

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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Plain English summary

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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.

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