Recruitment for the study was managed and recorded through the Central Portfolio Management System and closed on 31 January 2017.

The safety of all participants was a key priority of the research team at each stage of the study. Before undertaking this study, the ethics of observing care, and the ethics of reporting where necessary what was observed, was frequently discussed with staff in the hospital sites and our carers group. In meetings with the NHS REC that approved this study it was clarified that although neither of the researchers technically had a clinical duty of care (both researchers were academics without clinical qualifications or professional affiliations), they would still be bound to safeguard any patient participants observed over the course of the project.

Prior to granting research passports, the host site ensured that both researchers had completed Good Clinical Practice and the Protection of Vulnerable Adults (POVA) training to level 1. The researchers were made aware of safeguarding and whistleblowing procedures at each site and had a named member of staff (the site principal investigator or research nurse on shift) to contact if malpractice or behaviour that put vulnerable patients at risk was observed.

Over the course of the observations, the researchers saw many aspects of everyday practice that would not be considered best practice or in the interests of the individual patient at that time. However, the examples presented within this report were not isolated and formed part of systemic and established everyday routine practice within every ward at each hospital site. Over the course of the observations we did not observe individual malicious behaviour or isolated incidents of deviance that placed a vulnerable adult at risk. Instead, we observed how the everyday organisation and delivery of bedside care itself often places the vulnerable adult at risk, but that this is part of the routine and established culture of the hospitals and the wards within them. At no point did the researchers feel that any individual or ward team was acting in a way that required escalation or whistleblowing. Had the researchers observed behaviour that they felt breached POVA guidelines they would have immediately ceased observations and reported the incident in line with site procedures.

The researchers did, however, frequently intervene to support people living with dementia and their families and carers where they felt it was necessary to protect the comfort of the patient. People living with dementia would frequently tell the researchers that they wanted to go to the bathroom or that they were in pain or share their concerns (about their home, their family or their pets, or how to pay for their care). In response to these disclosures, the researcher (with permission from the patient) would inform ward staff and ensure that this was not forgotten and was attended to by the ward team.

In addition, the researcher was sometimes the only person on a hospital bay with patients and would regularly ask patients if they needed anything. Sometimes when staff were not present or able to be called quickly to a bay, the research team provided immediate support and help, for example if patients were trying to reach for a drink or a newspaper. However, if a patient was trying to get out of bed unaided and if they were in some physical danger or at risk, the researcher would call staff. Although the researchers accept that this may have, on occasion, contaminated the purity of the data, the welfare of those under observation was always their priority.

Between sites, our research was regularly presented to the research team, including nurses, clinicians and trust leads, and although it was agreed that the care observed could be detrimental or distressing to a person living with dementia, it was also routine and recognisable as the everyday practice of acute ward staff. Since collecting the data and completing the analysis, we have carried out a programme of dissemination to present these findings at conferences and symposia to clinicians, advocates and nurses. We have also carried out a series of consultation events with people living with dementia and their carers, where our findings have resonated with participants. This work represents a form of member checking or respondent validation and has reinforced how recognisable the everyday nature of the care observed by the researchers, and the reliability and validity of the data collection and analysis, is.

The data presented here report on patients left to shout in beds or being restricted, restrained and coerced into actions that they had verbally or physically refused. Although in isolation these actions may appear to breach patients' rights, the researchers hope that they have demonstrated that these are not isolated incidents but rather the everyday reality of care delivery that each person living with dementia will experience during their admission within an acute hospital. We also show that nurses and HCAs lack the support to respond to the needs of people living with dementia in ways other than those outlined in this report, and, because of the fixed timetables and culture of the ward, routinely prioritise nutrition, medication and routine over the comfort or preferences of the patient. The actions taken by nurses and HCAs presented in this report were taken in good faith and attempted to protect the patient and the ward and to respond to the policies and perceived expectations of the wider institution. The researchers hope that the evidence presented in this report highlights both the challenges faced by ward staff as they deliver care in the acute environment and the need to better support both staff and patients living with dementia within this setting.



## Chapter 6 Modes of analysis and interpretation

Data collection (observations and interviews) and analysis has been informed by the analytic tradition of grounded theory.<sup>175</sup> We have utilised the constant comparative method and theoretical sampling whereby data collection (observation and interview data) and analysis are inter-related<sup>175,177</sup> and are carried out concurrently.<sup>178,179</sup> The flexible nature of this approach is important, because it allowed us to increase the 'analytic incisiveness'<sup>176</sup> of the ethnography. As these data were collected at one site at a time, preliminary analysis proceeded in parallel with data collection, with this preliminary analysis informing the focus of later phases of data collection in the next site and the further subsequent stages of analysis.

We applied an inductive approach to our analysis, a widely used approach, which means that we developed our hypothesis from the data, rather than a priori.<sup>188</sup> Analysis involved the development and testing of analytic concepts and categories and the strategies that we used for their development included the careful reading of the data, looking for patterns and relationships, noting anything surprising, as well as inconsistencies and contradictions across the range of perspectives gathered. Initially this produced a collection of 'sensitising concepts'<sup>194</sup> and analytic memos, which then informed the development of more refined and stable analytic concepts. Line-by-line coding is not appropriate for fieldnotes; instead, coding was selective and involved whole events or scenarios.<sup>176</sup> The constant comparative method means that the coding of data into categories was a recurrent process. The data were then examined in the context of previous fieldwork and the analytic memos generated then informed further data collection within the next site and the next, more focused, stages of analysis.<sup>176</sup> The analytic concepts that emerged from this process were then further tested and refined to develop stable concepts that we believe transcend the local contexts to identify broader structural conditions<sup>177</sup> influencing responses to refusal of care.

A key aspect of our approach to analysis was to take a systematic approach to the development of the ethnographic analysis into tangible outputs and interventions, via the following phases:

1. We explicitly used multiple perspectives (sociological, policy, clinical, patient and carer) to inform the development of our analysis to identify both local organisational insights and broader structural conditions,<sup>177</sup> which we believed might influence care. The analysis of the observational data was supplemented by, and triangulated with, data from clinical, carer and patient interviews.
2. The development of our analysis into ward-based outputs was always undertaken in close collaboration with our Carer Steering Group and our participating hospital sites and ward teams to establish relevance and feasibility within wards, and the utility and transferability to other acute hospital settings that have different organisational contexts.<sup>195</sup> We worked on the development and feasibility of ward interventions in collaboration with our lead participating site to ensure that we took an approach that could respond to the complexities of implementing change within health-care systems.<sup>196</sup>



## Chapter 7 Analysis: results of the qualitative study

### Resistance: a routine part of everyday care

We treat 'resistance' as an emergent concept and we found that it surfaced in the ways staff interpreted and responded to and assessed people's behaviours within the ward as legitimate or not. Staff were aware that there were patterns of resistance throughout their shifts; however, they were typically not able to recognise the potential triggers or patterns of resistance for individuals within their bay. Resistance was typically seen as a feature of a dementia diagnosis and a behaviour to be expected from this patient group within every shift, as evidenced in the following fieldnote:

*HCA discusses the ward: 'It goes in waves, it's not bad today, I am watching [bed number]'. As we are talking a nurse comes over and says she will take over the 1-2-1 work and sits in the chair and fills in the patient chart and takes a new 'side room checks' document for him.*

*Site B, day 3*

However, despite these routinely observable patterns or 'waves' across shifts, staff interventions in response to perceived resistance could be highly variable.

Overall, we identified extremely high levels of resistance to care among people living with dementia within acute hospital wards. It was a common feature of ward life; every patient living with dementia who we observed within the acute hospital ward resisted care during our period of observations. In total, we identified 1052 (T&O,  $n = 523$ ; MAU,  $n = 529$ ) incidents or episodes of resistance to care. This could manifest in a number of ways:

- Attempting to get out (and getting out) of bed, standing and walking around. Episodes included the patient wanting to go home; trying to leave the bay, ward or hospital; going to other rooms or areas of the ward or unit; pulling at the bed rail; approaching the nursing station.
- Verbal and physical cues. These included shouting; becoming angry or sounding agitated; crying, screaming and sounding distressed; asking to go home, see family or be taken somewhere; biting, pushing, pulling, spitting at or holding on to staff; refusing to leave the ward, be transferred or be discharged.
- Not submitting to the timetabled rounds of the ward. This included problems in relation to mealtimes, medication, personal care, observation rounds and examinations.
- Removal of equipment. This included pulling or removing i.v. lines, gastric tubes, dressings, catheters, nebulisers, cannulas, oxygen masks and other medical equipment crucial to care; pulling sheets off the bed or removing clothing.

Resistance, in whatever form it manifested, was always identified and interpreted by staff as a feature of the person's dementia diagnosis that signified their lack of capacity, and, as such, was something to be overcome or managed. Similarly, it was often interpreted by family carers and visitors as 'bad behaviour', something to be embarrassed by and to apologise for. However, we identified that resistance was typically a response by people living with dementia to the everyday organisation of their care within the wards (fixed timetabled routines) and the ways in which ward staff delivered care at the bedside. Importantly, these findings were represented in our data within all hospital sites, regardless of ward, time of day, day of week, etc. Our ethnographic approach allowed the researchers (KF and AN) to spend extended time within and across shifts observing specific ward bays and the individual staff and patients within them. These extended periods of observation almost always revealed the potential underlying reasons or triggers for a person's resistance to aspects of their care or their admission. These were typically rational to that patient's present ontology and perceptions.

Ward staff responses to resistance were either (1) to ignore resistance, particularly if the behaviour was judged not to be an immediate risk for the patient or to interfere with the organisation of the ward, or (2) to intervene and manage, particularly if staff believed that the provision of care was essential, that there was an issue of patient safety or that resistance was interfering directly with or delaying the organisation, timetables and wider work of the ward. The subsequent patterns of responses and interventions typically involved nurses and HCAs using multiple interactional approaches that combined language (orient to reality, instructions to be obeyed, the necessity of the institution, negotiation and bargaining) and the performative (a focus on completing essential care and containment of the patient at the bedside). These approaches created damaging cycles of stress for patients, families and ward staff.

### Physical resistance: getting out of bed, standing and walking

People attempting to get out of their bed or bedside chair and, if that was achieved, to stand and walk, was interpreted by ward staff as a key form of resistance. This was the most overt and commonly observed resistive activity and was consistently high across all wards and sites (although slightly lower in Sites C and D). This response to care was expressed by the most immobile patients, such as those patients who were able only to clutch at or pull and 'rattle' the raised rails at the sides of their bed (for this patient group, if they were in bed, the side rails on the bed were typically raised); people sitting in their chairs, who were able to push down on the arms of the chair in an attempt to stand up; and people who were able (often unsteadily) to walk away from the bedside. However, this behaviour was an immediate concern for staff and was identified as particularly problematic only if the person was able to stand, which was likely to lead to the person walking from the bedside and walking unsupervised within, or from, the ward.

As one example, an 86-year-old woman who is living with vascular dementia was admitted following a 'fall' and over one afternoon made multiple attempts to try to get out of bed. Every time she tried to leave the chair or the bed the HCA in the bay immediately responded to and repeatedly helped her to sit back in the chair ('let's sit you up for lunch') or led her back to her bed. The team (particularly the HCAs) encouraged her to sleep, arranging the sheets and pillows and holding her hand to try to calm her. However, every time the patient appeared settled, she would immediately try to reach for something, to sit up and get out of bed or stand. Her need to get up can be related to the immediate concerns and anxieties she expressed for her home, where her house keys were and who was picking her up and taking her home. Throughout the course of this afternoon, staff responses to her ranged from distraction (lunch) to repeatedly questioning her 'what are you doing?', 'where do you want to go?' and 'who?', before escalating to giving her clear directives, 'you need to rest', and referencing the wider institution by suggesting that other people had the power to decide whether or not she could leave, saying 'We need to talk to the doctors first' and 'your sons will sort it out for you':

*She is wearing her dark red cashmere jumper over her hospital gown and she tries to get out of bed. She has lifted the sheets off her legs and swings round to a sitting up position with her feet on the floor. She has been looking in her handbag and getting out of bed a number of times all morning and I think she was looking for her key and expecting to go home. The HCA immediately goes over to her.*

**Patient:** *'Ooh I am out of breath' – she breathes heavily.*

**HCA:** *'It's lunchtime, let's sit you up for lunch'. She helps her to move slowly and gently from the bed to the bedside chair and puts lots of pillow behind her and tidies up the bed.*

**Patient:** *Thank you.*

*The HCA tucks her into the chair with her mohair blanket over her legs with the trolley long-ways right in front of her, which keeps her in place. The trolley wheels are on the mohair blanket that trails on the floor and she stoops to pull it off – she is perilously close to the edge of the chair because there*

are lots of pillows behind her that also are pushing her forward. The HCA goes over from her chair at the other end of the bay to help her, puts the blanket on the bed and helps her into bed . . .

**Patient:** *'It's a bit worrying they are supposed to come for me I only live over the way' – she points out of the window next to her bed. She looks uncomfortable in bed and looks around for something on the bed and then gets her legs out of bed.*

*The HCA goes over to her: 'What are you doing?' She lifts her legs back up into bed and tucks her back in and moves the trolley next to the bed within reach. As soon as the HCA leaves, she leans over to the end of the bed with some difficulty and gets her mohair blanket and goes to get out of the bed and lifts her legs over the bed and her feet on the floor. The HCA returns: 'Where do you want to go? Where do you want to go?' She is kind and gentle in tone, but also sounds slightly exasperated.*

**Patient:** *She's picking me up in a minute so she said.*

**HCA:** *Who?*

*The patient sits on the bed and shakes her head, she is trying to remember and the HCA leaves and as she turns this patient tries to get up from the bed so the HCA returns and goes to help her to pull her hospital gown down, it has ridden up, and helps her to move from the bed to the chair and sits her down and strokes her face – 'I am just over there' – she points to the chair in the corner.*

**Patient:** *Where are you staying tonight?*

**HCA:** *I am going home.*

**Patient:** *'Someone is going to pick me up, I only live across the way' – she points outside the window. The HCA holds her hand and strokes her gently and soothingly. 'I am waiting for someone to take me home.'*

*A young male HCA arrives and has joined them: 'Take your medicine, eat well and you can go home!' The HCA sits with her and a nurse comes over and relieves her while she goes on her break and helps this patient into the bed: 'You need rest'. She puts the bed flat and helps her to settle down in the bed – she is curled up on her side and she places one pillow behind her back and one in front of her shins and covers her up. She tells her, 'This is your blanket', and she makes sure the mohair blanket is over her and she can see. The nurse sits in the chair and holds her hand and strokes it gently.*

**Patient:** *'I wonder who has the key?' The nurse strokes her head gently. The patient sits up: 'What do you suggest?'*

*The nurse is next to her: 'Nothing, you need rest, it's best to sleep you need rest' . . . The nurse leaves and the patient then pulls the blanket aside and moves the pillows and swings her legs out of the bed and sits on the side of the bed. The HCA watches her and goes over: 'Where are you going?'*

**Patient:** *Someone is going to take me home I hope.*

**HCA:** *We need to talk to the doctors first.*

**Patient:** *OK . . . where are the keys for my home?*

**HCA:** *I am sure your son or daughter has them, you must stop worrying about it, try not to worry, your sons will sort it out for you.*

*Site E, day 11*

Although the bay team talked to the patient throughout the course of this afternoon, as they did this they also continued to subtly restrict her movement to the bed and the bedside. They started with tucking the blanket over her legs and placing the trolley in front of her in the chair and then used pillows around her body, covered her up with the sheets and sat next to her holding her hand.

Getting up, standing, trying to walk, walking or walking unaccompanied within the ward was always discouraged and problematised as a form of resistance for all patients. However, this could be subject to a variety of responses depending on the assessment of the immediate risks to the individual patient. Patients who evidently did not have the strength to follow through and achieve their aim of getting out of bed, standing or walking were typically not assessed by staff as an immediate concern. In the following fieldnotes, a 94-year-old man with a fractured hip and pneumonia continues to rattle and pull at the raised bars on the sides of his bed. However, even though he does this forcefully and over an extended period during the shift, an indication that he appears to be distressed, the team continue their focus on the routines that must be completed and recorded around him – the observation and medication rounds of the people in the other beds within the bay. They do not check on him directly; he is contained safely within the bed:

*The HCA returns to the bay with the mobile blood pressure unit from taking the measurements from the patients in the cubicles, the nurse finds the yellow charts for him have returned and are open on the trolley at the end of the bed and updates them. He is a very thin man wearing a hospital gown lying in bed – the sides of the bed are up and he is holding on tight to the left side bar and shaking it and rattling it as if trying to get out. He moans and sounds very distressed. The nurse continues and moves on with the medication round to other patients in the bay and as she is doing this, he holds tightly onto the raised side bar on his bed, continuing to rattle and pull at it.*

*Site A, day 4*

The organisation of care and the routines within the ward meant that, often, staff were not able to see this behaviour as a priority for care, and, if they did, the perceived priorities of the ward meant that they often appeared unable to respond. However, walking or walking unaccompanied within the ward was almost always discouraged and problematised as a form of resistance for all older patients. Staff typically questioned older patients who were walking and the language discussing walking referred to it as a danger or a form of 'escape', often using humour to reduce this behaviour:

*The HCA wakes a patient up for her observation and medication. As she does this a younger man in his 20s from the bay at the end of the ward walks past, he is just wearing his underpants and is holding a wash bag and pushing his mobile drip heading to the bathroom.*

*At the same time an 87-year-old woman with a diagnosis of dementia who has been admitted with a fracture is trying to get up from her chair. She is wearing a full-length quilted dressing gown that is buttoned all the way up to her neck (it is the middle of summer and very hot in the ward). It is purple with tiny sprigs of flowers like heather all over it. As she does this, the HCA calls to her: 'Where are you off to?'. She responds that she is heading to the toilet and the HCA is relieved: 'Oh I thought you were going to escape!'. She helps her to reach her walking frame and stands behind her as she mutters 'I know I know I know . . .' all the way to the bathroom and back. Afterwards she turns to the HCA and smiles and says, 'Thank you so much'. The HCA gives me a look as the young man from the bay at the end of the ward walks back from the bathroom in just his underpants.*

*Site A, day 1*

Throughout, judgements were also made about the person, their condition and whether or not their particular behaviour was legitimate and able to be permitted within the ward. A man in his twenties was able to walk up and down the ward in his underwear without comment; however, this woman with a diagnosis of dementia was met with close control over her movements.

