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

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Background and Aims

Although hospital is widely regarded as the least preferred place of death, it will continue to be where most people die.

Concerns have been expressed about the quality of care for patients dying in hospital, especially those affected by dementia.

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
- the environment of the acute hospital ward as a place of death

I held her hand and put my hand on her head and just spoke to her….it was lovely. And, in fact, it was the nicest way she could have gone, because she just went very gently. …It was a very nice, slow, gentle death.

Patient's daughter

Most families don't know they've (clinicians) made that decision (DNR), I think. Nobody actually says anything.

Staff nurse

The consultant on that ward was extremely good. He included my dad in all the conversations and he included me in all the conversations, and a lot of the conversations were three of us.

Patient's daughter

It was fairly obvious from the fact they took all the paraphernalia, the drip and everything off her that …. they were just letting her slip away. But they didn't ask me. I don't recall them actually saying.

Patient's husband

Conclusions

1. Accurate 'diagnosis' of dying is difficult, particularly in frail older people experiencing gradual decline .
2. There were no clear differences in the care and treatment of patients dying with or without dementia.
3. A cancer based model of palliative care does not transfer easily to the acute hospital setting.
4. The acute hospital ward is not a supportive environment for dying patients and their families.
5. Families' reported experience of care was very variable, but included some positive accounts of 'a good death'.
6. Hospital was not considered an inappropriate place to die, and may be preferred.
7. Hospital can support a 'good death', but often does not.
8. Staff attitudes and communication are critical to families' experience of death in hospital: much better 'sentimental work' is required from staff.
9. Hospital will remain the most common place of death: it is important to improve and adequately resource the care of dying patients on acute hospital wards.

And that's the problem. It's not nice dying in hospital. And some people aren't even lucky enough to have a side room to die in. They're dying in an open ward: that's bad. It's horrible, isn't it? Somebody's died and relatives come and they're having to grieve next to five other people watching. I mean, we pull the curtains round, but they're not soundproof. ….Maybe more side rooms. But, I must admit, I'm not a fan of nursing people in side rooms, because you can't always get in there to see to them and they're not easily observable.

Staff nurse

Family all arrived. She's in an open ward, it's visiting time. We're just sitting there, you know, not trying to let on to other people, because it's not nice for other people. In the end, went and asked the nurse if we could draw the curtains. She says, 'Yeah, course you can.' Nobody came to see her after that. Nobody came to see if we was okay…..And then, my mum died within the hour….we pressed the buzzer for the nurse to come. No one came. So in the end, I went out and I told them.

Patient's daughter

Communication and decision making

- Recognising dying is difficult and uncertain in a very challenging environment of care.
- Prognostic uncertainty intensifies the difficulties of communication between staff and families
- Staff lacked awareness of family concerns and responses, or the extent to which relatives' understanding of the situation could differ from their own.
- Families did not feel adequately informed, particularly about what would happen in the last days and hours before the patient's death.
- There was uncertainty 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 to balance family preferences and clinical judgements about best interests .
- Despite a longstanding policy commitment to patient centred care, staff contact with dying patients tended to be brief, functional and focused on the task in hand.

Method

Qualitative study set in 4 acute hospital wards focusing on care of older people

Ward observations	245 hours
Interviews with staff	38
Interviews with bereaved carers	13
Review of patient medical records	42

The hospital as a place of death

- The acute hospital ward presents a challenging environment for care and support of dying patients.
- Side rooms offered privacy but could leave patients isolated for extended periods of time.
- Across all wards, the variability in families' experience of care was striking.
- Some families reported feeling unsupported throughout the vigil they kept for their dying relative.
- For others, the hospital was, or came to be, the *preferred* or most appropriate place: it could even provide a *positive* experience of death and dying.
- Hospital was not always viewed as an inappropriate place to die.

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