

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

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Introduction

- Study aim: to explore care of patients
 - Dying on acute hospital wards
 - With and without dementia
- UK policy to
 - increase the number of patients who die at home.
 - avoid unscheduled admissions
- 55% of deaths in England occur in hospital
 - will increase with ageing population affected by complex co-morbidity
- Hospital is considered an undesirable place to die
 - Concern about quality of care for older patients
 - Especially patients with dementia
- Acute hospital not set up to deal with dying patients
- Pressing need
 - for greater understanding of the experience of death in acute hospital settings
 - how this may be improved.

Content

- Background and Method
- Recognising Dying
- End of Life Care Pathway
- Communication
- Dying in Hospital
- Conclusion
- The Clinical Perspective
- Discussion

Dying with dementia

- 25% of hospital beds occupied by PWD >65
- Care reported to be significantly poorer
 - Pain relief
 - Palliative care
- CFFOP found no difference in care of patients dying with/without dementia

Design and method

- Qualitative study in 4 acute wards
 - Oak, Ash, Elm and Fir
- 245 hours of ward observation
- 38 interviews with staff
- 11 interviews with 13 bereaved family carers
- 42 patient medical record reviews

Recognising dying

- Recognising transition point from possibility of recovery to inevitability of dying
- Avoid burden on patient and futile treatment
- Difficult in patient group: chronic co-morbidities, increasing frailty, possible cognitive impairment
- Difficult to tell how likely respond to treatment and likely outcome

Patients on EOLC pathway

	Number on EOLC at time of death	Number not on EOLC at time of death
Patients diagnosed with dementia	15	3
Patients not diagnosed with dementia	14	10

- Shortest time on EOLC pathway 2 hours
- Longest time on EOLC pathway 21 days
- 12 patients died within 2 days
- 1 patient on EOLC pathway for 3 hours, taken off and died 5 hours later

Benefits of the pathway

- ‘But if you can get somebody on the pathway, it just makes our job so much easier, to make them that bit more comfortable’ (Staff nurse, Elm)
- ‘The Liverpool care – I mean, is ultimately a checklist. And a very useful checklist.’ (Staff nurse, Oak)

Making the decision

- Process described by consultants as inclusive but final responsibility theirs to initiate and talk to family
- Nurses and junior doctors reported little direct input into decision
- Placement on pathway could simplify care management

Strategies of influence

- ‘So we are there, with our little input, but we can’t say, ‘We think this person needs LCP’. You can suggest it in a way that doesn’t offend the doctors.’ (Staff nurse, Oak)
- ‘We will say, ‘It’s been suggested this person goes on the pathway.’ And they always say, Well, we’ll review first and then we’ll see’... Sometimes just putting the idea in their head.’ (Staff nurse, Elm)

Simplifying management issues

‘I think the LCP is quite a relief for use as doctors because we somehow stop thinking in that way, that we could have helped more than we did or, do you understand? If the patient is suffering in front of you and you know that this decision made by a much more senior doctor than you are, then you quite accept the fact that the patient’s dying and you are just trying to keep him comfortable’ (Junior doctor, Elm)

Communication with families

- Key component of EOLC pathway – space to talk with patient's family
- Recorded in notes that decision to place patient on EOLC pathway discussed with family
- Most family carers interviewed recalled some discussion about approaching end of life
- Some carers had no such recollection

Staff perspectives

‘my usual way of saying is, “Where do you think we are, and what’s been happening, what’s your understanding been”you have to go very gently and then you have to think about having a further discussion the next day’ (Consultant, Oak)

Staff perspectives cont.

- Nurses described themselves as supporting the family:
‘it’s the nurse’s job to support the family after that decision’s been made’ (Deputy ward manager, Fir)
‘my responsibility... making sure the relatives are comfortable and they’re settled and, and they’re fully aware of what’s happening, and, and, it’s as much really as making sure the relatives are comfortable and happy, really.’ (Deputy ward manager, Ash)

Staff perspectives cont.

- Nurses also described themselves as acting as interpreters for family members:

‘a lot of people will just sit and nod at a doctor and when they’ve gone will ask the nurse...We had a relative last week that literally said, the doctor’s just been and told them what’s going off, I didn’t understand a word he said, can you tell me what he’s, what’s happening?’

Family perspectives

- Some carers felt well informed about their relative's status:

‘the consultant...was extremely good, he included my dad in all the conversations and he included me in all the conversations.’ (Patient's daughter, Ash)

‘my husband was...very happy with what they were telling him, and we were, we were relieved that they actually were doing something about M's pain... we wanted her to be comfortable, and the doctors did make us feel that's what they were doing.’ (Patient's niece, Fir)

Family perspectives cont.