## Verbal resistance: shouting, anger and agitation

It was common for people who were shouting, agitated or angry in the ward or bay to receive the most attention from staff. This was a key response across four of the sites and was low only at Site C. This behaviour often resulted in the individual being assigned one-to-one agency care within the shift ('specialing' a patient means that their needs have been assessed as being so great that they require care at all times and they are assigned a private agency HCA to provide one-to-one care). The key responses from ward staff to this behaviour were to (in turn) orient people to where they were, direct them to calm down and rationalise with them. Throughout these processes there were typically multiple attempts to contain the person at the bedside, which could lead to them being supervised more closely, which in turn could cause the patient further anxiety and trigger the ward procedures of 'specialing', a DoLS order and one-to-one HCA care. In the following example, a 77-year-old man with a diagnosis of dementia has been in this ward for > 5 months and, although he is 'medically fit to leave', there is no package of care organised for him. He is in an individual room and is 'specialied' with one-to-one HCA care and, although he has difficulty communicating, he is clearly waiting for his lunch. Shouting 'HEY' is his main form of verbal communication during the day and, as he waits, he gets louder. The one-to-one HCA and the team passing join in and they repeatedly switch between encouraging his excitement about the arrival of lunch and using a number of techniques in an attempt to calm him down when lunch does not arrive on schedule. They orient him to where he is, 'you are in your room', direct him to calm down and then rationalise with him, 'what do you want?':

*I am walking through the corridor with two HCAs and the person in the side room shouts for us. The door to his single room is open and he is sitting in the chair looking out wearing hospital pyjamas and red hospital socks and he has a large knitted hat on his head. The one-to-one HCA is sitting very close and opposite him filling in his bedside chart. We go over to see him and he holds up three of his fingers to indicate that there are three of us. The HCA with me asks him what he is having (pasty) and asks him what sauce he would like to go with it and she gets him sachets of sauce to have with his chips: red, brown and vinegar. He is now very excited about the chips. I introduce myself again and we talk about the hospital food and he tells me the food is terrible and then covers his mouth like he shouldn't say this and we laugh together and sympathise. He gets more and more impatient for lunch – 'Hey HEY' and asks for the time when the chips should arrive and the team count down the time – 15... 10... 6...*

**Patient:** HEY HEY Give it, give it, give it me.

*He is now getting very angry and agitated and repeatedly shouts 'HEY HEY' as people pass his door.*

**HCA:** What's the matter now? Listen you need to calm down.

**Patient:** Hey hey.

*The HCA continues to talk to him and repeatedly tries to calm him down...*

**Patient:** HEY HEY HEY.

*The HCA jokes and laughs with him and is very positive, 'Your pasty is coming and ice cream'.*

**Patient:** HEY

**HCA:** Are you alright?

**Patient:** NO I AM NOT

HCA: *'What do you want?' Lunch fails to arrive and the team call catering. When it finally arrives the pasty is cold, the chips are soggy and his agitation, unhappiness and frustration increases.*

*Site D, day 5a*

This behaviour suggests that the person was attempting to communicate with ward staff. Importantly, it was also a response to the ways in which care was organised and was being delivered at the bedside, especially (as in this case) if this does not meet the patient's expectations. In the case above, staff encouraged the patient's excitement about his lunch only for it to fail to arrive on time and be unappetising and inedible when it did.

## Resistance towards the timetabled rounds of the ward

Ward staff identified patients failing to submit to the timetables of the ward as a common way in which resistance to care was manifested. This resistance occurred in relation to mealtimes, medication, personal care, observation rounds and examinations. This study has a specific focus on examining mealtimes and medication rounds and resistance to food, drink and medications. Thus, we examine these aspects of routine care in more detail within the wider context of the timetabled rounds of the ward, which includes mealtimes, food and drink, medication, personal care, observation rounds and examinations.

### Mealtimes

The delivery of food and mealtimes were aspects of routine timetabled care within wards that typically prompted resistance to care (this was consistent across sites). Mealtimes were also points in the timetable when there was an emphasis on speed and efficiency, particularly for people who were assessed as needing support to eat. Resistance often took the form of a clear communication from a person that they do not want to eat (verbal or physical) or the absence of communication (silence in response to often repeated requests). In response, this was almost always viewed by staff as a feature of the person's dementia diagnosis, a sign that they did not have capacity and a form of resistance that must be overcome, with ward staff emphasising the importance of food and nutrition to recovery. Even when people clearly indicated that they did not want any more food, staff would typically make a further attempt to encourage them to eat more before stopping. However, staff responses to individual patients were highly variable and, although for some patients there appeared to be more flexibility that allowed for a wider range of behaviours and responses around mealtimes and eating, for others, mealtimes became a battleground. This meant that mealtimes often triggered anxiety and the potential for this resistance to escalate quickly into the person refusing all care.

### Needing help with mealtimes viewed as a feature of a dementia diagnosis

For ward staff, a person with a dementia diagnosis typically required help with eating meals, and not being able to eat independently was viewed as a key feature of the condition. In addition, rather than recognising that issues around food and food refusal may be signs of other underlying issues (confusion, anxiety, unsuitability), they are expected as routine and inevitable aspects of an admission for this population. This was also seen as a feature of their condition, which was either permanent or could be better managed once the patient was discharged or transferred to a specialist setting. The issues around food were recognised as problems that manifested within non-specialist acute wards and short-stay units such as assessment units but could not be prevented or solved within them.

Even when a person clearly refused food by keeping their mouth closed, by pushing food away or by stating that they did not want food, staff typically continued to try to encourage, persuade or put food into a person's mouth. This could be obviously distressing for the person, although this impact was typically not recognised by ward staff. In these interactions, the meal is no longer pleasurable and instead becomes a confrontation between the member of ward staff and the patient. The potential for this resistance to escalate quickly into the person refusing all care was high during mealtime interactions. When refusal and resistance was exhibited it could inform staff perceptions of that person and their understanding of the

impact of their dementia diagnosis and their capacity to make decisions, and create anxiety and confusion for the often-admonished patient. In what follows, despite finding speech very difficult, a 96-year-old woman with a diagnosis of dementia who has had surgery for a fractured hip is able to clearly and angrily articulate that she does not want any lunch. However, this is interpreted as a feature of her dementia to be overcome and the volunteer continues to place a forkful of pureed food in front of this person's closed mouth, starting with encouragement, 'just a little bit', but quickly moving on to a directive, 'you've got to eat', 'open up'. This is seen as essential work and this mealtime volunteer continues this approach and stops only once this patient has accepted a tiny bit of dessert into her mouth, even though she then spits it out. The volunteer does not wipe away the food around her mouth and leaves the bedside, clearly frustrated at her lack of progress. The experience of the repeated attempts to spoon puree into the patient's mouth despite her saying no appears to leave this patient in an increasingly anxious and fearful state and she resists all further care that day:

*This woman is lying in bed and I haven't seen her leave the bed yet. She is wide eyed, looking around the bay and has been talking quietly all morning. The mealtime volunteer arrives (a tiny woman wearing a tabard and who appears to be in her 70s); she places the tray of lunch on the trolley and sits on the chair next to her and then leans over the rails to talk to her. The plate has pureed food – a third is bright orange, a third is white and a third is a dark grey with bits in (I think this is pureed stew). She uses a large metal fork and puts pureed food on it, it is orange but hard to make out what it might actually be, possibly carrots? She puts the fork to her closed lips: 'Just a little bit'.*

*Patient: 'I don't want any'. This is the first time in 2 days I have heard her say something that is clear and easy to understand – it has clearly taken her a great effort to articulate what she wants and she sounds very angry. However, the volunteer continues in an upbeat and encouraging tone: 'You've got to eat, just a little bit.' She keeps the fork with the pureed food hovering at her mouth: 'Just a little bit!' She leans further over the side rails of the bed and holds the fork close to the patient's mouth. I am standing next to the sink and bathroom in the corridor opposite the bay and the volunteer turns and talks to me: 'I am a volunteer, I can't force them, I can only try'. She puts the fork back on the plate and moves on to the dessert. She takes a large metal spoon with a similar looking yellow/orange puree on it and holds it in front of her mouth: 'Just try a tiny spoon, listen, just try, unless you try you don't know, just try a little bit, open up just a bit'. She does open her mouth a bit and the volunteer spoons a tiny bit into her mouth. But she looks extremely unhappy at this and uses her tongue to push the puree out so that it sits on her chin at the side of her mouth. The volunteer stops trying at this point and for the rest of the morning the yellow-orange puree sits on the side of her mouth. As the volunteer puts the tray away and gets ready to leave the bedside she turns to me: 'I had to give up, she was the same at breakfast . . . I told my son if I get like this take me to the vet!'. She leaves and the nurse arrives with a syringe of liquid medication to take orally, but she won't take it and the nurse leaves and moves on to the next person. This woman is now talking in a low voice to herself, fiddling with her waistband (I wonder if this is anxiety or she needs to go to the bathroom) and looks around the room. She now looks very, very, anxious.*

*Site E, day 2*

An extremely common approach was for ward staff to emphasise nutrition and the importance of eating to the patient as they continued to try to put food into their mouths. Here, the team discuss the patients in their care and who needs 'feeding' in the bay (people living with dementia were often referred to not as people needing mealtime assistance, but as 'feeders' who needing 'feeding'). In the following fieldnote the nurse ignores a 95-year-old man who has had a hip operation following a fall and has a diagnosis of dementia, who repeats a number of times that this is 'the worst day of my life'; the nurse continues to encourage him to eat, emphasising the importance of nutrition. Although he clearly expresses that he does not want help, she takes the cutlery and puts a spoon of food directly into his mouth. This encounter is also punctuated by his chair alarm, which is repeatedly activated by his movement in the chair:

*Nurse: Hello, have you had lunch?*

*Patient: Everything in the world has happened to me today all the worst things.*

*He holds her [the nurse's] hand and she leans low over to talk to him: 'Will you have some lunch for me, we're having a party?'*

*Patient: I won't be able to eat it all.*

*Nurse: Your dinner is here my darling.*

*She speaks quietly to the HCA, 'Are you OK to feed him?'*

*She turns to him: 'If you can eat ice cream you can eat some actual dinner, you eat too many sweet things, you need some nutrition'.*

*However, he is so shaky that by the time it gets to his mouth it has fallen off the fork and is empty and, in addition, his seat alarm keeps going off. He tells them: 'I am sorry I can't eat it'.*

*The team offer help but he rejects this: 'I don't want help' and the nurse pops a spoonful in his mouth and he pulls away: 'Sorry love it's not very healthy to eat chocolate'. He responds: 'I can honestly say it is the worst day of my life, I won't have this (main course) but I will eat that' [ice cream] and he gets the ice cream and take bits of it with his fork as his chair alarm goes off intermittently blaring loudly throughout the meal.*

*Site C, day 7*

The repeated attempts to encourage people to eat and the approaches staff used to try to 'feed' someone typically made people angry and increased their anxiety and distrust of staff. In what follows, the HCA's encouragement becomes increasingly forceful and, despite appearing to ask this patient if she wants to try it, and despite the patient pushing her hand away, continues to repeatedly put large spoons of food near the patient's mouth. It is only when this patient, who is a tiny woman confined to the bed (a 96-year-old woman with a diagnosis of dementia who has had surgery for a fractured hip; see above), makes another attempt to communicate her wishes by forcefully pushing her hand away that she stops. This is a surprisingly fast movement, which indicates her underlying anger and frustration. The HCA is shocked and shaken by this and the patient looks increasingly anxious and fearful during the rest of the shift:

*Lunch arrives and there is a strong smell of cooked food in the ward. The HCA takes this woman a meal of pureed sausage, pureed peas, mash and gravy: 'I have a lovely lunch here for you, do you want to try it?' She is sitting next to her and puts a clean linen pillowcase across her chest and gives her a large metal spoon: 'You try it, hold the spoon'. She helps her hold the spoon and also holds it and guides it into the mash and then guides it towards her mouth. But this woman pushes her hand away from her mouth and puts the spoon back on to the plate. The HCA then once again uses the spoon to scoop quite a large amount of mash and gravy on to the spoon and guides it back to her mouth and she takes a tiny bit. The HCA is very encouraging and moves on to the dessert: 'I have apple and custard' (it is in a tiny pot). She sits next to her and puts a bit on a large metal spoon: 'Let's try again', she tries to put the spoon into her hand. In response, this woman takes it and pushes it away extremely forcefully, it is so fast and unexpected that the HCA jumps out of the chair in shock. I ask her if she is OK and she responds, 'You never know!' And she turns to say to the woman: 'Let's stop there'. However, this patient now looks very anxious and wide eyed as she sits in the chair.*

*Site E, day 5*

The frustrations that staff experienced around mealtimes could quickly become visible and they sometimes became angry and exasperated and raised their voice to patients. Although patients not eating a meal was seen as resistance to be overcome, for staff this also seemed to signify their own personal failure in delivering an essential aspect of patient care. Here, the HCA repeatedly tries to encourage an 82-year-old man with a diagnosis of dementia to eat lunch:

*The HCA encourages this patient to have dinner: 'Have your rice pudding, how do you know if you don't try it?' She raises her voice slightly and sounds exasperated: 'Won't you try it! No? OK, that's fine but it's a shame'. This man is lying in bed only slightly propped up in hospital pyjamas and as she writes in his bedside notes she asks again: 'Do you want something to eat? Shall we try again? Don't you like sweet things? Do you want a drink before I go?'. He responds: 'No'.*

*Site B, day 13*

### Interrupting, taking over and hurrying can lead to refusal

Mealtimes were also a point in the ward timetable at which there was an emphasis on speed and efficiency, particularly for people who were assessed as needing support to eat. Here, a 95-year-old man who has been admitted with a hip fracture following a fall and has a diagnosis of dementia is eating his meal without support, although he is doing this slowly. The HCA joins him and immediately interrupts, encourages him and takes the fork from him and tries to 'feed' him a forkful of food. In response, he refuses any more food, shakes his head and crosses his arms defensively:

*The HCA goes over to this man, she usually 'feeds' him, but when she goes over to him, she brings a chair and realises that he is eating by himself. She puts the chair next to him and sits very close to him: 'Do you want some gravy with that?' He is taking tiny bits of food on to his fork and eating it. She leans in: 'You are going to do some exercises [physiotherapy] so you need to eat to get your strength up'.*

*Patient: That's a good idea.*

*HCA: One more forkful?*

*He shakes his head, but she takes the spoon and tries and gives him one more spoonful: 'If you have one more spoon you will have eaten half your dinner'. He shakes his head and crosses his arms – he looks uncomfortable. The HCA asks him, 'Are you OK?'*

*Patient: 'I've got the bloody itch' [itchy back he has been complaining of on and off all week].*

*HCA: You don't want to eat more?*

*Patient: No.*

*Site C, day 6*

Even when people clearly indicated that they did not want any more to eat, ward staff typically would make further attempts to encourage them to eat before stopping.

Mealtimes often triggered anxiety, and a very common source of anxiety stemmed from people being worried that they did not have money to pay for their meal or drinks. It is not uncommon to see patients begin searching for wallets or handbags (which they often did not have and which created a further source of anxiety and distress) as meals were served (this is particularly the case in MAUs across sites). This could lead to real distress, and we observed several patients breaking down in tears at the thought of being unable to pay for their food. Although this was an issue that was often resolved by the presence of an attentive member of staff reassuring the patient, such distress could take more covert forms that

could go unnoticed. Here, a 96-year-old man with dementia and 'increased confusion' who was admitted following a fall responded to the tea round as follows:

*The tea trolley comes into the bay and the HCA asks him: 'Fancy a cup of tea?' He comes back over to us and asks: 'Is there anywhere I can get a coffee?' In response, I offer to make him one and he starts fishing for money in his pockets. The HCA and I both say: 'You don't have to pay for it, coffee and one sugar?' The HCA takes him a coffee (in a red plastic mug) and says: 'Here you are duck'. As she does this, the man in the bed opposite struggles with the biscuit wrapping and asks her, 'Do I have to pay for this?'. She replies, 'No, it's free darling'.*

*Site B, day 6b*

### Supportive and enabling approaches to mealtimes

Importantly, mealtimes could be very supportive and enabling routines within the ward timetable, with staff taking time to support, encourage and help people to eat. Mealtimes could also be a quiet time in the bay, a point of communication, and this could be transformative for the person living with dementia. Once people started to eat, this could have an immediate visible impact on the person and it could be a time when people would 'come back into the room' (ward sister, Site C) and their alertness and ability to communicate would visibly improve. In the following fieldnote, the ward housekeeper is with a 79-year-old man with 'acute confusion'; she starts by fully supporting him to eat breakfast and as she stands over him at the bedside, repeats a number of times the instruction to open his mouth. He finishes his porridge. She then asks what he wants, how he likes his tea and encourages him to help himself and hold the cup and he drinks it all. This is transformative and he becomes able to communicate with her, he is alert, his eyes focus on the ward around him and he starts to show an awareness of the room and his surroundings:

*The housekeeper takes the bowl of porridge (it must be cold by now) and stands over him at the bedside. She uses a plastic teaspoon and takes some porridge: 'Open your mouth . . . open your mouth . . . open your mouth . . . open it . . . open it . . . Just one more . . . open your mouth . . . wide . . . wide . . . that's it . . . porridge . . .'. He has finished the porridge and this is the first time I have seen him eat. She puts the bowl on the tray and turns to him: 'Shall I make you a cup of tea? How many sugars?'. He responds to her – again this is the first time I have seen him communicate. Later, she comes over to me where the tea trolley is and she talks about him: 'I know the tricks of the trade! I am not just a pretty face! I know how to do this! Don't use a metal spoon, use a plastic spoon, it is gentle and bends in their mouth and it helps them to eat, he had all his porridge. I daren't try the yogurt yet, but I will try him with a cup of milky tea'. She makes a very weak milky tea in a sip cup and adds a straw and says to him: 'I have a nice cup of tea for you', she takes it to him and then comes back and adds some more milk. She returns and stands over him holding the cup and he drinks a bit through the straw. As she leaves he is sitting in bed with his eyes open and looking around the room.*

*Site B, day 4*

Breakfast was a particularly powerful routine at the bedside when staff were able to take time to support people. This could make a difference to improving a person's alertness. Mealtimes could be a time for communication. This work included staff asking the person about their family and also sharing personal information about their lives. This emphasised the emotional importance of food and the potential for mealtimes to be a time of connection and communication.

