

Caring for frail or seriously ill older people on acute hospital wards

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Project Summary

Introduction

This study explored end of life care for frail older people with and without dementia in an acute hospital setting, and whether there were any differences between these two groups of patients. It focused on the ways in which medical and nursing staff came to recognise that someone was dying, how this was communicated between staff and with relatives, family carers' experiences of the hospital care of their dying relative, and the environment of the acute hospital ward as a place of death. To do this the researchers spent 245 hours observing care on four hospital wards, talked to 38 members of hospital staff including doctors and nurses who worked on the wards, interviewed 13 family carers whose relatives had died on the wards, and reviewed the medical and nursing notes of 42 patients.

Recognising dying:

Much emphasis has been placed on the need to accurately recognise the point when active treatment should shift to the provision of palliative care for dying patients, to enable them remain comfortable and free from pain. Withdrawal of active treatment and interventions which can no longer aid recovery enable the patient and their families to experience a peaceful and dignified death. However, the study findings highlight just how difficult it can be to accurately 'diagnose dying', particularly in frail older people who often experience a very slow and gradual decline in health in the months, and even years, preceding death. We found no clear differences in the care and

treatment of patients dying with or without dementia. It is difficult to apply the current model of palliative care, originally developed in relation to cancer, to the treatment of frail older patients approaching the end of life in acute hospital settings. A more appropriate model of care incorporates a 'twin track' strategy with treatment continuing alongside planning for the eventuality of dying in a more extended and uncertain future.

Communication and decision making

The uncertainty about prognosis makes clinical decision making difficult, and also causes problems for families supporting relatives in hospital. However, as with previous studies, we found that although staff were aware of the importance of talking to families and patients about decisions regarding care, communication about these issues was often poor. Staff lacked awareness of family concerns and responses, or the extent to which relatives' understanding of the situation differed from their own. Families did not feel adequately informed, particularly about what they should expect to happen in the last days and hours before the patient's death. Patients were rarely involved in discussions about care decisions or prognosis, regardless of whether or not they had dementia. There was uncertainty, and difference in practice, about the legitimate role, involvement and influence of family members in making decisions about patient care, particularly in relation to withdrawal of treatment, and how family preferences and clinical judgements about patient best interests should appropriately be balanced.

Task focused orientation of care

The study findings show that, despite the considerable and longstanding effort to develop patient centred care within the NHS, staff continued to maintain a task focused orientation to their work. There was very little conversation between staff and patients about anything not related to the task. Staff contact with dying patients also tended to be brief, functional and focused on the task in hand, with little interaction even when the patient was conscious and able to communicate (although this was not often the case). Several families reported that when they were spending time with their dying relative they felt ignored and unwelcome. In particular, these families described an experience of what the researchers have termed 'abandonment', particularly in the lack of support and consideration they received at the time of their relative's death and just after.

The hospital as a place of death

Hospital is generally considered an undesirable place to die, and most people are thought to want to die at home. However, it is the most common place of death, and will remain so for the foreseeable future: over half of all deaths occur in hospitals. It is important that hospitals are able to provide excellent support to dying patients and their families. However, acute hospital wards can be busy chaotic places, and open bays, where most of the patients in this study died, cannot provide the privacy for dying patients and their families, which is an important component of a good death. All the wards had several side rooms which offered privacy and space for families undertaking a – sometimes extended - vigil beside their dying relative. However, this left the

patient very isolated and alone when visitors were not present. For this reason, some families as well as staff preferred that patients remained in the open ward, where they could be easily seen and helped if necessary. The acute hospital ward does not provide an appropriate environment to support dying patients and their families.

Conclusion

Across all the wards, the variability in the families' experience of care was striking. Most respondents (staff and relatives) did not consider the hospital to be an inappropriate place to die, and for some, it was preferred. In several cases, families who had initially hoped that the patient could be discharged home to die changed their mind. As death became imminent they came to doubt their capacity to cope with care at home. Some accounts of death in hospital were very negative, and this could have a lasting impact on relatives' experience of bereavement. Other respondents were fairly neutral in their assessment, describing an experience that was more or less in line with expectations. However, a few respondents described the occurrence of the patient's death in hospital as a positive experience. This shows that the hospital can be a good place of death, but that considerable changes - and resources - will be required to make this routine, rather than exceptional. As the population ages, it can be expected that the number of hospital deaths will increase, rather than diminish. Consequently, it is important that the hospital is adequately resourced to provide sensitive, compassionate care to dying patients and their families. This will require substantial changes in the physical environment, organisation and delivery of care, and in staff understanding of their role in supporting and communicating with patients and their family carers. In presenting a detailed account of routine care of dying patients on acute hospital wards, the study findings will make a substantial contribution to the evidence underpinning the need for change.

For further information about the study findings, please contact

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