Understanding approaches to continence care for people living with dementia in acute hospital settings: an ethnographic study

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

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Scientific summary

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Scientific summary

Background

People living with dementia (PLWD) are one of the largest populations in our hospitals, with the Department of Health and Social Care recognising that between 25% and 50% of all acute hospital admissions are people who are also living with dementia. In addition, evidence suggests that approximately 50% of these dementia patients remain undiagnosed during their admission. A diagnosis of dementia is associated with an increased risk of unscheduled and emergency hospitalisation, typically for potentially preventable conditions, such as pneumonia, sepsis, urinary system disorders and fractures. The prominence of the acute hospital setting and its impacts on PLWD, their families and the nursing and care staff delivering bedside care cannot be ignored.

People living with dementia are a highly vulnerable group in the acute setting, with their hospitalisation associated with an increased risk of deterioration, functional decline and a range of adverse outcomes, including delayed discharge and institutionalisation. PLWD have a markedly higher short-term mortality than patients of a similar age with the same acute admitting condition but without a dementia diagnosis. Acute hospitals have been described as 'challenging' places for PLWD, with health-care-related harm and the adverse events experienced typically associated with 'falls', delirium, distress, functional decline and incontinence. These adverse events during an acute admission can lead to further dependency and institutionalisation.

Continence care is a key part of everyday personal and intimate care to support PLWD during an admission. However, it is essential care that remains unexamined by the research and policy agenda. These forms of care work carried out on the bodies of others have been described as 'dirty work', 'elimination work', 'body work' and 'body labour', and are habitually regarded as low status, bordering on the polluted. In addition, this body work is often gendered and higher-status workers often distance themselves from it. Despite its central role in supporting the maintenance of patient dignity, well-being and quality of life, continence care is often described as 'basic', rather than essential care or dignity work.

However, to the best of our knowledge, there is little empirical research examining the continence care that PLWD receive during an acute hospital admission. Despite the growing population of PLWD and the importance of continence care, little is known about the appropriate management of and organisational and interactional strategies for PLWD admitted to acute hospital wards.

Research aims

The goal of this ethnographic study was to provide a detailed understanding and directly observed examples of the organisational and interactional processes that influence how acute hospital staff respond to the continence needs of PLWD.

Objectives

The focus of this study was to examine a common, but poorly understood, aspect of everyday care for PLWD during an acute admission, that is continence care. PLWD are a significant population in the acute setting; however, the research agenda has lagged behind and new approaches are needed to improve the care of PWLD. Detailed research is required to identify appropriate clinical, organisational and educational strategies to deliver supportive continence care for PLWD in acute hospital settings. Such research is urged by patient advocacy groups, as well as government inspectorates. In response, the research objectives were to provide detailed understandings of the organisational and interactional processes that influence the ways in which acute hospital staff organise and deliver continence care and how they respond to the continence needs of PLWD during an acute hospital admission. Our questions were as follows: what caring practices are observable when interacting with this patient group? How do ward teams respond to and manage continence needs and what informs these approaches? What are staff doing and why?

This study set out to explore and establish how ward staff account for and make sense of the continence needs of PLWD, how staff respond to and rationalise these needs, and the consequences of staff actions over time. As a result, we have presented findings that provide an original and detailed understanding of the social and institutional forces that shape and influence everyday organisation and delivery of continence care in these acute wards for this significant patient population.

Methods

Our approach to ethnography was informed by the symbolic interactionist tradition, which aims to provide an interpretive understanding of the social world. This tradition places an emphasis on interaction, understanding how action and meaning are constructed in a specific setting, and also acknowledging the mutual creation of knowledge by both the researcher and the researched. Ethnography allowed us to focus on how the wide range of social actors in these acute hospital settings, including the large number of ward staff that patients will come into contact with during an admission, actively respond to the continence care needs of PLWD through their actions, and the consequences of these actions. Ethnography allows us to examine not only these elements, but, importantly, the interplay between them. We carried out a mixed-methods systematic narrative review to refine our approach to fieldwork and analysis. Our approach and subsequent analysis were also informed by understandings of the wider literature in the context of our systematic review, which focused on synthesising what is known about the organisation and culture of the delivery of continence care across a range of settings (i.e. acute, long-term and community health-care settings and home settings) and across different areas of continence care (i.e. faecal and urinary).

This ethnography was carried out across six acute wards in three hospitals in England and Wales that were purposefully selected to represent a range of hospitals types, geographies and socioeconomic catchments. A range of variables was identified that may influence the phenomena to inform purposive and maximum variation sampling to select sites. Across these sites, 180 days of observational ethnographic fieldwork were carried out in those areas of acute hospitals known to admit large numbers of PLWD for acute conditions [i.e. general medical wards (including acute wards for older people) and medical assessment units or variants thereof]. Approximately 500,000 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 (during observation) interviews with ward staff ($n = 562$) and with 10 case study participants and their family members, observing care at the bedside throughout their admission (and in some cases following discharge).

Research Ethics Committee (REC) approval for the study was granted by the NHS Research Ethics Service via the Wales REC 3 on 19 April 2018 (reference 18/WA/0033), with approval from the Health Research Authority and Health and Care Research Wales granted on 5 September 2018 [Integrated Research Application System (IRAS) 239618/protocol 4804]. The research project was approved for the purposes of the Mental Capacity Act 2005 (section 31) (Great Britain. *Mental Capacity Act 2005*. London: The Stationery Office; 2005).

Results

Our detailed analysis provides understandings of the complex social relations that occurred in these wards, that is the ways in which the organisation and delivery of continence care at the bedside connected closely with and was informed by wider institutional expectations, policies and priorities, which, in turn, shaped the personal impacts of continence care for both patients living with dementia and ward staff. Given the scope of our data set, we focus in this report on presenting the five major themes that emerged from our analysis: (1) continence as a significant, visible and public phenomenon; (2) continence communication; (3) rationales of safety; (4) 'pad cultures'; and (5) impacts of continence care.