### Drinking and hydration

We did not observe people living with dementia resisting drink or opportunities for hydration. In contrast, we observed high rates of patients without a drink within reach, unable to drink from the cups they were provided with, or their requests for a drink not being prioritised by staff. On only one ward (Site C) did we observe that it was regular practice to focus on optimising hydration and to consistently offer people a drink of water or tea during the majority of the routine encounters at the bedside. Within this ward there was a regular emphasis by all staff on supporting hydration at the bedside during every encounter with a

person. In the following example, 'sippy cups' were used, but the site also used the simple straw in the spout method in addition to this so that people did not need to tip a cup to drink from it. Staff handed people the cup to hold and emphasised the importance of drinking. Here, a 95-year-old man with a diagnosis of dementia has been admitted with a hip fracture:

*He is sitting in his own pyjamas with the TV [television] monitor low and in front of his face, his glasses are on and he is watching the news; he dozes and watches a bit and then dozes again. He has a sippy cup of tea in front of him and a glass of water with a tiny bit of water in and a straw. The HCA comes over: 'Can I do your blood pressure?'*

*She places the cuff on his arm and the BP [blood pressure] machine beeps: 'There you are all done, it's fine, you just need to keep drinking water for me darling, I want that whole cup done!' She passes him a glass of water with a straw and he drinks it.*

*Site C, day 7*

However, overwhelmingly, within all other wards it was extremely common for glasses of water at the bedside to be empty, to have low levels of water in them or to be out of reach. Across the wards, as well as traditional institutional-style china or ceramic cups, saucers and mugs, 'sippy cups', tinted and coloured plastic water glasses, straws and thickener were all used to provide water, tea and coffee and to support hydration. However, these technologies were not always enabling and could be difficult or confusing for people to use. The 'sippy cup', a spill-proof drinking cup originally designed for toddlers, was commonly used for people living with dementia in all wards. In the following example, a 94-year-old man with 'memory problems' is trying to drink from a plastic sippy cup. However, to drink from it, it must be raised high and tipped up to position it at an angle. Although he tries a number of times, the patient does not have the strength in his arms and cannot raise it high enough:

*He is lying propped up in bed, the sides of the bed are raised and on the right side the side bar is padded with a thin mattress and the trolley is over him in the bed with a sippy cup of water. He keeps his eyes closed and takes the sippy cup and puts it to his lips. He tries a number of times to suck water into his mouth, but can't lift it high enough to get any water in his mouth and he puts it back on his tray.*

*Site B, day 6b*

The use of sippy cups was common and, although such cups are designed for people with a weaker grip or people lacking dexterity, their use did not take into account the strength needed to lift them high enough to use them effectively. Importantly, for people living with dementia, even if water was within reach, it may be that they either do not recognise the glass, mug or sippy cup in front of them or do not recognise that they are thirsty. This underlying dehydration became apparent only during the course of a shift, when patients were passed glasses of water and in response would often thirstily drink everything.

### **Resistance to medicines and the medication round**

The majority of encounters with patients during medication rounds were unproblematic. However, when examined across whole bays, wards or units, resistance was a common occurrence during each medication round. It was rare for a medication round within a bay of 6–8 people to be completed without any resistance and it was usual for the routine to stall with a person at one or more of the bedsides (with particularly high rates seen at Sites A and C). Routine cycles of conflict and resistance during the medication round were observed, which were repeated every shift, often with different staff rehearsing and duplicating the interactional performance and routines of the medication round during encounters with the same patient. This often escalated into conflict and led to a patient being labelled as 'difficult'. Resistance to medication was not a feature exclusive to patients living with a dementia or with cognitive impairment, although it was more pronounced within this group and was common among older patients within wards.

Medication rounds were a key ward routine during which staff expected that patients would exhibit resistance. The medication round was always a time of increased urgency and often increased anxiety for nursing staff, which was driven by perceived constraints within the ward timetable in completing this task and the importance of patients taking all of their (typically multiple) medication. Staff expressed a clear sense of relief and accomplishment if the round was completed without perceived resistance and delay. Common reasons for people resisting, querying or challenging their medication included the medication being offered not being the same as their home prescription (including variation in brand, dose or delivery of familiar medications) or being apprehensive that the medication would have side effects such as nausea. Although this was a typical feature of the routines, this is always viewed by staff as problematic and resistive and appeared to increase their anxiety, stress and frustration. Here, the nurse focuses on providing repeated information about who has prescribed this new tablet (the 'doctor' and the 'psychiatrist'). It is only when this patient, a 70-year-old woman who has been diagnosed variously with 'dementia', 'delirium on a background of dementia' and 'manic/hypermanic behaviour', demonstrates in a number of ways that she would not take the tablet by disposing of it in her teacup, followed by 'no', that this nurse gives up. She writes this in the notes, but predicts that she will be criticised for not completing this:

*The nurse goes over to her with medication in a pot. She has a loud voice and is very strident: 'I have one little tablet from the doctors who saw you today'. She puts it into her palm and the woman looks at it closely: 'It's not the blue one'. She picks it up and puts it in her teacup straight away. The nurse is clearly extremely exasperated: 'Can I explain to you! Because you have been seen by the psychiatrist today he has given you this'. Patient: 'No it's rubbish'. She is very clear that she doesn't want it.*

*Nurse: He has prescribed it, OK you don't want to take it.*

*She is very exasperated and puts the rest of the medication into her personal drug cabinet, saying to herself and the wider ward: 'It's the first one that has been prescribed!' She sounds very frustrated and writes in her bedside notes and says to me: 'They will say you haven't tried!' [it's the lorazepam].*

*Site E, day 8*

This frustration is also linked to the visibility of the medication round. When a medication round has not been completed, nursing staff appeared to feel exposed to the scrutiny of others in the institution for this apparent failure to complete the task. However, the medication round and the persistence of the team trying a number of approaches, despite a person clearly stating 'no', could cause anxiety that has repercussions for a person's care throughout the shift. In the case of this 96-year-old woman admitted with a fractured hip, her anxiety increases and she refuses all further care during this shift:

*The HCA goes over to her: 'I will just wipe your mouth'.*

*Patient: Why?*

*HCA: You have food around it.*

*However, she doesn't like this and makes it clear and as this is happening, the nurse arrives with her medication in a pill pot – two pills – and the HCA takes one and tries to help her take it by putting it in her mouth: 'Can we give you this tablet? Can I pop it into your mouth and a bit of a drink?'*

*Patient: No.*

*HCA: With the dessert?*

*She seems to agree. 'Do you like custard?'*

*The HCA puts custard on the spoon and places the tablet on top: 'Try a little bit'.*

*She puts it close to her mouth.*

**Patient:** *No.*

*However, the HCA continues to try to get her to take the tablet: 'This medicine will help you!'.*

*The tablet is now just in her mouth with a bit of the custard, but she spits it out and it is in her hand and she tells the HCA: 'You are a bloody nuisance you are'.*

*The HCA picks it from her hand and puts it in a tissue and puts it in the bin. However, the HCA perseveres and returns with another tablet, but does not manage to get the tablets into her mouth and in the end places the second tablet also covered in custard in a tissue and in the bin. The HCA leaves, but now this woman is quite distressed and talking to herself and looks very anxious and wide eyed. Some time later, the nurse does a quick sweep clearing up the bay and goes over to this woman who is now talking to herself and looking anxious. She checks the pill pot, sees that it is empty and puts it in the bin; she clearly assumes that she has taken the tablets.*

*Site E, day 4*

For many people, resistance and rejection of their medications was part of their wider rejection of all care.

### Attributing agency

A key element to conclude most nurses' medication routine at the bedside was to check that medication had been swallowed, usually by asking patients to open their mouths. However, it was still common for patients to spit tablets out, to hide them or to throw them away. There was sometimes a recognition that for some patients this was a reasonable response, 'I can't blame you'. However, ward staff typically interpreted this as a wilful and resistant act by the patient, who was described as 'naughty' or being 'crafty' and 'he's a monkey', as in the case of this 95-year-old man admitted with a fractured hip:

*This man tells the nurse that his pain is 'nasty'. The nurse responds: 'Here are some painkillers, if you eat more I can give you stronger ones, here you are, hold it'. She gives it to him. The medic comes over to the bedside and interrupts, emphasising to this patient: 'The nurse has given you this to help you'. However, he wants to save it for later and so the nurse encourages him to take it now: 'Do you want some more dinner? Do you want to try the tablets now? The painkillers are for the pain'. In response, he puts it in his mouth, puts the next one in and he sips his drink. He spits it out and the student nurse notices and repeats: 'It's a painkiller so you don't have pain, you remember you broke this leg, you need painkillers, if you need more I can give you more, we just don't want to be in any pain'. In response, he has quietly spat them out and there are large pieces of tablets surrounding him on the floor. The student nurse tells me that he showed me his mouth to show me it was empty and then spat them out and told me to keep quiet! She giggles and cleans up his tablets from the floor and shows him: 'Naughty!'*

*He demonstrates how he spat them out undetected: 'I just went like this!'.*

*Site C, day 5*

### Performance: putting tablets directly into the mouth

The most common and widely used approach across all sites to deliver medication to people living with dementia was to put tablets directly into a person's mouth. This technique included putting tablets on spoons, putting spoons or tipping pill pots into a patient's mouth during these encounters. Tablets were also crushed or mixed in with food, particularly desserts such as yogurt, mousse or trifles. During the work of completing the medication round the nurse would sometimes tell the patient that they were going to place tablets in their mouths, with the patient opening their mouth to receive them. In the following fieldnote, the nurse is with a 73-year-old woman who has been admitted following a fall and is described

as 'pleasantly confused'. The nurse describes the medication and that she is going to place them in the patient's mouth and she continues to talk to her and explains what is happening step-by-step throughout this encounter:

*Nurse: We have your tablets, can you open your eyes for me? I have two tiny tablets here I am going to put them in your mouth. If you can swallow them for me, one at a time, I am going to put it in, well done darling. I am just going to pop this one in now. They are a bit big aren't they, come on.*

*Her tone is very gentle and relaxed, no sense of hurry: 'Well done darling, it looks like we have some more tablets! Sorry.'*

*Patient: I keep thinking we are done but she gives me more!*

*Nurse: Just one more tablet, just one more.*

*She touches her shoulder and leans over her and puts the tablet in her mouth and helps her with a sip of juice.*

*Site D, day 2a*

However, this technique was used extensively in response to a patient's resistance to taking tablets, using spoons to open often unresponsive mouths or to tip tablets into a mouth that did not seem easily able to respond and swallow them. In the following fieldnote, the nurse expresses her frustration and annoyance that the patient, an 86-year-old man with a diagnosis of dementia who has been admitted with pneumonia, has spat the tablets out. In response, she uses the teaspoon with pills on to pry open his mouth and tries to push them back into his mouth:

*Nurse: Oh you have spat it out! It's me again! It's a pain in the backside, you need to take them!*

*She uses a plastic teaspoon to push the tablets into his mouth: 'Shall we try one more?' She puts the tablet on a teaspoon again and puts it in his mouth and tries to give him a sip of juice: 'Can you feel it, it's your cup?' She puts it in his mouth: 'A bit higher darling', she helps him and guides it up to his mouth and he takes the cup and raises it to his mouth. She sits next to him: 'Have another sip, have you got it? Have a sip darling'. She guides the cup to his lips.*

*Site B, day 4*

Often this was part of an extended process of negotiation and pleading with the person. In the following fieldnote, the nurse kneels in front of the patient and, after describing the tablet and asking her to put it in her mouth, he pleads with her and seems exasperated and at a loss as to what to do next. The HCA sitting with the patient, who is a 90-year-old woman admitted with a fractured hip who has a diagnosis of Alzheimer's, takes the tablet, puts it in her mouth and follows this with a spoonful of ice cream:

*She is sitting at the dining table in the middle of the room. The nurse comes over and kneels next to her: 'Look at this, here is a tiny tablet, put it in your mouth'. In response, she picks it up and throws it down.*

*Nurse: Try my little tablet!*

*He is now pleading with her and is slightly exasperated, but it also betrays his tiredness and that he is not sure what to do next. The HCA comes over, takes the tablet, puts it in her [the patient's] mouth and scrapes the last of the ice cream on to the spoon for her to eat.*

*Site D, day 11*

This emphasises the challenges for staff as they try to negotiate with people living with dementia. For staff, delivering each patient's medication was viewed as what should be a short interaction, a fast-paced task within their overall routine and the ward's timetable. Although the medication round could often start in a relaxed way, as it progressed it often appeared to take longer than the timetable allowed, which led to nursing staff often becoming anxious and feeling that they were taking too long and that they needed to speed up the process at the bedside to complete the round. It was typical for nursing staff to appear frustrated at the length of time the medication round was taking. Even within this round, when there were few distractions and the bay was quiet and calm, this nurse sighs and indicates that it is taking her too long:

*Overall it is very quiet in the bay, just the low hum of the bed pumps and the nurse is with the first person in the bay to complete the medication round. It takes time for this first patient, who is a person living with Lewy Bodies dementia and has been admitted with a fractured ankle. She hands him all his tablets and he picks up the pill cup and shakily tips them into his mouth and then takes some water and drinks about an inch of water. There is also another soluble medication in a cup and he takes it a bit at a time. The nurse puts the packet of medicine back in the box and says to me and the wider ward: 'The medication round, it's very slow!'.*

*Site B, day 5*

### Triggers for patient anxiety

During the medication round, nurses were very task focused, working on dispensing medication at the bedside. However, this focus on completing a task meant that other features of the interaction or the impact of the round on the patient at the bedside became invisible. In the following example, the patient seems agitated (he is 94 years old, has been admitted with a fractured hip and pneumonia, and has been agitated for some time and pulled out his i.v. port previously) and, although she reassures him, once he has taken the tablets, she does not enquire further or check if there is an underlying reason for this agitation. She continues with the medication round and moves on to the next patient:

*The HCA is with him and she talks to him as she works: 'I have some blankets for you, you seem a bit cold this morning'. She also wipes up the floor after the spill from the i.v. unit that he had pulled out and uses antiseptic wipes to clean the i.v. unit. She keeps gently talking to him and he responds: 'I SHOULD BE IN THE CLINK'. He is very fidgety and this increases. The nurse comes over to him: 'You're confused this morning, you are not well at the moment, you've got a chest infection', and she repeats this in a calm and clear voice and moves on to the next bedside.*

*Site A, day 4*

The medication encounter appears to have left this person more distressed and the HCA is left to follow up on his care at the bedside. She reassures him and focuses on orienting him to the reality of his situation.

### Personal care

Ward staff always explicitly sought a person's permission to carry out the personal and intimate care of washing, changing clothes, changing continence pads and changing sheets. However, they also typically started work on the body immediately and continued with the task in question (whether or not the patient assented), highlighting the perceived essential nature of this care should the patient not accept or submit to their request. In this context, the person often had difficulties communicating verbally, was often woken up by the request and appeared to be anxious or afraid of moving, and so any negative response that they had to this type of request was often in the form of a physical (pushing away, pinching, hitting out) or verbal (shouting, screaming, telling staff to stop) act of resistance, while staff continued with their focus on completing care. This was the case across wards and sites, although resistance to personal care was lower

at Site E. For staff, this work was of additional importance to the wider ward in terms of presenting a neat and tidy patient, bedside and bay to meet the timetable, routines and expectations of the ward:

*The bay team are with an 84-year-old man admitted with 'confusion'. They are behind the curtain and they chat to him asking him about his life: 'What was your job when you were young, where did you work? Do you remember?'. In response, he whimpers loudly and they apologise if they are hurting him and tell him what they are doing: 'Sorry it is hurting you, we will dry it now we will put some cream on'. He cries out: 'OW, OW, AAAH', and this turns into a high-pitched scream. The team continues to explain to him what they are doing: 'It's to protect you, some lotion for your feet OK? I will roll you over. OK, we will roll you this side, hold on to the bar, well done, nearly there. We are trying to clean your back, well done!'. In response, he whimpers, and lets out a very high-pitched cry.*

*Site B, day 5*

This was a routine feature of care that occurred 'behind the screen' and so the analysis is based on observations blocked by the privacy curtain or screen, but where verbal cues (the conversations between staff and to the patient) and physical cues could be picked up (by moving curtains, sounds and odour).

### Observation rounds

Observation rounds were interpreted by ward staff as an essential feature of the organisation and timetable of the ward shifts and these observations (blood pressure, temperature, oxygen saturation, heart rate were typically recorded) had to be completed and recorded within a patient's bedside records (typically secured to the end rail of the bed). However, for people who appeared to have tiny arms, or very 'thin', fragile or bruised skin, the observation round, and specifically the blood pressure cuff, seemed to cause a lot of distress. However, any resistance to the cuff on a patient's arm was typically interpreted by staff as a feature of their dementia, rather than a potential physical impact of the cuff, which was rarely taken into account (this was consistent across wards and sites). When faced with resistance, although staff stopped in some cases and moved on to return later, staff typically continued to attempt to take a recording, and, as with the medication round (although less common), the observation round typically stalled at the bedside of a patient who resisted the blood pressure monitor:

*The HCA is carrying out the observation round and starts at the bedside of a 96-year-old woman with a fractured hip and a diagnosis of dementia. She tries to put the BP [blood pressure] cuff on her arm: 'Just relax it's nearly done'. However, she is getting increasingly agitated, pulls at the cuff, is making moaning sounds and is clearly distressed and in pain from the cuff on her tiny arm. The HCA tries to reassure her: 'I know, I know, it's nearly done', and she holds her hand in an attempt to calm her. But she is getting even more distressed: 'You need to relax, otherwise it won't read, I know it's not nice, I know, just hold my hand, just relax'. As this is happening, a mealtime volunteer arrives with her lunch (a plate of pureed food) and sits down on the chair next to her and tries to distract her with the food, 'You've got your lunch here', as the HCA continues trying to attach the mobile monitor to her arm and to get a reading. This continues for some time and the HCA stays with her and tries to get a reading and gives her further instructions: 'Keep your arm still, nearly done, it's alright, just keep your arm still nearly done, it's alright, just keep your arm still for a minute, keep your arm still' and eventually the HCA decides that this is not going to work and she [the patient] is getting more and more distressed and is now whimpering. Throughout this, the HCA has been holding her hand and she takes the cuff off her arm. She continues to whimper, is very distressed and immediately covers up the arm where the cuff had been with a sheet to protect it and is looking around her and looks very anxious and afraid.*

*Site E, day 2*

This cycle continued with this patient during every observation round that followed and had a detrimental impact on this person, who became increasingly fearful of ward staff. It also had a wider impact on other patients in the bay who could hear the patient's cries and also became distressed. However, for ward staff, this was viewed as essential work to be completed and recorded.

