

Bereaved families' experiences of end-of-life care in the acute stroke setting in Wales, UK: a qualitative interview study

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Background

- Stroke is a major cause of mortality (Feigin et al. 2013).
- Access to specialist palliative care in the aftermath of severe stroke is rare (Payne et al. 2010).
- High quality end of life care following severe stroke is a professional priority (Royal College of Physicians 2012).

AIM

To establish how bereaved family members of people who have had a severe stroke experienced end of life care in the acute stroke setting.

THE INTERVENTION

- Classroom based training at hospice
 - Symptom control
 - Care Decisions for End of life tool
 - Bereavement
- Ward –based case discussion

Methods

- Qualitative.
- Convenience sample.
- In-depth interview.
- Thematic analysis.

Findings

- Nine participants;
- The variable nature and quality of interaction with healthcare professionals.
- Doing care at the end of life;
- Toward the realisation of a certain manner of good death.

The variable nature and quality of interaction with healthcare staff

*It was quiet in Casualty. They rushed her straight into CAT scan (...) the CAT scan came back, and she's had a massive bleed, brain haemorrhage so and the doctor who read the report said it would be an end of life. He said that there would be **no turning back**. (Louise)*

*He [ITU consultant] was absolutely brilliant. He talked us through and he was, you could see **he was being very much aware of how we were reacting to him**, both of us and how he was going to handle the way he needed to get the information to us (...). I thought that they were very, very caring. (Carolyn)*

The variable nature and quality of interaction with healthcare staff

*We told him [doctor] that he [patient] was an intelligent man. He loved his books, crosswords, uhm he knew a bit about everything (...) he's been ill all his life (...) so I've been his carer. And I said 'no' I said, 'the **last** thing he [patient] wanted was to be a vegetable and we don't know what the outcome's going to be'. He [doctor] said, 'right, we will put him into a ward, put him comfortable'. (Joanna, emphasis original)*

The variable nature and quality of interaction with healthcare staff

*The doctor from [name's ward] rang me and said 'can you come in I need to see you' (....). When I went in [to the hospital] he [doctor] said 'it's not looking good at all'. He said, 'he's had a terrific cerebral haemorrhage and we don't expect him to last till the end of the week. If there's anyone needs to see him they need to see him now'. (....). So **he was straight, he told us exactly what to expect** (Jenny)*

The variable nature and quality of interaction with healthcare staff

*It's trying to find somebody as well. (...).I didn't see them [doctors] as regularly as I would have liked (...). **We always had to go and find the doctor** too. In fact, I can't ever remember a doctor coming into the little room, the little side room. It was always either me or my sister going to find the doctor. (Connie)*

*The only time I spoke to any of the staff nurses was **when we went asking** questions. (Ruth)*

The variable nature and quality of interaction with healthcare staff

*A Sister came down one evening, from ITU, (...) asked me how everything was and I said 'well I do have a question' I said '**we were told that this is the end with [name]** basically and making her comfortable and what have you and she is in the severe stroke ward **but** I said, '**they're telling us something different**', I said 'is there something good happening here or are we being prepared for the end'? (.....) **The nurses were saying 'oh, she's had a really good day' and then talking about the physiotherapy and what have you.** That's when the confusion set in. (Carolyn)*

The variable nature and quality of interaction with healthcare staff

*I phoned in the morning to find out how she was and to be told that she'd been taken out of bed. So I was **really, really shocked** when I went back in to find that she was back in bed in a coma. (Connie)*

*I left the hospital at 04:30 and then I went back, about 8:30 in the morning, because (...) I'd forgotten her dressing gown (...) and she was still conscious then. And I said 'we're taking Dad', my father, 'to (...). We went back to the hospital, we were there by about 3 o'clock and she's gone into a coma. So **I felt really guilty, all the emotions.** (Louise)*

*It was so much of a **shock** that she passed away (...). When you're in there you don't look at the bigger picture oh you think "she's getting better". (Ruth)*

Doing care at the end of life

*They [nursing staff] were in and out all the time making him **comfortable**.* (Joanna)

*Making sure that she was **comfortable** underneath, you know, I mean changing the sheet underneath her.* (Connie)

*When I went there [to the ward] he'd be **clean** and he'd be tidy (...). His mouth was kept moist.* (Jenny)

*She was always **clean** and tidy and you know in terms of that like she never, there was never any issues.* (Ruth)

Doing care at the end of life

*She was making this awful noise, **the rattles**. We thought she must be in pain, but they assured us that she wasn't in any pain and then they were clearing the mucus that was collecting so they used some suction (...). It [death rattle] was just horrendous to listen to. (Connie)*

*Her **chest** was **rattling** like anything. It was really getting quite bad and it was distressing for the other patients to see (...). It was very **distressing** for us to have to listen to. (Louise, emphasis original)*

Doing care at the end of life

They [nurses] let us stay with mum for as long as we wanted to [after she had died] so we rang [name] and my other daughter [name] and they came down as well and we all stayed with mum for about an hour and a half (...) they [nurses], they didn't pressure us to go at all we were all able to say our what we needed to say her. (Connie)

Toward the realisation of a certain type of good death following a major stroke

You just want “it will be painless” or “It’ll, we”, help. “Don't worry,” “we will make sure she's”. Just things like that you needed to know. (Connie)

I said ‘does he know anything?’ They [doctors] said ‘as far as we are aware no, there's no brain function at all’. (Jenny)

Toward the realisation of a certain type of good death following a major stroke

We sat with him all day, all night and the following day until 7 in the evening when he just gave his last breath and went (...). I don't think he moved one second when he went into that bed, he never, his head was straight ahead. There was nothing. (Joanna)

She just turned as if she could look at me, but she didn't look at me, obviously. She couldn't open her eyes and she just held, I was holding her hand. It was just so very peaceful and she looked beautiful. (Carolyn)

Toward the realisation of a certain type of good death following a major stroke

*On the death certificate it was pneumonia and we didn't know she had pneumonia. If we would have known, **we would have been more prepared** [for her death] (...). The word pneumonia had never cropped up. [Mari]*

Toward the realisation of a certain type of good death following a major stroke

It took a week. She [mother] was in that, she was there, in that bed a week. (Louise)

She [mother] never regained consciousness and it was nearly 3 weeks, two and a half, three weeks. It was quite a length of time you know because my sister came back, because my sister was panicking that she wouldn't get here [in time]. (Connie)

Twelve days he went on without fluids without water. It was horrendous to see. (Jenny)

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My sister had said, 'isn't there anything you can do, she can't go on like this' you know uh and he [doctor] said, 'we can only do within the legal requirement of the dosage of morphine'. (Connie)

I did say to the doctor 'Have you got a form I could sign?' I would have given my permission to up his morphine and just let him go. Can't do it. (Jenny)

Conclusion

- Acute ward settings are places where people die;
- End of life care in these busy, noisy and fast paced environments is not without challenge;
- The manner of a person's dying casts an indelible mark on those who live on.
- Areas where continuing improvements are warranted, include:
 - Communication;
 - Clear lines of responsibility;
 - Regular review;
 - Proactive symptom management.

Thank you for listening

Does anybody have any questions?