Continence as a significant, visible and public phenomenon

Continence was a significant, visible and public phenomenon, representing a considerable aspect of the care for PLWD that is part of the everyday bedside care routines predominantly carried out by health-care assistants, but also significant within the routines of nursing. Considerations of privacy were often over-ridden by the recording practices and required documentation of these wards, which could also lead to close monitoring and control of the person living with dementia at the bedside.

Continence communication

Despite its apparent centrality in the everyday work of these wards, communication was significant, primarily in the silencing of continence and the work of continence care. Ward staff's discomfort surrounding continence care could be seen in the communication strategies and the language used on these wards during bedside care for PLWD, but also extended to staff discussions of continence during team meetings. The use of euphemisms, particularly for genitalia, bodily functions and urine and faecal matter, during intimate personal care was notable, with euphemistic and infantilised vocabulary used to communicate intimate continence and personal care to PLWD. Importantly, there was little evidence that staff were able to determine PLWD's comprehension or to vary their language to suit the individual.

There was an explicit requirement on the wards for PLWD to communicate urgency and request continence care at the bedside using institutionally recognised forms of communication through verbal requests and using the personal call button to seek help. Permission was also required to leave the bedside and walk to a toilet, even if the person was able to do so independently. For PLWD, the communication of an urgent continence care need was often not verbalised (through either difficulties in communication or embarrassment), but rather embodied, and could be identified only in the body and via changes in behaviour. It was unusual for staff to respond to these non-verbal means of communicating or to recognise an underlying continence care need.

Rationales of safety

Ensuring safety and minimising risks often featured in discussions of continence care for PLWD. A person living with dementia leaving or repeatedly attempting to leave the bed or bedside was always interpreted by ward staff as a risk to be managed, and ward staff typically focused on the immediate behaviour, with the goal of containing and repositioning the patient in the bed or bedside chair. This focus on immediate risks of falling may reduce one risk, but meant that staff typically did not recognise immediate continence needs, other potential impacts on the person or the reduced opportunities for independence and rehabilitation, such as regaining the ability to walk.

'Pad cultures'

We identified 'pad cultures' as the routine use of continence pads in the care of a wider group of PLWD (regardless of continence and independence) as a precautionary strategy, a strategy viewed by staff as essential to providing safeguards, ensuring containment and preventing 'accidents' or incontinence episodes, but with an expectation that patients living with dementia not only wear pads, but use them. These cultures enabled wards to reduce unscheduled interruptions and ensure containment at the bedside. This approach meant that continence care could be reduced to containment practices and the 'checking' and replacing of soiled or wet pads as part of other scheduled task-based bedside care during a shift.

Ward staff described continence care as a ‘heavy’ burden and a ‘heavy load’, which expressed not only the physically demanding nature of this care, but also the experience of isolation and feeling abandoned with the responsibility of caring for large numbers of PLWD who require highly supportive care.

Impacts of continence care

This characterisation of the dependency of PLWD in these wards had wider and significant impacts on the individuals and their identities. These impacts were intrinsically linked to ‘pad cultures’. Placing a person into ‘pads’ and institutional gowns during bedside care could lead to the reclassification of PLWD (and could become applied to a wider group of older people) who have been grouped together as being highly dependent in a given bay or ward area. The everyday use of institutional gowns was also a response to the routine failure of ‘pads’ as a containment technology, a failure that routinely resulted in changing clothing along with pads. Therefore, the requirements and failures of the pad technology itself were expected, normalised and prioritised.

This could also extend to recognition and understandings of individual behaviour. Walking to the bathroom could become understood by staff as ‘wandering’, that is no longer a sign of continence, capacity and capability, but a risk factor for ‘falls’ and recognised by staff as a potential sign of confusion or resistance to ward care. Distress at experiencing intimate continence care from strangers, often carried out in silence or without adequate warning, could also become quickly perceived as ‘aggression’. Forms of embodied communication of continence care needs could be viewed as transgressive or as a form of behaviour constituting a feature of their dementia, rather than an expression of urgent and underlying need.

Conclusions

This study identified ‘pad cultures’ as an embedded practice in these acute wards. We recognise that the use of continence pads is necessary in the case of PLWD who are incontinent. However, ‘pad cultures’ refers to the routine use of continence pads in the care of a wider group of PLWD (regardless of continence and independence) as a precautionary strategy, a strategy viewed by staff as essential to providing safeguards, ensuring containment and preventing ‘accidents’ or incontinence episodes, but with an expectation that patients living with dementia not only wear pads, but use them. These cultures enabled wards to reduce unscheduled interruptions to the timetabled work of these wards and to ensure containment at the bedside. This approach meant that continence care could become reduced to containment practices and the ‘checking’ and replacing of soiled or wet pads as part of other scheduled task-based organisation and delivery of bedside care during a shift.

These ‘pad cultures’ had significant impacts on PLWD and ward staff. These practices informed wider understandings and characterisations of PLWD (i.e. individuals and groups grouped together) in these wards as being highly dependent, which had wider and significant impacts on the person and their identities. In turn, ward staff described continence care as a ‘heavy’ burden and a ‘heavy load’, which expressed not only the physically demanding nature of these ‘pad cultures’, but also the experience of isolation and feeling abandoned with the responsibility of caring for PLWD without support. Staff also often expressed the view that, although they wanted to support their patient’s continence, they believed that it was not possible to work in other ways.

Study registration

This study is registered as PROSPERO CRD42018119495.

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