## Removal of equipment

### Treatments and tubes

It was common for people living with dementia to try to remove physical interventions and treatments that were attached to their bodies. This included pulling or removing i.v. ports and lines, gastric tubes, dressings, catheter tubes, nebulisers, cannulas, oxygen masks and other medical equipment. These interventions were seen by ward staff as critical to care, and resistance was typically responded to by repeatedly tightening or securing the equipment in place or out of reach:

*All is quiet in the bay and this 83-year-old man admitted with pneumonia hasn't moved for ages. His eyes are open and he is intermittently pulling at the i.v. port in his arm and around the bandaged area. It looks like a whole roll of bandages have been wound round his entire arm to secure this in place and he is starting to cry out. He keeps tugging at the i.v. port and brings his hand and arm close to his face as he tugs and fiddles with the bandages holding it in place trying to get it off. The nurse comes into the bay with the mobile medicines station, walks past him and goes over to the man at the end of the bay who is lying in bed and reading the paper. As she is doing this, this man now has the i.v. tube in his hands and is now pulling at the tubing from the mobile drip stand and is feeling along the length and coiling it up in his hands. He continues to pull at the tubing.*

Site B, day 4

This behaviour was typically interpreted by staff as a feature of a dementia diagnosis and as indicating that the person lacked capacity. As in the cases outlined here, the key response was replacement and securing and tightening the equipment in place. We observed few (if any) attempts to consider if there was an underlying reason for such actions, such as the person not recognising what is attached to them or why it is attached to them, or the equipment being uncomfortable or causing pain or distress:

*This woman, who is 87 years old, has vascular dementia and has been admitted following a fall and has a minor head injury (stitches on face) and fractured right wrist is sitting (perched on a large pillow) in the chair at the side of her bed, wearing a pink hospital gown, grey pressure socks and black leather shoes. She calls me over and tells me she is very unhappy: 'I am not happy, I don't want to be here, my arm is hurting me'. She rubs her tiny thin arm, the i.v. port in her arm is secured in place with a huge amount of white bandage wound tightly around it, presumably to keep it in place, it covers almost all of her lower arm. She rubs her arm and I can see the very delicate and thin skin on her upper arm is covered in dark purple bruises. The trolley is in front of her with her lunch, scampi, peas and chips, which is untouched.*

Site E, day 4

This type of resistance often interfered with or interrupted the processes identified by staff as being crucial to patient care and could delay discharge or transfer to a more appropriate setting, which could be particularly frustrating for staff. The following example relates to a man living with dementia admitted to a MAU who needed a blood transfusion before he could be discharged back to the care home where he was living. He repeatedly removed the cannula in his arm and allowed the team to repeatedly reconnect it and restart the blood transfusion he needs. He becomes increasingly frustrated with being kept on the ward:

*I have a conversation with the SHO [senior house officer] as regards this patient, who has again removed his cannula so he can go and put his uneaten sandwich in the bin. She tells me that you just have to keep retrying and hope he stays distracted long enough to manage it. She says she will not restrain him as she believes this is morally unacceptable, she also will not classify him as refusing the cannula as he always allows them to (re)connect it and consents to his treatment, he just later forgets what it is and pulls it out, she says they are: 'Running out of places to put it. What do you do if a patient needs blood but won't keep the cannula in? Keep trying till I get pissed off and pass it on to some other poor sod to try!'.*

Site C, day 9

### Removal of sheets and clothing

Although the removal of bed sheets by a patient may appear to be a relatively non-problematic form of resistance in the context of the delivery of care, it could have a wider impact on how a patient was viewed by staff. The removal of bed sheets often resulted in the patient exposing their genitalia or continence pad to staff or to the wider bay (across all sites). Unlike shouting or crying, the removal of bed sheets and subsequent exposure would always be immediately corrected, the sheet replaced and the patient covered by either the nurse or HCA present on the ward. The act of removal was typically interpreted by staff as a feature of dementia and staff responses were framed as an issue of patient dignity, or the dignity and embarrassment of other patients and visitors to the ward. However, the response to removal was always the replacement of the sheet and this could trigger further cycles of removal and replacement, leading to the escalation of other behaviours associated with resistance.

A 90-year-old woman admitted to Site C presents one such example. She had been admitted to the MAU despite having no immediate medical need apart from her dementia diagnosis. She was admitted from a care home, where she has been placed as a result of her husband having had a stroke and no longer being able to care for her. Her behaviour over the previous evening and morning has involved shouting and refusing all food and care and has required assistance from the specialist Dementia Care Worker. However, she has been calm since a visit from her husband earlier in the day and has eaten. The care home will not readmit her, so she is now stuck on the unit (in this case an overflow unit as a result of the high number of admissions to the emergency department during a patch of exceptionally hot weather) until an alternative appropriate destination can be found for her. During observations, she remains calm for the first 2 hours. When she does talk she is very loud and high pitched, but this is normal for her and not a sign of distress. The attention of the staff on the bay is elsewhere, because, of the other six patients on the unit, one is on suicide watch and another is refusing their medication (but does not have a diagnosis of dementia). At 15.10, the patient begins to remove her sheets:

*15:10: This patient has begun to loudly drum her fingers on the tray table and still has not been brought more milk as requested from the HCA an hour earlier. The unit seems chaotic today. As it is a temporary overflow unit staff do not know where things are, noticeably there are no cupboards or units. She has moved her sheets off her legs, bare knees peeking out over the top of piled sheets.*

*15:15: The nurse in charge says hello when she walks past her bed, and she looks and smiles back at her. She explains to her that she needs to shuffle up the bed and she asks about her husband, and reminds her that her husband was there this morning and that he is coming back tomorrow. However, she [the patient] does not believe the nurse who tries to reassure her that he has been, and she sounds upset.*

*15:20: She now asks every passing nurse or HCA if she can go, and it sounds as if she is pleading because her voice is so high.*

*15:25: I overhear the nurse question, under her breath to herself, why this patient has been left on the unit and she has started asking for somebody to come and see her. The nurse tells her that she needs to do some jobs first and then will come and talk to her. The lady in the next bed reassures her, tells the nurse she will talk to her instead. The patient goes quiet.*

*15:30: She has once again kicked her sheets off her legs. A social worker comes on to the unit looking for a different patient and the patient calls her over. The social worker replies, 'Sorry I'm not staff, I don't work here', and leaves the bay.*

*15:40: She keeps kicking sheets off her bed, and she now whimpers whenever anyone passes her bed, which is whenever anyone comes through the unit's door. She stops whenever the neighbouring patient reassures her. She is the only elderly patient on the unit and again the nurse is heard sympathising that this is not the right place for her to be left . . . this continues and eventually the patient starts sobbing, getting more and more upset as she talks, the ward staff keep talking about her husband and home, which is where she wants to be and the one place that she cannot go.*

*Site C MAU, day 13*

Of note is that the unit was uncomfortably hot and stuffy, and a need to be uncovered and cooled down could be viewed as reasonable, and, in fact, was considered acceptable for other patients (without a classification of dementia) provided that they were otherwise clothed. This is an example of an aspect of care where the choice and autonomy granted to patients assessed as having capacity is not available to people who are considered to lack capacity (i.e. classified as having dementia) and carries the additional moral judgements of the appropriateness of behaviour and bodily exposure. In the example given above, the actions were linked to the patient's resistance to their admission to the hospital, driven by her desire to return home and to be with her husband. Throughout observations over this period, patients perceived by staff as rational agents were allowed to strip down bedding for comfort, whereas this was often interpreted as a deviant behaviour for people living with dementia and would be challenged and corrected by staff.

### **Language and performance: communicating the 'rules' of the ward in response to resistance**

The ways in which ward staff talked to patients living with dementia in terms of the provision of care at the bedside and in response to perceived resistance were highly repetitive. Staff typically addressed the person by locating them very clearly in relation to the reality of where they were, what had happened to them and what was going on around them. This talk focused on reorienting and locating the person to the rules of the ward and the accepted behaviour within it, and on overcoming perceived resistance to care or managing and containing the person within the context of the routines of the ward. However, people living with dementia did not learn the rules and fit into the timetables of the ward. Importantly, this talk was rhetorical and did not require or expect the patient to respond or assent. The content of this talk did not necessarily reflect what staff actually did, with care and work on the body continuing during these encounters.

The most common approach staff used in response to resistance was to locate the person living with dementia within the institution, 'you are in hospital', and within the reality of what had happened to them, 'you have broken your hip'. Staff also gave very clear instructions to be followed and obeyed, often emphasising the potential imminent danger caused by a patient's actions; these instructions typically contained a powerful sense of urgency that often displayed staffs' own underlying anxiety and fears. Staff also negotiated and bargained with patients, offering to leave them alone and stop disturbing them if they co-operated with the request. Appeals to the necessity and expectations of the institution were commonly made, and these appeals emphasised that there was no choice for either the person or the ward team caring for them, 'we have to change you'. This repetitive talk was directed at reminding the person living with dementia of their place in the world and of the status of ward staff; they must all fit in with the expectations and timetables of the institution.

These exchanges provide ways of uncovering aspects of the loss of identity and social standing of people living with dementia. It is important to note how much of this talk is directed at trying to remind the patient of their place in the hierarchy of the ward and of the rules to be followed. Although staff often gave the appearance of seeking permission and negotiating with the person, the delivery of care typically continued as staff carried out this 'talk', with a tacit assumption of assent, focused on obtaining the correct response from the person to allow care, which was already being carried out, to continue.

#### **Use of multiple interactional approaches**

Importantly, this talk was repetitive and cyclical. Although orienting people to the reality of where they were, 'you are in hospital', and what had happened to them, 'you have broken your hip', were the most common ways in which staff responded to resistance, they typically employed a cascade of techniques as each in turn failed to obtain the appropriate or required response, namely the patient's acceptance of their request and then allowing the delivery of care to continue.

In the following fieldnote, the team use a number of different techniques with this 95-year-old man with a diagnosis of dementia who has been admitted with a fractured hip: they start by asking this person if he wants to get out of bed, they emphasise the necessity of this and then appeal to the requirements of others (the physiotherapy team and his family). Throughout this encounter the team discuss together what they are doing and emphasise the patient's autonomy and his ability to decide, 'I won't force him'. However, as they talk they start to work on the patient's body. When they complete this task and he is sitting in his chair, they praise him and reward him with a chocolate:

*He is lying in bed and the bed is very low to the ground, the nursing team go over to him and ask him if he wants to get out of bed.*

*Patient: No leave me here.*

*The team remind him that his daughter will be here soon: 'You were going to walk with the physio [therapist] for her, you need to be up in the chair when your daughter arrives, your family will be with you soon and they will like to see you up in the chair, are you sure? I am not going to force you but it would be good to have you sitting up. Let's make a deal, we will give you this morning to rest and get you up later in the afternoon. We just need to check your pad.'*

*Patient: I am not well . . .*

*HCA: We still need to check the pad for you, we must get you up this afternoon.*

*They discuss together that they won't force him: it's not fair, he can still tell you what he wants, it's not fair. They draw the curtains back and sort out the bedside around him and tidy up the trolley, and give him some chocolate and pass him some water with a straw and he drinks it. The physiotherapist comes over to chat to the team and they discuss him, they have arranged to work with him and get him standing when his daughter arrives at 1pm: 'Your daughter is coming at 1 o'clock so we can do some walking, will you let the nurses help you up'. He is clearly not keen and they remind him: 'you broke your leg a few weeks ago. I will see you at 1pm'. She [the physiotherapist] kneels at the side of the bed and leans over the bed to him. She has a very kind tone. Later they go back over to him and wake him up: 'Sorry my darling, we are going to get you up in your chair for your lunch. As we discussed my darling, your daughter will be here.' She bends low chatting to him in a very friendly and chatty tone and they draw the curtains: 'We are going to get you up.'*

*Patient: Can I stay here? He sounds frail and very pitiful: 'Can't I stay here, don't make me get out of bed, my back aches.'*

*Team: We spoke about this, you need to get in the chair, you are doing some exercises, your back probably aches from lying in bed.*

*Patient: I'm going to die.*

*Team: You're not going to die, can you roll that way or lift your bum please, you liked to be in your chair yesterday, can you roll on your side?*

*Patient: It hurts.*

*Team: Well done, we know, we are being as quick as we can.*

*Patient: Sorry I am like this.*

*Team: It's not your fault, well done! There we are, well done, just relax, pop your hands on your chest for me.*

*They are using the hoist suspended from the ceiling – I can hear it buzz. 'Put your hands on your chest and we will do the rest my darling, that's it well done, there we go, see not too bad. I know, we will be as quick as we can, we will get you in the chair as soon as we can.'*

*They position him in the chair: 'There we are, don't you feel better sitting in the chair? For all that hard work would you like a chocolate? I thought that would make you feel better'. She gives him a chocolate from the bowl on his trolley.*

*Site C, day 6*

It is important to consider the intensity of this work, given that all the work of the wards and routines, which are not bundled together but are separated out into individual timetabled tasks, are provided by different members of staff. This meant that such exchanges were a recurrent feature of the timetables of the ward and repeated again and again at each bedside throughout a shift.

### ***Orienting the patient to the reality of their situation***

A key approach staff used to communicate with people living with dementia when faced with resistance was typically locating them very clearly in relation to the reality of where they were, what had happened to them and what was going on around them. This was the most commonly used approach, consistent across institution, and was the most frequently and universally utilised approach when faced with resistance. Within only two MAUs (Sites D and E) did staff consistently not use this approach with patients.

Typically, these rationalising statements placed an emphasis on the reality of where the person was, 'you are in hospital', the fact that they cannot go home and the details of their condition, 'you have broken your hip' or 'you have an infection', and directly contradicted patients' statements or their perceived reality, for example 'there are no policemen'. During these encounters, ward staff appeared to be actively trying to support and orient the patient to the reality of where they were and what was happening to them. However, this approach always appeared to increase the person's anxieties and concerns and triggered further resistance. In this example, the team either acknowledged only briefly or did not respond to the anxieties (wanting to go home, the cost of hospitalisation and where her family is) expressed by an 87-year-old woman with vascular dementia who had been admitted following a fall, and who had a minor head injury (stitches on face) and fractured right wrist. Instead, they focused on repeatedly reminding her of where she was, 'you are in hospital':

*HCA: Do you want to go to bed?*

*Patient: NO, I want to go home.*

*HCA: You are in hospital, you are in hospital.*

*Patient: I can't afford it.*

*HCA: It's free.*

*She rubs her arm with the bandaged i.v. port and runs her hand along the long tubing leading to the mobile stand and the HCA states that this is 'for your medicine'.*

*Patient: I don't like being here I don't know it.*

*HCA: I know, you are in hospital.*

*She puts the orange juice pot from lunch into her sip cup and puts it in front of her.*

*Patient: Where is my son?*

*HCA: He will be here soon.*

*The physio[therapy] team arrive and the young female physio[therapist] stands next to her while the other gets a walking frame from the bed opposite and brings it across.*

*Patient: I am NOT staying here.*

*The physiotherapist crouches down beside her and looks up at her: 'At the moment you are in hospital, you are in hospital. You have hurt your hip.'*

*She is sitting slightly propped up and lying on one side and she is hanging on to the side rails and she is looking very agitated again.*

*Patient: Where is my son?*

*Physiotherapist: I am sure he is coming later, would you like your cardigan?*

*She is just sitting in her hospital pink gown and now they have mentioned it, she does look a little cold. They get it from the cabinet and help her to put it on and she instantly looks more comfortable. They ask her: What country are we in?*

*Patient: I don't know, I can't afford to pay for it anyway.*

*The physio[therapy] team decide to give up and to leave her and they move on.*

*Site E, day 4*

This approach also extended to family, who also typically repeatedly reminded the person of the reality of their situation.

### **Clear instructions to be obeyed**

Ward staff typically gave people very clear instructions to be obeyed, often emphasising the potential risks and imminent danger of their actions if the person living with dementia did not comply. These instructions typically contained a powerful sense of urgency that often displayed their own underlying anxieties and fears. These exchanges provide ways of seeing the loss of identity and social standing of people with dementia within the ward. Staff often raised their voices as they gave very clear and often very pared down and simplified instructions to the patient. In the following example, a HCA is providing one-to-one care to a 74-year-old man who has a diagnosis of dementia and has been admitted with a chronic subdural haematoma:

*The HCA is talking in a very loud voice to him: 'EAT YOUR BREAKFAST SITTING DOWN, NOT STANDING . . . EAT YOUR BREAKFAST SITTING DOWN, NOT STANDING.'*

*He stands over the patient as he is sitting on the bed. He is in pyjamas with a beige jumper over the top and the pyjama bottoms are far too long and are puddling around his feet on the floor. He is staring unfocused in front of him with a very blank expression on his face and although the HCA is shouting at him, he does not appear to respond to what is going on around him or to the team. The mobile trolley is in front of him with his breakfast and he has buttered his own toast, he eats a bit of this and also quite a bit of his Rice Krispies [Kellogg's, Battle Creek, MI, USA]. The HCA sits in a chair at the door and occasionally as the patient starts to stand as he eats his toast, the HCA goes over to him and tells him: 'EAT YOUR BREAKFAST SITTING DOWN, NOT STANDING.'*

*After breakfast they walk together down the corridor to the day room and back again. When they get back to the single room, the HCA says: 'SIT IN THE CHAIR, SIT DOWN'.*

*He does not respond and stands still in the middle of the room and the HCA repeatedly tells him: 'YOU ARE IN HOSPITAL . . . YOU ARE IN HOSPITAL . . . YOU ARE IN HOSPITAL . . . THERE IS NO GIN AND TONIC, SORRY MATE.'*

*Site B, day 3*

This demonstrates how repetitive behaviour is viewed as particularly problematic and becomes the focus of care. In the example above, repeated attempts to stand become an urgent focus of control. Such rationalisations also typically included repeated warnings of danger and the likely consequences of patients' behaviour if they continued their actions and did not modify their behaviour. A common fear among ward staff of people living with dementia was the high risk of falling.