- Some family carers had little or no recollection of being told that their relative was dying:

‘No, I don’t think they did, no, no. Perhaps they thought he wouldn’t be able to take it...I don’t know, might not. Nobody wants to be told for sure that he’s not going to be with you very long, do they?’ (Patient’s wife, Oak)

Family perspectives cont.

- Uncertainty could be exacerbated by lack of clarity in communication. The same patient's wife said:

'...(he) was always asleep when I went. And the nurse said, well, you can come in, bit more alert in the morning, come then. I ought have just, alarm bells rang, but anyway he woke up then, he looked at me, says, hello duck, smiled, went back to sleep' (Patient's wife, Oak)

Family perspectives cont.

- Some family carers were unsure of what or when they had been told:

‘I don’t recall them actually saying. I’m not too sure when I actually realised it...I’m not sure quite when I realised it, yeah. I think they did, actually. I think they did. Because I had a little chat with them at one point’ (Patient’s partner, Ash)

Family perspectives cont.

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Family perspectives cont.

‘lady doctor... announced that, you know, he was really poorly. I said, yes, clearly, I realise that, we’ve been through this many times before. And she said Well, we don’t think he’ll pull through this time... About three o’clock in the morning, he kept waking up, and I was sitting holding his hand and he was squeezing my hand really hard and I thought, No, this isn’t what a dying man is, he’s too strong.’ (Patient’s wife, Ash)

Communication with families

- Quality of communication variable
- Use of vague language could make it difficult for family carers to interpret what they were told
- Family carers sometimes had difficulty in finding someone to ask about what was happening
- Staff sometimes avoid engaging in difficult conversations with family members

Environment

We haven't really discussed the actual environment in terms of what it's like, the noise factors, the buzzers and machines. And, the lighting. Particularly if it's end stage dementia. Our environment is very set up for a clinical, acute medical ward. It is not set up for patients with dementia. It's not set up for patients who are end of life. So it'd be very nice to have somewhere a little bit more homely.

Ward manager, Oak ward

Privacy

I'd asked for him to be in the side room. Because I don't want people seeing him, you know, especially when I knew he was going to go. You know. So, I thought it were a lot easier [to be in a side room].

Patient's daughter, Oak ward

Well, knowing that she was dying, I think it would have been better if she was segregated, rather than mixed in with everybody else. I know it's because they want to keep an eye on the patient and that, but if they really know that there's nothing they can do, then there's no reason for that, is there really?

Patient's daughter, Ash ward

The bay can be a preferred place of death

The family wanted her to stay in the bay so we could keep an eye on her, if the family couldn't get to her, and that way,someone could be with her if the family couldn't.

Staff nurse, Oak ward

They even offered to put him in a side room because he was very sick. But I refuse, because I know, if he go into the side room he might die at any moment, before anybody ever know that he died. And that's the honest truth. That's the honest truth.

Patient's partner, Oak ward

Dying in a bay

When you've got relatives behind a curtain sitting with somebody who's dying, and you've got a relative opposite sitting, having a laugh and a joke, about, you know, whatever, I think you're not, you're not providing the best. For all of them, if you're doing that. So that's sometimes quite difficult to cope with, the fact that they haven't got that privacy that they deserve and need.

Staff nurse, Oak ward

The dilemma

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 on 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 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, Fir ward

Trying not to let on

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, 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, Ash ward

A good death

The hospital rang and said, 'I think you need to come now'. So we jumped in the car and we were there in twenty minutes.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. She looked very comfortable, very peaceful. When we were there, she calmed right down. And it was a very nice, slow, gentle death. I actually counted her breaths getting less and less, and it was a most amazing experience to be with her.

Patient's daughter, Oak ward

Dying alone

And that is, to be honest, that isn't something that happens a lot, nurses sitting with dying patients. It's very difficult to find the time to do that. And obviously, families do what they feel they have to or can do, but they're not necessarily with the patient twenty four seven, and it's the first thing every relative will ask, 'Were they on their own when they died?' And then, if I'm truly honest, it's not, it's not something I would ever say 'Yes' to. Because I know how distressing that would be for someone.

Staff nurse, Oak ward

Conclusion 1

- No difference in care of patients dying with/without dementia
 - Variability across all wards
- Recognising dying is difficult and uncertain
 - In a very challenging environment of care
- This intensifies the difficulties of communication between staff and families
- Staff tend to be
 - Task focused
 - Unaware of /unwilling to engage with family expectations and perspectives

Conclusion 2

- Hospital will remain the most common place of death
- Families value compassionate care over environment
- Hospital could
 - be a preferred choice
 - provide a positive experience
- Current environment does not facilitate compassionate or appropriate care of dying patients
- Important to plan for substantial changes in resources and infrastructure
- But better staff understanding and care of families is required and possible.

Thank you!

Further information

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Project web page:

<http://www.nottingham.ac.uk/research/groups/srcc/projects/frail-older.aspx>

