

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

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Disclaimer: This report contains transcripts of interviews conducted in the course of the research, or similar, and contains language that may offend some readers.

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Scientific summary

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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.

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