### **Appeals to the expectations of the institution**

Appeals to the expectations of the institution were commonly used to persuade people living with dementia to accept care, and these typically emphasised that there was no choice for either the staff members or the patients, for example, 'we have to change you'. It is important to note how much of this talk took place as staff were already delivering care and working on a patient's body. Such talk was directed at trying to remind the patient of their own status and the status of ward staff caring for them; they must all fit in with the expectations and rules of the institution.

In the following case, the HCA initially asks the nurse in the bay to help her to change some wet, soiled sheets. She emphasises, 'we need to move you' and 'we can't leave you' while the patient (a 94-year-old man admitted with a fractured hip and pneumonia) remains lying in bed and is shouting '999', which may indicate that he sees this as an assault or attack. The shouting alerts the wider team and another HCA joins them behind the curtain to provide additional help:

*The nurse and HCA are back at his bedside: 'Sorry'.*

*They use the shortened version of his name and keep forgetting his first name.*

**Patient:** *GET OUT GET OUT.*

*The nurse talks to the HCA, 'He's soaking, we are going to have to change his sheets', and then to the patient, 'You are wet'. The nurse asks for more help from staff in the ward to help them to roll him and then goes back to the patient: 'We need to move you, it's not good to lie in a wet bed' and in response he shouts: '999 YOU CAN LEAVE ME ANYWHERE YOU LIKE'.*

**Nurse:** *Come on now we can't leave you in here, we are just going to change the sheet, you need a new sheet.*

*He is clearly struggling with them behind the curtain and is clearly not happy and his cries and groans can be heard from outside of [sic] the curtain as they change the sheets. They draw back the curtains and the patient looks very small in the bed with his head resting on large white pillows. He is now wearing a blue hospital gown and the sheet and a thin blue blanket are tightly tucked in around him with the side bars of the bed raised. He doesn't move.*

*Site A, day 4*

Despite the patient's verbal and physical resistance to the immediate task in question, once this has been completed the patient is almost instantly settled. This can also be a feature of resistance to care; resistance can sometimes appear to be limited to the immediate and specific task in question:

*Here, the ward team approach the person emphasising that they need to 'clean' her and need her to keep covered to fulfil the requirements and rules of the ward. As they deliver this personal care behind the screen the team emphasise that they 'have to' clean her. The patient, who is a 96-year-old woman living with dementia who has been admitted with a fractured hip cries out, 'they are hurting me', asking for help, 'OH PLEASE HELP ME'.*

*The bay team have pulled the screens around her bedside and sound as though they are changing her clothes and the bed sheets. As they do this she cries out, 'OW, it hurts'. The team reassure her as they work: 'We have to clean you, you are alright you are not falling, we need to clean you', as she continues to cry out: 'Please, please, help I am getting hurt, it's hurting, HELP ME, OH PLEASE HELP ME, HELP ME, HELP ME oooowOW' and this ends with a piercing scream. The team reassure her, 'You are not falling', and have drawn the curtains back and take large piles of linen away in a bag. The patient is a tiny figure in the large bed, covered in fresh sheets and a blanket. Immediately she pulls off the blanket and sheet from her legs – she exposes her tiny legs that are both covered in thick bandages up to the knees. The tea trolley arrives and the young man with it says: 'Cup of tea darling?'. In response she pleads for help: 'Please, please, help me'.*

Site E, day 8

Care that was seen by the ward staff as essential typically continued despite a patient's resistance, which could be expressed either physically (pushing staff away) or verbally (crying out). Rather than walking away and leaving the patient, resistance to everyday routine care often resulted in staff continuing with the task while also emphasising the necessity and expectations of the institution by repeatedly emphasising to the patient that they must accept care. Typically, other team members within the ward would be called on to help and provide support, or they reacted to the disturbance and noise by leaving their work (there is rarely a moment when a member of staff is inactive and obviously between work, or not actively working at the bedside or completing paperwork) to support and help complete the delivery of care.

### **Negotiation and bargaining**

Staff also negotiated and bargained with patients. This was an approach often used when all previous techniques and approaches had been repeated and had failed and when staff appeared to be becoming tired. The nurse leading the medication round often negotiated with patients that, if they co-operated with the request, they would be left alone and staff would stop disturbing them. In the following example, as a nurse dispenses medication, he reminds the patient, who is a 98-year-old woman with a diagnosis of Alzheimer's disease who has been admitted following a fall, of where she is, emphasising the institutional requirements and negotiating with her to complete her care:

*The nurse is at the bedside for the medication round and asks her: 'What is your birthday? When is your birthday? Do you remember your birthday?'*

*She wakes up and listens and points to the wall. 'Do you want your paracetamol? So just a couple of tablets? One at a time?'*

*He stands at the side of the bed, passes her the tablets one at a time followed by a glass of water. She tells him she wants to go home.*

*Nurse: Yes how far is home? You are in hospital now, this is one the doctors asked me to give you.*

*He puts a tablet in her mouth and holds a cup of water while she sips on a straw, but she takes it out. He repeats: 'You need to take that one darling you've got to take it my darling, pop it into your mouth, I will wipe your hands for you, take a drink and try to wash it down for me. I tell you what, once you have taken these tablets you can shut your eyes and I can leave you alone for a while'.*

*Site C, day 2*

### **Family members' and carers' responses to resistance**

Family members typically struggled with resistance and found this both embarrassing and stigmatising within the ward. This was particularly the case if a person's diagnosis of dementia was recent (a diagnosis was often received during an admission) or if their condition had deteriorated or changed significantly during admission. In response, families also typically attempted to rationalise with the person, contain them at the bedside or limit their behaviour in some way. They were also very likely to apologise to staff. The patient in the following example has a diagnosis of dementia and has been aggressively refusing medication and personal care all day. It has taken up to five members of nursing staff to change her clothes and bed sheets, and they continued as she carried on shouting, swearing, spitting, biting and scratching. Of note is how upsetting this behaviour is to her adult daughter and son-in-law, but also how embarrassed they are by it:

*15:45: Two visitors are with her. Daughter and son-in-law. I speak to them and take verbal consent to observe them and the RN [research nurse] comes over and explains her history since admission. Concerns have been raised about her taking medication. Because of her aggression they have resorted to crushing up her medication and feeding them to her in her porridge. The visitors are shocked to hear that she has been biting the staff but say that shouting is not out of the ordinary. They say her standard voice is the loud one, but she still often demonstrates a sense of humour, and puts on a bad northern accent. They are not surprised she is refusing medication and are impressed staff have had any success. They warn the nurse that she can be very strong. A doctor then comes over, the RN leaves, and the doctor begins to discuss her condition with them. They stand at the foot of her bed, discussing her while she sleeps. While the nurse discussed social and behavioural aspects of care the doctor is much more clinical. Later I speak to her daughter. She has been crying and is embarrassed to hear about the biting but says at the same time it is a relief because yesterday she was barely moving – at least the agitation shows that she is awake.*

*Site D, day 9*

Such responses were not uncommon, and across all five sites families of patients who were shouting, 'wandering' or refusing food instructed their relatives to fit in with the routines of the ward and 'behave themselves'. Their response in part is similar to that of the parents of a naughty child, in that although what would be construed as bad behaviour is understandable to them, it is also embarrassing (courtesy stigma). This is associated with the wider moral assessment often underlying staff approaches to resistance.

### **The moral classifications of resistance**

We found that people living with dementia who resisted care, particularly when this was regularly disruptive to the ward routines and timetables, were vulnerable to moral assessment. Their resistance was often interpreted by staff as another feature of who the person was and this could become a key part of their identity in the context of the ward. In addition, some patients were also identified by the ward team as more likely to resist care based on their assessment of the patient's personality and background.

### **Judgements of individuals: resistance as identity**

Although resistance was seen by ward staff as a feature of dementia, staff also judged longer-term, chronic and disruptive resistance as another feature of who the person was, and this could become their identity in the context of the ward. In a small number of cases this could take the form of affection from staff [‘she’s all right, she just likes a bit of a strop’ (Site B, day 15) and ‘she does make me laugh though’ (Site D, day 8)], but more often it was viewed negatively [‘he is a puncher’ (Site C, day 2), ‘she is a hitter’ (Site E, day 5), they are ‘a climber’ (Site A, day 18)]. Such people were typically approached with caution, but there was always an underlying expectation from staff that a patient resisting care could respond physically. Some, usually (although not always) male, patients would be approached by staff in pairs, or a male member of staff would be asked to approach them, regardless of their mood or behaviour at the time.

Some people were also identified by the team as more likely to resist care based on their assessment of their personality and background. In the following fieldnote, the team discuss a 94-year-old man with a diagnosis of dementia admitted with a hip fracture and pneumonia who had resisted care the previous night, and they rationalise that this person’s character and heritage means that he is likely to resist further care. In response, they decide to approach him with caution. Two members of staff approach his bedside and focus on asking his permission, standing at either side, holding his hands as they gently talk to him, checking whether he prefers that they use the full or shortened version of his first name and checking his ‘this is me’ document. (This is a form to support ‘person-centred care’ and includes space for families to provide details about the person’s cultural and family background, key events, people and places from their lives, preferences, routines and personality.) He resists their request by shouting ‘NO’:

*All is quiet in the bay. The nurse talks to him: ‘Are you cold? You sound chesty?’. The bay team and the anaesthetist discuss him: ‘When he came to us from A&E, he was fine yesterday. Chesty, it started overnight. He was fine yesterday, I don’t think we should do him, he’s strong willed, Irish people.’*

*The HCA and the nurse are on either side of him and hold a hand each: ‘Can I take your temperature?’.*

*Patient: NO, MIXED UP.*

*He pulls his i.v. out of his arm and they try to take his temperature. They ask him his name and whether he prefers his full name or a shortened version and they refer to his ‘this is me’ document.*

*Site A, day 4*

### **Resistance as deliberate and wilful**

Resistance could also be interpreted by staff as an act of wilfulness by patients to express their responses to their hospitalisation. This in turn overshadows the person and any opportunities to identify any potential underlying need. In the following example, a 94-year-old man admitted with a urinary tract infection who has ‘acute confusion’ is in a single room and regularly cried out for help and had fallen a number of times during his admission. The repetitive nature of this behaviour meant that he was characterised by ward staff as deliberately acting in this way to disrupt the ward and their work. The ward sister rushes to the room and expresses her frustration and shouts ‘WHAT ARE YOU DOING?’ at him:

*The ward sister tells us he is in pain, but he knows what he is doing, he says ‘I will shout as much as I want!’. I asked the doctor for some diazepam to calm him down. Later there is a crash and cry near the entrance to the ward. The ward sister immediately pops her head out of one of the bays and asks me – is that in this ward? She runs into his room: ‘WHAT ARE YOU DOING?’. She shouts for everyone and they all go running down the corridor and all are with him.*

*Site A, day 10*

In some cases, although resistance could be interpreted by staff as a deliberate choice, they also attached wider emotional meaning to this. During the shift handover, the team discuss a patient who is resisting all care, 'he is declining everything'. They suggest that although he is 'confused', the underlying reason for this behaviour is that he has 'given up' and does not want to live:

*I am immediately struck that they are doing a handover at the bedside and the details of patients on the handover sheet [are] incredibly detailed for each patient. I follow the team and they head to the bay at the far end of the ward, there are five nurses including the handover person, although I am a bit overwhelmed because so much is going on. One of the team is pushing the mobile computer station and is updating the notes as we go through them. The team help me to find the right page – we are working back from the end to the beginning of the handover sheet and we go from bed to bed. We stop at the bedside of an 83-year-old man who has a diagnosis of Alzheimer's, admitted following a fall and 'general decline'. The team discuss him: 'He was very confused overnight, declined everything, I think he has given up, very confused, he was fighting with us.'*

*Site B, day 1*

This is associated with staff beliefs about the potential future and quality of life for people who have dementia.

## The emotional and somatic impacts of the organisation and timetables of the ward

Our observations identified that resistance appeared to be a response and reaction to the impact of an admission on individuals. These responses were both emotional and somatic and included difficulties in communicating needs and high levels of anxiety as a result of the unfamiliar environment of the ward, which could lead to disorientation. A key impact of this was the person being viewed within the ward as having increased dependency, which in turn resulted in them losing skills and independence.

Resistance was typically triggered by unfamiliarity with the ward, or the fixed routines, timetables and organisation and delivery of care within an acute ward itself. Loud noises, bright lights and unfamiliar people were distressing for many of the people living with dementia. Because care in these settings is delivered by shift and rota, there was little continuity of care, exacerbating the unfamiliarity of the environment and the wider distress of other patients within it.

As such, resistance can be framed as a rational response to the organisation and delivery of care, with routinised, timetabled and compartmentalised care producing fear and anxiety within a patient but never being acknowledged in the assignment of staff at each shift handover. Our analysis was drawn from observations that allowed the researchers to spend extended time within and across shifts, monitoring specific ward bays and the individual staff and patients within them. This almost always revealed the potential underlying reasons or triggers for patients' resistance to aspects of care or their admission. These were typically rational to that patient's present ontology and perceptions.

### Difficulties communicating care needs

Trying to stand, standing, walking, displaying agitation or being unsettled in bed or at the bedside was typically interpreted by ward staff and responded to as resistance to care. The most typical initial response from ward staff was to return people to the bedside, to encourage them to remain in the bed or the chair and then to repeatedly try to contain them at the bedside. There were common patterns across all sites of an agitated patient standing and being repeatedly returned to the bed or chair before staff recognised an underlying care need or the patient was eventually able to communicate verbally that they needed care, such as continence care or wanting to go to the bathroom.

Trying to stand, standing, walking, displaying agitation or being unsettled appeared to be common forms of communication and indicated that a person had an underlying care need. For patients living with dementia, who often had difficulty articulating and communicating their needs verbally to someone, there were often extended periods of staff returning people to their beds or chairs before ward staff recognised that there was an underlying care need. However, this recognition did not always occur. This was often associated with people trying to go to the bathroom or requiring help with continence care. In the following example, the immediate staff response was to return a 93-year-old man, who has a diagnosis of dementia and has been admitted following a large number of falls, to his chair, and it took time and repetition for his underlying care need to be recognised:

*The HCA remakes the sheets of the neighbouring bed and while she does this he starts to stand up, holding on to the sides of his chair. She sits him down. The HCA is focused on his neighbour and asking him what he had for breakfast and he asks for more tinned fruit, there is a tin open on his trolley. As she does this, the 93-year-old man stands up and the HCA goes and gets him to sit down and he says he wants the bathroom.*

Site A, day 6

However, even if a person living with dementia did display the signs and cues in their body that something was wrong and that they were seeking attention and help, this could be a low priority for ward staff. In the next example, a 96-year-old woman with a diagnosis of dementia admitted with a fractured hip became increasingly anxious and distressed, which can be seen by her fiddling with and pulling at the band of her skirt, talking in an increasingly animated way and trying to get attention from passing ward staff. However, even though this seems to be causing her great anxiety, it appeared to be a low priority for the ward team, particularly as there was no immediate risk to the person (she was safely contained in the bedside chair) or perceived urgency as the woman was wearing a full continence pad:

*She now looks very distressed, she is talking to herself and looking around the room wide eyed and fiddling with her skirt. Everyone is busy, the nurse is focusing on the drug round and no one else is here, so I go over to see her and she reaches out and holds my hand. Her speech is very hard to understand, but she tells me that her leg hurts and she touches her knee. I tell the nurse in the bay and she says they will put her back to bed soon and check on her. I go back to the bedside and let her know and she keeps me at her side and says clearly: 'Can you take me to the toilet? Can you take me? Can you take me?'. I say I will tell the nurse and I do that again, and she responds that she will check her pad when they put her to bed soon. Some time passes and she is now fiddling with her skirt even more, no one has come after I alerted the nurse so I go over to the male HCA and tell him and he responds: 'I will get the hoist to put her back into bed and I will check her pad then but she fights!' He smiles. Later the bay team use the hoist to put her back into the bed and she becomes very upset.*

Site E, day 4

This woman had been described by ward staff as difficult to care for and as someone who 'fights' staff providing care. This exacerbates the delay she experienced because they decide to bundle her care (personal care and toileting) together. However, by the time the team were ready and have all the equipment (the hoist must be found and brought from the other end of the ward) at the bedside, the patient is extremely distressed and although the team asked her why she is upset, they did not connect this to the delay she has experienced and her underlying anxiety at losing her continence.

### **Unacknowledged anxiety and the impact of an unfamiliar environment and routine**

People living with dementia appeared to have high levels of anxiety throughout their admissions, with high levels of underlying anxiety observed in every person living with dementia within the study at some stage during their admission. This included anxieties about where they were and what was happening to them.

A key anxiety was not knowing when they were going home, whether or not they would be able to leave and go home, and if they still had a home. An 81-year-old woman with a diagnosis of dementia, who had been admitted with a fractured hip but was now medically fit to leave, woke up during the day and in a very anxious and trembling voice asked me and the HCA a large number of questions that displayed the uncertainty she was feeling about what would happen to her:

*She wakes up and the HCA goes over to her and checks on her, she is very gentle and props her up in the bed and gives her a sip cup of juice and she takes a drink. She sees me and calls me over and I take her hand and she looks and sounds quite anxious and asks in a tiny trembling voice: 'How long have I been here? When can I go home? I will get well won't I? Do I have a home to go to? Have I been here long? When can I go home? I will get well won't I? Do I have a home to go to? Have I been here long? When can I go home? Why am I so tired? I will get well won't I? Do I have a home to go to? Have I been here long? When can I go home? I will get well won't I? Do I have a home to go to? Why am I so tired?'. I hold her hand and reassure her and tell her she is safe and I give her the sip cup to drink and she takes a sip and I encourage her to drink a bit more. She has a nasty chesty cough that she didn't have the day before, which worries me. She is lying slightly propped up in bed covered in a blue blanket tucked around her feet. I suggest she closes her eyes and that I will stay here until she falls asleep. She falls asleep straight away.*

Site E, day 13

In addition, a person's anxiety about where they were and what was happening to them could also quickly heighten if the unfamiliarity of their experiences increased in any way. In the next example, the same 81-year-old woman as in the above fieldnote becomes increasingly distressed during a shift. She has no clean clothes left so the ward staff have dressed her in a hospital gown. However, for this person, not wearing her own clothes, particularly her bra and trousers, which were to her essential garments, appeared to contribute to her becoming increasingly anxious and upset. It increases her confusion about what is happening to her and where she is, and makes her feel that she has 'lost' her clothes. It also confirms to her that she is somewhere unfamiliar and emphasises that she cannot leave:

*I arrive at the ward and go over to say hello and she says: 'I still love you.' The one-to-one HCA is with her and tells me that she is very teary and upset today, that she has just had a shower and she doesn't have any fresh clothes and so she is now in a hospital gown.*

*Patient: I want my trousers, where is my bra, I've got no bra on.*

*She is very teary and upset, she is sitting in a pink hospital gown and her lilac cardigan is on over it and it is clear she doesn't feel right without her clothes. The HCA asks her: 'Your bra is dirty do you want to wear that?'*

*Patient: No I want a clean one. Where are my trousers? I want them, I've lost them.*

*The HCA explains that her clothes are dirty and this discussion continues for some time. The ward cleaner arrives to sweep around her and as he does this he says hello to her and she tearfully explains that she has lost her clothes and he listens and is sympathetic. She repeats: 'I am all confused, I have lost my clothes, I am all confused. How am I going to go to the shops with no clothes on! Will I get out of here?' She is very teary and upset. I sit next to her and hold her hand and the therapy dog arrives to see her.*

Site E, day 5

### **Disorientation: place and time**

People living with dementia could quickly become disoriented; sleeping patterns could become altered by the acute condition, their treatment, the ward environment and the fixed routines of the ward. Sleeping during the day (although staff talked about the importance of discouraging daytime sleeping, in practice

leaving people living with dementia to sleep during the day was normal across all sites) and the phenomenon of 'sundowning' were patterns of behaviour that were widely reported and recognised by ward staff, whereby people became increasingly agitated and active at the start of the night shift and did not sleep during the night. In addition, during night shifts, the routine work of ward staff, which involved delivering care to the patient at the bedside, continued. During night shifts, many people living with dementia believed that they were in their beds at home and so ward routines such as personal care, medication and turning people in their beds (to prevent pressure sores), which were typically carried out in the dark to people living with dementia who were asleep or semiconscious, could further disorient them and increase their anxiety and fear. This meant that the night shift could be a very frightening time for people living with dementia and even for people without cognitive impairment, it could be disorienting. For an 85-year-old man admitted to hospital with a fractured hip, who does not have dementia and is blind, the experience of the ward team at the bedside was very frightening and disorienting:

*The team are at the nurses' station discussing what happened during the night shift. They chuckle as they tell me that in the night a male nurse and a male HCA were caring for him and he thought they were attacking him. He said he was going to call the police, but they didn't think anything of it, but he used his mobile phone and called the police and told them that someone was attacking him in his own home. They went round to his house and eventually they called the ward. They laugh and tell me it happens sometimes. Later that day he calls me over to his bedside and tells me: 'I am so upset with myself after all the care they have been giving to me, to sort of throw it back in their face. It was so real to me, it was dark and I really thought I was in my own home and I could just see shadowy figures and I called the police, I am so sorry I am ashamed.' He starts to cry and big tears roll down his face, I give him a tissue and he dabs his eyes and screws it up in his hands. I hold his hand and reassure him and he asks me: 'Can you apologise to the nurses for me?' I pass this on to the nurses and return to his bedside and we discuss his travels around the world; we talk about Rio and his experience of sailing around South America and Cape Horn.*

*Site C, day 8*

Although this was not seen by ward staff as unusual, the additional feature of it leading to the involvement of the police meant that it became an amusing story that circulated quickly around the ward. However, this could have longer-term consequences for the person and their sense of self.

### Ward strategies of care in response to resistance

Overall, the key response to refusal and resistance to care by people living with dementia was one of containment and restraint. Although there was some variation in specific techniques between wards, the overall strategy was always to keep the person living with dementia within their bed or sitting at the bedside. Across all sites, staff expressed high levels of concern and anxiety about people living with dementia attempting to leave or leaving the bed or bedside, and this increased exponentially if they were standing or walking in the bay, the wider ward and corridor or close to the ward entrance. Multiple techniques of containment and restraint by ward teams were observed. Importantly, these approaches to patient care and containment at the bedside were both a response to resistance and also frequently the trigger of resistance or the cause of patient anxiety.

In addition, a key response to ongoing regular patterns of resistance by individuals living with dementia within wards was 'specialing' and the assignment of one-to-one agency HCA staff to care for them. This was used particularly when individuals were disrupting the ward routines and was described as a way to support both people living with dementia and ward staff.

### Cultures of containment and restraint

Multiple techniques of containment and restraint were observed being used by ward teams. This included raising the side rails of the bed or tucking bed sheets in tightly around a patient, both of which were common and covert means to contain a patient within their bed. For those patients sitting at the bedside, the close placement of the mobile tray table, unreachable walking frames and technologies such as chair alarms were used to contain people and keep them sitting in their bedside chair. Clinical technologies, including continence technologies (particularly full continence pads and using bed pans and commodes at the bedside), medication and sedation, and tightly secured medical equipment also limited or restrained movement from the bedside. Importantly, these approaches to patient care and patients' containment at the bedside were both a response to resistance and also frequently the trigger of additional resistance or a cause of patient anxiety.

Walking away from the bedside or walking within the ward was overwhelmingly categorised by nurses and HCAs and medical teams as a deviant action. Although the question 'where are you going?' would frequently be asked of patients, it would be done so only in a rhetorical sense, a cheery admonishment used as the person living with dementia was led back to their bed or bedside. It was rare for it to be considered that the patient with dementia could be purposeful, with their actions instead always categorised by ward staff as 'wandering'.

With the exception of two closed wards (MAUs) in which some movement was permitted to patients classified as being at a low risk of falling, walking in the ward was always viewed by ward staff as a problematic activity. One closed acute ward also carried out these restrictions on their patients living with dementia, which meant that they were not permitted to leave the room or to walk in the corridor. For the person living with dementia, in their temporary role as patient, to be labelled as a 'wanderer' led to the patient being classified as someone requiring supervision, restraint and control. Such categorisations were made without an assessment of or consideration for the patient's mobility or independence of movement prior to their admission. Walking was considered a purposeless activity, with a 'wanderer' seen as drifting on the ward, and walking viewed as an activity with little reward but high risk (falls, leaving the ward, approaching other patients). What was not considered is that for the person living with dementia, the activity had purpose. They may have been walking to the toilet, looking for someone or something, or simply stretching their legs for stimulation. Often, however, they expressed a strong (and arguably rational) desire to leave the ward and to return home. As such, stopping a patient from leaving or 'escaping' the ward was an everyday and common ward activity.

These approaches to containment, through the use of the previously described covert techniques of restraint, coupled with the verbal techniques of orientation and rule repetition, often triggered resistance and unhappiness in patients. This led to patients experiencing high levels of anxiety about what was happening to them and where they were. People living with dementia reported that they '[felt] like a prisoner' (Site C), 'feel terrible' (Site B), 'want to go home' (Site E) and were 'unhappy' (Site E) during their stay. Some patients were observed shouting for the police (Sites A, B and D) and even surreptitiously using the telephone at the nursing station to call their family for help (Site B), because they believed that they had been kidnapped or were being held against their will. More often, however, the distress of feeling imprisoned by a culture of containment was manifested in a patient's body language. Anxiety was shown through defensive poses such as folded arms, pulled up bed sheets, tightly holding on to bed rails or nervously staring at doors and people passing by. In the following example, an 85-year-old man with a diagnosis of Alzheimer's disease who had been admitted with a fractured hip tells the researcher that he feels 'like a prisoner' and is very anxious, as he cannot make sense of the rules of the ward:

*He is wearing hospital green pyjamas and is sitting in the chair at the bedside. When he wakes up and I go over and say hello and he tells me: 'I am very frustrated and angry, it's like being in a prison here, one minute they say keep drinking and then next they won't let you and no one tells you anything in here, this is like being a prisoner!'.*

Site C, day 9

Techniques of containment and restraint had detrimental consequences for people living with dementia during their admission, in terms of both their emotional well-being and their physical rehabilitation. The role of physical rehabilitation was often the point at which the culture of restraint and containment could become visible to the observer. The therapy team, physiotherapists and occupational therapists (with crucial decision-making power around discharge routes) could be observed encouraging patients to get up and move around, only for the ward team to immediately approach patients in order to prevent this and to admonish patients for doing so. One 73-year-old woman living with dementia and admitted following a fall had refused to carry out her rehabilitation session with the physiotherapy team earlier that day and, during this shift, the HCA discusses with her and her husband the importance of rehabilitation and attempting the prescribed exercises in order to be fit for discharge. At the same time as these discussions and throughout this shift, she keeps attempting to get out of the bed by putting her legs over the raised side rails of the bed. However, this does not prompt the HCA to help her out of bed or support her walking. Instead, each time she does this, the HCA lifts her legs back over the rails and within the bed. Even when she becomes increasingly restless and agitated, the HCA instructs her to 'stay in bed' and 'try to sleep' and eventually reminds her of the rules of the ward, 'I don't want you to get out, I'll get the sack if you do that', emphasising her interpretation of her role as one of containment and restraint of the patients within the bay:

*It is very quiet in the ward, there are a few buzzers going and there are a few members of the team at the nursing station – a mix of ward staff and the medical team. This woman is sitting propped up on the bed, but she looks uncomfortable and she groans. The HCA goes over and puts the side rails up on her bed. She tries to get out and has a leg over the side rails, but the HCA comes over and puts her leg back in: 'Don't go, you need to be here, lunch is coming soon and then we will get you in a chair, try to sleep.' She adjusts the height of the bed and puts the blanket over her and she is now propped up and holds the blanket to her with both hands on it. She is very tiny and wearing a pink jumper, black leggings and red hospital socks, which are huge on her, her husband tells me she has size 3 feet. It is a warm autumn day and the sun is streaming into the room. All is quiet; there is the sound of buzzers outside in the corridor and there is a low hum in the room from the bed pumps. She continues to try to put a leg out of the bed and she tells us: 'I am not good at just lying here, but I must!' She closes her eyes and lies back on the pillows. She again tries to get out of bed and has a leg out over the high sides. The HCA spots this, 'No, stay in bed', and she discusses with her husband that she didn't do the stair exercises with the physio[therapist] that morning and they encourage her, if she does the exercises that she will be able to go home quicker: 'You need to do the exercises so that you can get home.' The patient responds: 'I have no intention of getting anywhere near those stairs!'. She puts a leg out of the bed again and the HCA repeats: 'Put your leg back in I don't want you to get out, I'll get the sack if you do that.'*

*Site D, day 11*

Across all sites, staff expressed high levels of anxiety about people leaving the bedside, and this strategy of restriction usually involved repeated efforts, with staff utilising a range of strategies to limit the person to the bed or the bedside, such as shadowing them as they walked, barring their way and making repeated attempts to encourage or instruct the person to return to the bedside. Any apparent resistance to care typically increased the restriction experienced by the patient. However, this strategy typically triggered further resistance and increased the person's feelings of anger and anxiety about their situation. It also meant that the person's underlying need may remain unexplored, unidentified and unmet or significantly delayed.

In the next example, an 81-year-old woman living with dementia, who was admitted with a fractured hip but is medically fit to leave and is waiting for her 'package of care', is walking away from her bedside. The HCA gives her a walking frame to use and immediately leads her back to the bedside. This restriction makes her very angry. In response, the HCA reminds her that she cannot leave her and shadows her a step behind with her arms crossed; however, the patient does not comply and she continues to walk out of

the bay and tries to open the (locked) doors at the end of the ward. The HCA takes the frame from the patient and turns it around to face into the ward. During this encounter, the HCA starts with emphasising the reality of the ward, 'I can't leave you alone', repeatedly reminding the patient of the rules of the ward, 'You need to go back to bed', before resorting to giving instructions, 'turn around'. However, by the end of this encounter the HCA is very frustrated and the patient is very tearful and upset and is shouting in frustration to be left alone. This created a lot of attention from other staff in the ward who crowd around the patient, which further upsets her and adds to her frustration:

*She has just woken up and starts to walk away from the bedside. The HCA gives her a walking frame to use from another bedside and stays with her and leads her back to the bedside.*

**Patient:** LEAVE ME ALONE.

*She is very angry and wants to leave. The HCA responds, 'I can't leave you alone, hold on to it (walking frame) with both hands.'*

*As she uses the walking frame to leave the bay, the HCA is staying with her as she goes, shadowing her a step behind, with her arms crossed. The patient turns to her sharply and shouts, 'LEAVE ME ALONE'. She walks up and down the corridor using the walking frame and has arrived at the doors at the end of the bay and she looks through the glass panels and tries to open them (they are locked). The HCA stops her and asks her to turn the frame around and to go back. She then forcefully takes the frame from her and turns it around to face into the ward. This really upsets her: 'LEAVE ME ALONE . . . I WISH YOU WOULD LEAVE ME ALONE. I wish she [HCA] would stop following me around! I am not going anywhere!'. She is very angry and frustrated.*

*This continues and a member of the physio[therapy] team returns and says in a very bright and friendly voice: 'Hello! Come with me!'. She puts an arm around her shoulders and steers her down the corridor in the other direction: 'How about a nice up of tea?' The patient now looks very upset and tearful.*

*Site E, day 2*

This restriction of people living with dementia to the bed or at the bedside was extended to older patients, even when ward staff were aware that they needed to be mobilised and required rehabilitation.

### **Outsourcing care and ward cultures of containment**

A key response to an identified pattern of resistance by people living with dementia within wards was to assign one-to-one agency HCA staff to care for them. This was a policy within almost all hospitals and wards as a way to support both people living with dementia and ward staff. In practice, this meant that once a person living with dementia was identified as resisting care within the ward, they could be classified as 'specialised,' a DoLS could be obtained and the ward could legitimately request additional support and assign an agency HCA to provide one-to-one care to manage that person during their admission.

However, as well as having an impact on the person living with dementia, this could have a powerful impact on the wider ward culture. Ward staff appeared to be less concerned about de-escalating and supporting a person who was resisting care. This request could also function as a means to demonstrate to the wider hospital system that this was a ward and a team that was experiencing specific strains and required additional support staff.

The role of the one-to-one carer was significant in that it was almost always interpreted as a role that required them to restrict the person living with dementia to the bedside, to limit their impact on the wider work of the ward and to enable the ward team to continue their work without interruption.

They operationalised their work as primarily involving containment of the person with dementia at the bedside and ensuring that they fit within the rules of the ward. In addition, ward sisters reported that, although they could request one-to-one HCA care for people living with dementia who were resisting care, they did not believe that they could direct HCAs on how to provide care for the person, as this was not in their power (Sites A, B and D). Throughout one particular shift we observed how a HCA called on the requirements and rules of the ward in a way that limited both their work (safety and risk) and the person with dementia by locating them within the chair. When this did not happen, both the HCA and the patient became increasingly anxious and agitated. This can be seen in the language used when talking to an 83-year-old man admitted with 'increased confusion', namely the loud shouting and the exaggerated slow pronouncement of words even though the HCA and patient are next to each other in a very small room, both of which indicate how dementia as a condition is believed to affect the person. It is predominantly conceptualised as meaning that repetitive loud and simplified language will eventually enable the person to understand, comply with and follow the rules of the ward:

*He is standing at the door to his single room and using his walking frame, shouting and heading out of the room. The physio[therapist] and the OT [occupational therapist] working in the bay go over to him: 'LET'S HAVE A SIT IN THE CHAIR'; she speaks in an exaggerated slow and loud voice. He tells them: 'I want to go home'.*

**Physio[therapist]:** *YOU CAN'T LEAVE YOUR ROOM, YOUR BEDROOM IS RIGHT HERE, COME AND SIT IN THE CHAIR.*

*He tells her 'No' but she tells him, 'YOU ARE NOT SAFE OUT ON YOUR OWN', and she takes his walking frame away and leads him back into his room, telling him: 'YOU ARE IN HOSPITAL, YOU NEED TO STAY SITTING IN YOUR CHAIR.' Some time later, he is in bed and appears to be asleep and there is now a one-to-one HCA sitting in a chair at the doorway watching him.*

*Site B, day 3*

A typical technique when a person living with dementia was walking within the ward was for staff to shadow them and to stand very close with arms folded. It was less common for a one-to-one carer to walk alongside the person and their role was typically focused on containing patients at the bedside, directing them away from other bays, preventing them from talking to and shielding other patients, family or staff, and diverting them away from the exits to the bay. As demonstrated during the care of a 79-year-old man admitted with a fractured hip and described as 'confused', the main organisational force underlying and directing all of this work is the extreme fear of the patient in their care falling:

*The room is darkened at the start of the night shift and the nurse and HCA are trying to get him back into bed: 'Get back into bed.'*

**Patient:** *NO.*

*The team respond 'You will end up falling, you will end up falling, get into bed it is night time.'*

**Patient:** *NO.*

**Nurse:** *What will happen if you fall, if you fall you will be in hospital longer.*

*The team get him back into bed and put the side rails up, but he is very agitated and pulling off his sheets. The HCA stands over him by his bed and as he repeatedly tries to get out of bed she keeps him within it: 'Put your leg back in you will fall.'*

*Site A, day 18*

However, for families, such restraint was difficult; the impact of containment and restraint was that people became deskilled and could lose their ability to walk. This has implications for outcomes and discharge plans. Here, a daughter and son-in-law talk about her mother, who is 96 years old, has a diagnosis of dementia and was admitted with a hip fracture:

*They won't let her walk, they are worried she will fall. She has walked with a Zimmer [frame] for 7–8 years, so why can't she still use it? They say it's not safe. They say she has to pass the red thing first (the steady or rotunda) and once she can use that then she can move on to the Zimmer. But she's too frightened of the red thing (the steady or rotunda) so she has never been able to try the Zimmer and now she's lost the strength to walk, she can't get up herself now . . . They tried holding her up on either side, but she got a chest infection and didn't eat and then she was just not strong enough and they have not tried her since . . . They use the hoist (to get her from the bed to the chair or to the commode), but even we would find the hoist scary. How many times you say are you going to help her [We look at her legs – they are dark red/black and they tell me she has cellulitis]. It is getting worse, her legs are going a funny colour and getting darker.*

Site E, day 7

Dementia specialist teams were available in some of the hospitals (Sites B and D). These were typically small teams (2–6 members of staff) that worked across a large number of wards and, in some cases, all wards within the hospital and thus had limited time to spend within specific wards or with individuals. Individual patients could also be identified by ward staff and medical teams as requiring support from the specialist team. These teams worked only within 'office hours' (i.e. 08.30–16.30, Monday to Friday). This group of dementia specialists were typically highly skilled HCAs; however, their time within wards and with individual patients was limited and carried out in isolation from that of the ward teams. The ward and bay teams identified the patients who needed their support and expertise but did not discuss strategies or approaches with them. In practice, the role of these teams was interpreted by ward staff as doing the interactional work with patients so that they did not need to do this. These specialists and their work with patients occurred in isolation and they described how they also felt unable to pass on their skills and knowledge of the person to other members of staff.

This outsourcing had a wider impact on the expertise of the ward team. It meant that caring for a person living with dementia who was refusing care was never seen as the work of the ward but as the work of other people who could be temporarily brought into the ward. This also emphasised to the ward team that caring for large numbers of people with dementia was a temporary issue to be managed within their ward and not a permanent change in their patient population. The staff who had this one-to-one role typically had general HCA skills and only a small number talked about their expertise in dementia or had any continuity with the patient. The ward team and the individual typically identified the role of the one-to-one HCA as relating to containment and keeping the individual out of the way so that ward staff could continue uninterrupted with the timetable and schedule of the ward.

The effects of having a one-to-one carer on a person with dementia were increasing levels of surveillance and monitoring and repeated requirements for a patient to remain at the bedside; the repeated fear of falling and associated risk increased patients' anxieties about where they were and what was happening to them.

### Visibility and invisibility

The work in the ward is driven by routine and timetables, but staff were also very responsive to individual buzzers, alarms and calls for immediate help. One impact of this was that patients who were silent or classified as 'sleepy' by ward staff were not a priority and so were less visible to staff during a shift, particularly in the context of staff responding to multiple resistance within the bay and the wider ward. As a group, these patients were also unlikely to be assigned one-to-one care, with this generally being assigned to patients who were identified as more actively agitated and resistant. We saw this pattern across all wards and sites (although there was a greater focus on this group of patients at Site C). However, a silent or 'sleepy' patient or silence in a bay does not mean that all is well. Typically, within a ward, patients were

lying in bed or sitting in their bedside chairs and were often quiet or did not move and appeared to be asleep. However, this does not mean that they are not agitated or upset. In addition, there may still be observable body language that might give some insight into a patient's emotional state. Within encounters such as the one above (the 79-year-old man admitted with a fractured hip and described as 'confused' at Site A), the focus on patients who were actively resistant meant that the apparently silent 'sleepy' patient was not a priority. Within the same bay was an 84-year-old man admitted with a hip fracture and pneumonia:

*He is lying totally still and is slightly propped up in bed, his tiny head is lying back on the pillows, he has his glasses on and is staring up at the ceiling. He has an i.v. inserted in his left arm attached to a mobile drip stand – the night shift reported that he had pulled out the drip from his left arm in the night and they had to put it in again – I can see there is some fluid spilt around his bed and there is a yellow 'caution wet floor' sign placed in the area around his bed. His bed covers are off and he is only partially covered in a thin sheet with his bare feet sticking out, which look very cold. He is also holding very firmly on to the side bars that are up on either side of his bed, but, unlike previous days, he is not pulling and rattling them or trying to get out of bed. He continues to lie very still in the bed for some time and then starts to fiddle with and tries to pull out the i.v. line in his arm. However, it looks as though it has been very firmly and securely re-attached, there is [sic] lots of thick white bandages have been tightly wound around it covering a large part – over half – of his arm. He is unable to pull it out, but he keeps pulling.*

Site A, day 5

Once a patient is made invisible by their condition, their quiet resistance became normalised for their admission, which could have a significant impact on care. As recognition of the patient as a 'person' declines, so too do their opportunities for rehabilitation and options for discharge.

## Chapter 8 Discussion

The study analysis has been drawn from detailed ethnographic observations that allowed the researchers to spend extended time within and across shifts, observing specific bays and the individual staff and people living with dementia on hospital wards throughout England and Wales. This approach allowed us to identify the scale of resistance to care, and, importantly, to explore the potential underlying reasons or triggers for a person's resistance to aspects of their care or admission. We have identified that these responses to the organisation and delivery of care at the bedside were typically rational to that patient's present ontology and perceptions. Importantly, the study shows that resistance typically did not take the form of isolated events whereby only one or a small number of individuals within the ward or bay resisted care. Every person we observed resisted care at some point during the observations. It was also typical for a number of patients to resist care at the same time and within the same bay, particularly when staff delivered routine timetabled care that they considered essential, such as personal care, observation rounds, medication rounds and mealtimes.

In isolation, each of these instances of refusal and resistance appeared relatively minor in terms of its overall impact on the ward (if not in terms of its impact on the patient) and was often easily rectified. Tubes can be reinserted, machines reset, patients can be led back to bed, questions can be asked later. In combination, however, these minor acts of resistance, carried out by many patients, if not simultaneously then in close association, had a significant influence on ward cultures and approaches to and recognition of people living with dementia within the wards. Resistance to care has become something viewed by ward staff as a regular feature of a dementia diagnosis and as both an expected and accepted feature of an individual with impaired capacity. This meant that staff responded to a person living with dementia who was calling out, shouting or walking in the corridor not as a person expressing an underlying care need, but as a person demonstrating their diminished capacity, with this behaviour always attributed to their dementia diagnosis.

The more these acts of resistance occurred over a shift or a person's admission, the more staff normalised resistance, to the extent that it became interpreted as an everyday feature of ward life and a feature of a dementia diagnosis and who the person now is. The impact of this was that staff responses to people living with dementia became viewed as less urgent. An issue such as shouting or calling out may come to be viewed by ward staff as a symptom of a pre-existing morbidity, rather than a feature of the acute admitting condition to which staff must quickly attend. Rarely will the reason or intent of the patient's actions be discussed with the patient, beyond rhetorical platitudes such as 'where are you going?' and 'what's wrong darling?'. A perception that there is a heterogeneous 'dementia patient' means that individuals become overshadowed by the perceived homogeneity of their condition.

The focus on completing the routines and 'rounds' of the ward timetables to schedule was always paramount and dominated ward life. Ward teams' approaches to patient care were typically focused on carrying out very specific routine care for the person at the bedside, with a focus on completing the wider ward routines and timetables. This extended to their responses to resistance, which were typically to see these as potential interruptions to the work of the ward and to carry on and try to complete that specific aspect of care. If a patient responded by resisting, or by saying 'no' to care, although staff would acknowledge this in their talk at the bedside, they typically reminded the person that they were in hospital and emphasised the rules of the ward. This highly repetitive talk was always directed at reminding the patient of their place in the world and of the status of ward staff; they must all fit the expectations and timetables of the institution.

These exchanges provide ways of uncovering aspects of the loss of identity and social standing of people living with dementia during an acute admission. It is important to note how much of this talk was directed at trying to remind the patient of their place in the ward and of the rules to be followed. Although staff gave the appearance of seeking permission and negotiating with the person, the delivery of care typically

continued, with a tacit assumption of assent, and was focused on obtaining the correct response from the person to allow care, which was already being carried out, to continue. However, this approach, which was highly repetitive, appeared to increase resistance, anxiety and fear for people living with dementia.

The focus on the completion of ward routines and timetables meant that staff did not consider it possible to focus on what appeared to be low-level resistance that was not an immediate priority or risk, particularly in the context of pressing demands of the ward routines of personal care, bed making, observation and medication rounds. There were often subtle signs that could be identified in a person's body language and changes in behaviour that indicated resistance or the potential for resistance, for example patients looking uncomfortable, displaying potentially defensive body language (crossed arms), not talking and remaining silent. Importantly, the challenge for ward teams in the context of busy wards was to recognise these early signs and feel that they were able to respond to and prioritise them and acknowledge that this constituted a valid form of work.

When ward routines and timetables were interrupted by a number of people resisting care, staff responses typically focused on short-term management and containment so that they could focus on the completion of the task in question and the timetables of the ward, rather than responding to individual concerns. However, if these non-urgent signs of resistance were not acknowledged, then they typically escalated into the person developing a longer-term entrenched pattern of resistance. These perceived expectations of the timetables and their apparent conflict with patient needs could also create high levels of stress and anxiety for people living with dementia and for ward staff.

The key ward staff response to people living with dementia within their care was one of containment and restraint. Although there was some variation in specific techniques between wards, the overall strategy was always the same: keep the person living with dementia within their bed or sitting at the bedside. Across all sites, staff expressed high levels of anxiety about people leaving the bed or bedside, and this increased exponentially if they were walking in the bay, the wider ward and corridor or close to the ward entrance.

Multiple forms of containment and restraint were observed being used by all ward teams. Raising the side rails of the bed or tucking bed sheets in tightly around a patient were both a common and covert means to contain that patient within the bed. For those patients sitting at the bedside, the close placement of the mobile tray table and unreachable walking frames and technologies such as chair alarms were used to keep people in their chairs. Clinical technologies, including continence technologies (particularly full continence pads, bed pans and commodes), 'specialing', medication and sedation, and secured medical equipment also limited or restrained movement from the bedside. Importantly, these approaches to patient care and patient containment at the bedside were a response to resistance and, frequently, the trigger for resistance or a cause of patient anxiety.

This contributes to what is seen commonly on wards throughout the acute hospital today, namely the outsourcing of dementia care. A key response to an identified pattern of resistance by people living with dementia within wards was to assign one-to-one agency HCA staff to care for them. This was a policy within almost all hospitals and wards as a way to support both people living with dementia and ward staff. In practice, this meant that once a person living with dementia was identified as resisting care within the ward, they could be classified as 'specialised,' a DoLS could be obtained and the ward could legitimately request additional support and assign an agency HCA to provide one-to-one care to manage that person during their admission.

The role of the one-to-one carer was significant in that it was almost always interpreted as a role that required the restriction and containment of the person living with dementia to their bedside. The aim was to ensure that the patient fitted within the rules of the ward and that their impact on the routines and timetabled schedules of care that dominated ward life was limited. However, as well as having an impact on the person living with dementia, this approach could have powerful effects on the wider ward culture.

Ward staff appeared to be less concerned about de-escalating and supporting a person who was resisting care. This request for one-to-one support could also function as a means to demonstrate to the wider hospital system that this was a ward and a team that was experiencing specific strains and required additional support staff. Caring for people living with dementia also came to be seen not as the core work of the ward but as something to be outsourced. This in turn led to the assignment of agency staff to such areas, contributing further to the stigma of care work for this patient group.

Once a person is made invisible by their condition and their resistance became normalised as a feature of a dementia diagnosis, this could have a significant impact on care. Such processes, generated from the restricted repertoire of work possible within the routines of these settings, leads to cultures of dehumanisation for patients but also has negative impacts on staff, who do not consciously create these cultures but operate within them, leading to potential emotional burnout and exhaustion. It was not uncommon for staff to want to avoid assignment to bays or areas of wards or units that admit high numbers of people with dementia. The work in wards is driven by routine and timetables, but staff were also very responsive to individual buzzers and calls for immediate help. One impact of this was that patients who were silent or classified as 'sleepy' by ward staff were not a priority and became less visible to staff during a shift, particularly in the context of staff responding to multiple resistance within the bay and the wider ward. As a group, these patients were also unlikely to be assigned one-to-one care and were less likely to get staff attention than those patients identified as more actively agitated and resistant. However, as recognition of the patient as a person declines, so too do their opportunities for rehabilitation and options for discharge.

In response, we believe that our ethnographic 'thick description' is particularly applicable to developing organisational and interactional training and interventions at ward level. Ethnography provides ways to connect ward staff with key issues by providing detailed 'real' empirical examples<sup>173</sup> of care that bring these issues alive and provoke better awareness. We believe (and have found in our discussions with ward staff) that these detailed accounts of the organisation and delivery of care within wards will support and encourage staff to develop a strong connection with and understanding of the social world of their ward, the ways in which the organisation of work influences them, how ward cultures of care develop and become normalised, and the perspectives of people living with dementia and their families. We believe that it is only through an empirical detailed understanding of the complex social relationships involved in the current provision of care for people living with dementia in acute wards and the significant impacts this has on them, on their families and carers and on ward staff that we can identify ways in which to deliver high-quality care for people living with dementia that also support ward staff.



## Chapter 9 Conclusions

### Interventions to improve care

We have provided a detailed analysis of the experiences of care and of the impact of the culture and organisation of wards and interactional work of delivering care at the bedside from the perspectives of people living with dementia, their family carers and ward staff. We have identified the ways in which resistance to care manifests, is recognised by staff and is responded to routinely. We have also examined the impact of these responses over time. A number of studies have highlighted the difficulties of caring for people living with dementia within the acute hospital setting;<sup>24,132</sup> however, there is an evidence vacuum in understanding how the care of these patients can be improved within the acute setting,<sup>20</sup> and few studies have demonstrated how to practically address these challenges. In response, within this chapter, it is demonstrated how the findings of this study can be used to develop training and test the feasibility of interventions to improve the quality and humanity of care for this key population and to support the ward staff caring for them.

Within this chapter we focus on our approaches and strategies to build on and utilise the study findings to (1) consult with, raise awareness of and inform wider user communities and the public about our findings and the experiences of care in acute wards for people living with dementia, their family carers and ward staff, (2) extend the dissemination and delivery of training to nurses and HCAs working in acute wards via open-access online training and (3) develop and test interventions at ward level to improve the quality and humanity of care that people living with dementia receive during a hospital admission. To do this, we have:

- involved people living with dementia, their carers, their families and the wider public in the research process and in the discussion of initial findings via an ongoing dissemination and consultation process in collaboration with the arts through the development of a programme of dementia-friendly film screenings and festivals
- presented the initial findings of our research to nurses, students, care staff, patients, advocacy groups and experts from a variety of disciplines in the UK and Europe
- extended and enhanced our community of interest by developing social media programmes to extend the reach of our research via a co-ordinated cross-platform campaign of films, training and research updates on open-access social media platforms [dedicated website, Twitter (Twitter, Inc., San Francisco, CA, USA), Facebook (Facebook, Inc., Menlo Park, CA, USA), Instagram (Instagram, Menlo Park, CA, USA) and YouTube (YouTube, LLC, San Bruno, CA, USA)]
- established a website ([www.storiesofdementia.com](http://www.storiesofdementia.com)) via accessible logos and illustrations to create an inclusive, distinct, memorable and consistent identity that reflects the overall objectives and values at the heart of our research and to ensure that our outputs are instantly recognisable as belonging to our project
- collaborated with Dementia UK and Admiral Nurses on developing –
  - no-cost interventions or ‘hacks’ for acute wards
  - short training ( $n = 17$ ) and ‘trigger’ ( $n = 12$ ) films for nurses and HCAs working in acute wards available via open-access online training
- conducted a feasibility study within one ‘laboratory’ ward to introduce three interventions or ‘hacks’ and to establish the feasibility of introducing them in acute wards.

Our detailed analysis has identified features of the social and organisational context of front-line care and key moments within the hospital system and ward routines and timetables that we believe are pivotal opportunities for change. In response, we have developed small changes or ‘hacks’, which do not require ‘permission’, cost money or demand involvement of the hospital management or wider governance structures. We believe that these changes can improve both the quality and humanity of care for people living with dementia and also improve the working lives of ward staff. An individual nurse or HCA may believe that they lack the power or influence to make large transformations to their hospital, but small changes can have a significant impact on the local culture of the ward, the ward team and patient care.

We are extending our training and interventions to involve other hospital trusts and applying our findings to other areas of care (delirium) that affect people living with dementia during an acute hospital stay. The findings have also informed another Health Services and Delivery Research study that is currently ongoing [Understanding how to facilitate continence for people living with dementia in acute hospital settings: raising awareness and improving care (project number: 15/136/67)].

### ***Dissemination and delivery of training to staff working in acute wards***

We have begun the process of disseminating the findings of our research in an effort to improve the care of people living with dementia within the acute setting. In order to best reach as many nurses and HCAs as possible, we have provided multiple pathways of engagement, from in situ ward ‘hacks’ to online open-access films.

### ***Need for training***

The majority of nursing staff (89%) working in the acute setting have identified working with people living with dementia as challenging,<sup>22</sup> with health-care professionals within the acute setting identified as lacking the necessary skills and knowledge to care for this patient population.<sup>12,23,24</sup> However, without the appropriate training and support, there is a recognition that health-care staff will become resentful and demoralised and cut themselves off from patients, all of which can lead to the depersonalisation and dehumanisation of people in their care.<sup>25</sup> The failure to provide appropriate training for hospital staff in caring for people living with dementia has been identified as a key contributor to the poor outcomes and long inpatient stays for this patient population.<sup>27</sup> Training in the care and support of people living with dementia must also be part of the continuous professional development of nurses,<sup>12</sup> with a further emphasis on the need for training all staff working in health or social care settings.<sup>14,21</sup> Training is recognised as the key to reducing stigma<sup>14</sup> and delivering dignity in care.<sup>17</sup>

### ***From ‘bundles of care’ to ‘hacks’***

We initially used our findings to develop a number of ‘bundles of care’. The current care bundle for dementia patients in hospital advocates a series of measures such as using reminiscence artefacts, developing communication strategies and having a communal dining room where possible.<sup>197</sup> Clearly, such measures are inappropriate within many acute areas where patient turnover is high (e.g. MAUs), where medical interventions are often complex and have priority, and where staff are focused on clinical outcomes. Indeed, when observing staff in their day-to-day interactions with patients living with dementia, the main issues they raised were the need for support and training on how actually to care for people living with dementia in their wards and how to respond to and manage resistance to care when caring for people at the bedside.

In response, we have used our findings to develop a number of ‘bundles of care’, which each comprise a small, straightforward set of five evidence-based practices. We have piloted these bundles within undergraduate nursing modules and consulted with ward staff. Our goal was to provide structured ways to improve the processes of care and interactions with patients, and to inform ward culture to support people with dementia and ward staff caring for people with dementia in acute wards and MAUs. We also aimed to develop ward cultures that support people with dementia and to promote the high-quality care of people with dementia who are medically fit to leave hospital.

However, following a consultation process with ward staff in a number of hospital trusts and with Admiral Nurses, we identified that there was already 'bundle fatigue' (meeting with nurses and ward managers, Site A, October 2017) among nurses working in acute wards. The key finding of our consultation was that ward staff were wary and cynical of any intervention that could involve new paperwork or additional forms entering their ward because they were always viewed as adding to their workload. Instead, they asked for simple, no-cost interventions, techniques and training that they could implement within their practice and their wards without having to seek 'permission' (meeting with Admiral Nurses, November 2017) from the wider hospital administrative and executive systems. As one nurse asked, 'how can we make changes when I still can't get permission to put a nail in the wall to put a clock up in the ward?' (meeting with ward staff, Site A, October 2017).

In response, we held a national expert 'hackathon' event (1–2 November 2017, Birmingham) with dementia specialist nurses and Admiral Nurses from across England and Wales, specifically to refine our approaches to implementation. We focused on exploring the ways in which our study findings could be adapted into implementable and maintainable solutions on acute wards, in the form of small 'hacks'. We use the 'hack' analogy to describe a particular problem-solving approach or 'social hacking' that is focused on identifying ways to solve social issues.

We believe that this approach can be applied to acute care. We are using our analysis to identify key moments within the hospital system and ward routines and timetables that we believe are pivotal opportunities for change. From this, we have identified a number of simple 'hacks' that allow us to intervene in ways that we believe could change ingrained behaviour and improve care. These are simple, no-cost interventions that we believe can be embedded into everyday practice. These 'hacks' are designed to improve the experience of patients living with dementia, as well as the experience of the ward staff caring for them during their admission to an acute hospital setting. A key aspect of this process is to continually test and refine the 'hacks' to learn from them and to improve them.

The hackathon event identified three 'hacks', each covering a specific area of everyday care, that we believe are key to improving care for people living with dementia: (1) communication, (2) mealtimes and hydration and (3) movement and rehabilitation within the ward. These are being used to:

- inform online training films available to hospital staff (open access via our blog)
- inform the development of a masterclass and a future massive open online course (MOOC) (NIHR funded)
- inform the design of a NIHR-funded feasibility study within one acute 'laboratory' ward to test and refine the 'hacks' and to establish their feasibility within the acute ward setting
- provide the foundations for a collaborative funding application for a multicentre intervention study.

Following consultation with a NHS REC, on 26 February 2018 we were granted permission to trial the feasibility of the proposed 'hacks'; however, we were asked to rename them as 'interventions', as the committee felt that 'hack' may have negative connotations for participants. The interventions due to be implemented are as follows:

1. hand to hydrate –  
all staff within the ward will be encouraged to hand patients a glass of water and to encourage them to drink before delivering care or when interacting with the patient at the bedside
2. spend five to save ten –  
ward staff will be encouraged to spend time with each patient and to listen to their concerns at the beginning of shifts and prior to delivering and organising care on the ward
3. movement and rehabilitation within the ward –  
ward staff will be encouraged to ask patients at regular points in the shift if they want to leave the bedside, walk within the ward and/or walk to the bathroom and to support the patient in doing so where necessary.

Each of the three interventions was trialled in isolation, over a period of 5 consecutive days (for a total of 15 days overall) at one of the sites included in the original study.

### **Online training in collaboration with Dementia UK**

Our development work with Admiral Nurses and Dementia UK will form the basis of our training films, masterclasses and MOOC for nurses, HCAs and ward staff in caring for people living with dementia within acute ward settings. It will also be integrated into Cardiff University undergraduate and postgraduate nursing training (via Cardiff University) and is available via our own dedicated website (see [www.storiesofdementia.com](http://www.storiesofdementia.com)).

To date, we have published 29 short training films, including:

- films that include 'Top tips', 'Do', 'Do not', 'If I could change one thing', and 'My biggest challenge' ( $n = 17$  films)
- awareness-raising stories and 'trigger' films ( $n = 12$  films) from the perspectives of people living with dementia, carers and families, and nurses.

### **Carers' perspectives**

Our ongoing work with the Carer Steering Group is focused on developing ways in which the findings generated by the study should be communicated to user communities. So far, in collaboration, we have developed:

- short films with people living with dementia and their family carers, discussing their experiences of hospital care to raise awareness and to be used as 'trigger' films in wards to support ward change and development to improve care for people living with dementia
- a short report and factsheet for carers and families focusing on 'top tips' and things that are important for families to be aware of and to consider during a hospital admission for a person living with dementia.

The Carer Steering Group has provided invaluable input towards ensuring that the language used in the reports and factsheets is both appropriate and accessible.

### **NHS trusts**

We have presented our findings at a number of NHS sites and hospital-level meetings, including dementia boards, nurse divisional meetings, senior nurse meetings, research days and working groups. These meetings include managers of acute settings and senior nursing teams. We are currently working with nurses and acute wards across a number of hospital trusts, teams of dementia specialist nurses and Admiral Nurses across England and Wales. We plan to involve these teams and sites in our ongoing work to develop and implement interventions and 'hacks' at ward level.

### **Developing no-cost interventions at ward level: a feasibility study**

Our findings have revealed the complexities of caring for people living with a diagnosis of dementia within acute wards. In response, we are working on establishing the feasibility of introducing these small interventions to 'hack' an identified set of micropractices. Our aim is to utilise small 'fixes' to address particular 'problems' found in the current provision of care for people living with dementia when admitted to acute wards.

This feasibility study uses an experienced-based co-design framework, which involves gathering experiences from patients and staff through in-depth interviewing, observations and group discussions, identifying key 'touch points' (emotionally significant points) and assigning positive or negative feelings. The approach was designed for and within the NHS to develop simple solutions that offer users a better experience of treatment and care. This approach has already been used in a range of clinical services, including cancer, diabetes mellitus, drug and alcohol treatment, emergency services, genetics, inpatient units, intensive care, mental health, orthopaedics, palliative care and surgical units. However, it is relatively untested in the field of dementia care and, in particular, no work has focused on people living with dementia receiving acute care for unrelated health problems in non-specialist settings.

## Research aims and objectives

This study explored the feasibility of introducing and implementing the low-to-zero-cost recommendations of the MemoryCare project within the acute care setting. Our key research questions were: 'Is introducing and implementing the recommendations of the MemoryCare project or 'hacks' within the acute care setting feasible?' and 'Can they improve the delivery and experiences of care for people living with dementia, for both staff and patients?'

The objectives were to examine and assess if the findings of our detailed ethnographic analysis can be implemented and if they can improve the delivery of care for people living with dementia, for both staff and patients. Within one acute ward, the feasibility study (ongoing) is:

- providing ward staff with the opportunity to discuss the three 'hacks' identified from analysis of the primary study and from the discussion of findings with practitioners and experts at the 'hackathon' event (held 1 November 2017)
- assessing the potential use of the three 'hacks' with ward staff for improving care for people living with dementia, and the feasibility of implementing each of the three 'hacks' within their ward
- running a co-design group with ward staff and users over a 4-month period to work on agreed improvements in the form of 'hacks' or 'hacks'
- using patient outcome measurements and patient and staff satisfaction surveys to establish the feasibility of using the 'hacks' to inform quality improvement at ward level
- further refining the 'hacks' and using this information to inform a larger-scale, acute-setting-wide pilot study to examine whether or not the interventions and the approach to supporting change at ward level are scalable.

## Implementation and evaluation

This implementation phase, which is ongoing, is being carried out in collaboration with one site. We have approvals in place and are carrying out this feasibility study within a large general hospital, working in collaboration with the deputy ward sister of the Acute Medical Frailty Unit. We have introduced the 'trigger' films and potential 'hacks' that emerged from our 'hackathon' event and have discussed them with front-line nursing and HCA staff to support discussion about the challenges of caring for people living with dementia within their ward and how to implement the ideas and possible solutions via the 'hacks' produced by the forum. These 'hacks' were all identified as potentially useful by ward staff and are currently being implemented and evaluated in turn to test the feasibility of implementing them in an acute ward and to provide an indication of their effectiveness.

Process evaluation involves critically observing the work of intervention staff, in this case nurses and HCAs, and it is important that the research team sustains good working relationships while remaining sufficiently independent for evaluation to remain credible. This has been facilitated by the relationship already developed in the initial NIHR study as the site being used was also the original pilot site. Using the MRC process evaluation model allows us to:

- provide a clear description of the intended intervention
- observe how it was implemented
- observe how (if) it worked.

The findings of this feasibility study will be used to, where necessary, refine our hacks, and we hope to use this to inform a larger-scale pilot to examine whether the 'hacks' and the approach to supporting change at ward level are scalable.



# Chapter 10 Recommendations and limitations

## Recommendations

### *Improving care in the acute setting*

Our detailed analysis has identified features of the social and organisational context of front-line care that we believe can be improved to support the quality and humanity of care for people living with dementia. In this chapter, we emphasise the importance of (1) recognising that people living with dementia are a significant population within acute wards, (2) the need to train acute staff, (3) recognising the impact of fixed timetables of care, (4) improving the understanding of refusal and resistance to care, (5) developing appropriate responses to, and reducing instances of, restraint, and (6) challenging low expectations of ward staff with regard to people living with dementia.

### *Recognition that people living with dementia are a significant acute population*

Although significant numbers of people living with dementia are admitted to acute settings, they are typically not recognised as forming a significant population. From a top-down organisational level to the level of staff on wards, there is a reluctance to accept that people living with dementia not only belong in acute care wards but are becoming the typical patient.

A first step towards improving care in the acute setting is to increase the recognition and awareness among all ward staff that people living with dementia who are admitted with an acute condition are in the right place. An acknowledgement is needed by staff that patients living with dementia are not a temporary population who belong in other wards or settings but belong and need to be cared for in their acute ward. This is the first step in staff recognising that they must develop appropriate skills and expertise in dementia (and for hospitals to support the development of these skills) alongside their specialist expertise, whether that is emergency medicine, orthopaedics or gastroenterology, for example.

### *Training for all acute hospital staff*

There is an urgent need for acute hospitals to support ward staff to develop specific care practices that bring together the care of a person's dementia with their acute admitting condition and any other multimorbidities that they may have (there are high rates of multimorbidity among older patients and people living with dementia). Clinical specialisms typically prioritise the treatment of the patient's acute admitting condition, with the care of their additional dementia diagnosis often not recognised by clinical staff as a priority (e.g. see Tolson *et al.*<sup>34</sup>) or deemed an 'inappropriate' admission (e.g. see Rockwood and Hubbard<sup>35</sup>). Too often we observed how the specialisation of care both compartmentalised staff within their remits and roles and excluded the needs of people living with dementia who did not fit neatly within these specialties. In response, we must dispel the myth that ward staff do not need to develop these skills because there are dementia 'experts' or other specialist dementia wards where people living with dementia 'belong'.

### *The impact of fixed timetables of care*

The well-established timetables and routines of acute wards do not fit the needs of people living with dementia. A ward overly focused on fitting the care of patients into the traditionally fixed and fast-paced timetable of mealtimes, personal care, observations and medication rounds can have adverse consequences for people living with dementia, and, in turn, a person living with dementia's response to these routines can have significant consequences for the fixed timetables of the ward. Ward routines and rounds such as personal care and mealtimes should be flexible to suit the patient. Ward staff need to be given the opportunity to recognise the importance of flexibility in the delivery of care for people living with dementia in their ward. The delivery of routine care within wards can provide key opportunities to listen to and see the person, not their diagnosis of dementia, and this also has benefits for ward staff by improving

communication, reducing conflict between patients and staff during the shift and reducing the potential for staff burnout.

### **Understanding refusal and resistance to care**

Refusal and resistance to care by people living with dementia is a well-recognised phenomenon within ward life. However, a fundamental step is to recognise that refusal or resistance to care is not a feature of a dementia diagnosis but a response and reaction to the way care is being delivered at the bedside to this patient population. Ward staff often assume that refusal and resistance is a feature of patients' dementia and demonstrates that they lack capacity to make decisions. In contrast, it is typically a response to ward organisation and how ward staff are delivering care to the person at the bedside. Ward staff must recognise, and, importantly, be enabled and given opportunities to listen to the person living with dementia, and to recognise that when they are resisting timetabled care, there is always an underlying reason. They are trying to express a need or to express their autonomy and assert their own wishes and needs. A key role for nurses and HCAs is to identify what that underlying need is, for example an expression of underlying pain, a care need, continence needs (such as wanting to go to the bathroom), an underlying anxiety about home (where their keys are, or concerns about a pet or their family) or wanting to go home.

### **Reduction in the restraint and containment of patients**

Key responses to refusal of and resistance to care were typically the use of containment and restraint. In part, this is because ward staff are not trained to investigate the underlying causes of resistance to everyday care, nor do they always have the opportunity to do so within the fixed timetables of the ward routine. Ward staff must be supported to develop the skills to respond with appropriate communication, behavioural and psychosocial techniques (e.g. see Teri *et al.*,<sup>145</sup> Werner *et al.*<sup>133</sup> and Rantala *et al.*<sup>146</sup>).

Hospitals need to recognise that the implementation of ward policies can have unintended consequences for patients and staff. Containment and restraint was a response both to resistance and to ward policies associated with the reduction of fall risks. This was observable in staff anxiety around patients living with dementia who were attempting to walk or walking unaccompanied within the ward and was typically discouraged and problematised. We know that patients who fall and fracture something during their admission have poorer outcomes, longer inpatient stays and increased mortality. However, safety concerns should not reduce or eliminate activities that are important to people, such as being able to independently go to the bathroom, because, although it may reduce risk, it can affect their personhood and their opportunities for independence and rehabilitation, such as regaining the ability to walk.

### **Challenging low expectations**

Stereotypical beliefs about people living with dementia must be persistently challenged. Ward staff can often hold assumptions about the quality of life of a person living with dementia, which can block or hinder them from seeing the person and their potential. This can manifest in low expectations about an individual's capacity for rehabilitation and independence, assuming that they are dependent and possibly nearing their end of life. Importantly, this sense of low expectations, of assisted 'feeding', of continence pads and bedpans and of protection from falls affects when a patient can leave an acute ward and where they are ultimately able to live. However, a key focus of routine care must be on enabling people living with dementia to regain their independence and to enhance skills such as eating meals independently, walking and being continent.

## **Reflections and limitations**

Key limitations identified from the study included the potential for the Hawthorne effect to influence data collection and establishing the generalisability of the findings.

We are aware of the potential for the Hawthorne or researcher effect to have an impact on research. Importantly, ethnography does not aim to achieve distance and detachment, with one of the strengths of

this approach being the development of close ties with social actors (those being observed) in the field. It has been argued (e.g. by Monahan and Fisher<sup>198</sup>) 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 have been changed by the researchers' presence in the wards and believe that it is important to explore this potential effect and to learn from it.

In acknowledging this limitation, we enrolled a number of strategies intended to minimise this potential effect on our data:

- we believe that our extended periods of observation mean that the participants became used to the researchers' presence and supported the development of trust with ward staff
- we believe that our extended periods of observation made it difficult for participants to maintain performed or exaggerated behaviours over time
- interviews with ward staff, patients and carers during the periods of observation also explored this effect and participants were explicitly asked if they felt a need to change or adapt practice (staff) or if they experienced any changes in the care they received (patients and families) during the research and when care was being observed.

Our approach emphasises the importance of comparisons across sites,<sup>189</sup> which we believed allowed us to optimise the generalisability of our findings.<sup>190</sup> We identified a range of variables that we believed may have influenced the phenomenon by using purposive and maximum variation sampling to include five hospitals that represent hospital types, geographical location, expertise, interventions and quality.<sup>199</sup> However, there may be other important variables that we did not consider that could have affected the generalisability of our findings. Although at first glance hospitals may appear to operate in similar ways, they often have their own unique culture, which is informed by local dominant cultures and belief systems, and which in turn means that care and decision-making can vary widely within institutions.<sup>191,192</sup>

Practical limitations presented themselves throughout the research. As a result of the permissions granted to the researchers, they were unable to follow or track what happened to patients once they were transferred to other parts of the hospital. Thus, we are unable to provide evidence of whether or not the delivery of care, and a patient's response to it, changed after a patient was moved to another ward, or of whether or not the patient's resistance or behaviour changed in a new setting. As such, the research recounts the interactions around resistance to care only while individual patients were admitted to MAU or T&O wards.

Similarly, the researchers could observe and make notes for only a limited number of hours and days at each site. It was not uncommon to arrive on a ward and be told that we had missed a patient behaving in a certain way or had missed the team identifying a patient need. Nor was it always possible to stay on the ward long enough to see how a patient's behaviour may or may not have changed over the entire period of their admission, if nurses adapted their strategies or if a shift change could prompt any differences to care delivery and/or the management of resistive behaviours. However, the everyday and routine nature of the interactions observed leave the researchers confident that they did not miss significant changes to care (or response to care) once observations ceased.

A final limitation is that acute wards are difficult to observe. By their nature, they are large and busy places. It is simply not possible to observe everything going on at any given time on a ward. The researchers acknowledge that a lone researcher can focus on only a single area of the ward or unit and cannot be aware of all interactions taking place around them.



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## Contributions of authors

**Katie Featherstone** (Reader in Sociology and Medicine) was the chief investigator for the study. She led the initial conception and design of the project, managed the day-to-day running of the project, led the ethnographic fieldwork across all sites, conducted ethnographic fieldwork at five T&O wards and transcribed fieldnotes. She led the analysis and theory development, prepared the results for publication and was a primary author of this report.

**Andy Northcott** (VC2020 Lecturer, Sociology of Medicine) was the lead researcher for the study. He conducted ethnographic fieldwork at five MAUs, transcribed fieldnotes, conducted analysis of data, prepared the results for publication and was a primary author of this report.

**Jane Harden** (Senior Lecturer, Adult Nursing) contributed to all stages of the study. She contributed to the initial conception and design of the project and the recruitment of hospital trusts, and prepared the results for publication. She has led the engagement with curriculum development, continuing education outputs, the theoretical development and implementation of interventions.

**Karen Harrison Denning** (Head of Research & Publications, Dementia UK) has made significant contributions to the review of literature, the project's engagement with curriculum development, continuing education outputs and the development of interventions. She has also made significant contributions to the project engagement with Admiral Nurses, Dementia UK and UK health-care policy.

**Rosie Tope** (Carers UK Trustee) contributed at all stages of the study. She contributed to the initial conception and design of the project and the consultations with carers and people living with dementia and public collaborations, contributed to the review of the literature and the analysis, and ensured that the perspectives of carers were represented throughout the study.

**Sue Bale** (Director of Research and Development and Professor of Wound Management) contributed to the initial conception and design of the project, site recruitment, research governance, participant identification and recruitment and the preparation of results, with a focus on dissemination, interventions and follow-up studies.

**Jackie Bridges** (Professor of Older People's Care) contributed to the review of the literature, site recruitment and analysis, and to the preparation of results for publication.

## Publication

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## Data-sharing statement

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

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