

‘No one told me he was dying’: End of life care in the acute hospital environment, family members’ perspectives.

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Why?

How does a terminally ill patient with clearly documented limitations of care on previous admissions, return to hospital only to have full resuscitation efforts for 30 mins on a Saturday night before he is pronounced dead?

This is the question his family asked.

Adverse event and patient feedback investigations showed us that end-of-life care we provide requires significant improvement



A decorative border of colorful puzzle pieces surrounds the central text. The pieces are in various colors including red, blue, green, yellow, purple, and black, and are arranged in a pattern that frames the central message.

We needed a Framework to
put all the pieces together –
comprehensive,
integrated,
coordinated

But first we needed to hear from the experts...

What is end of life care like here at Ballarat Health Services?

We asked bereaved families..

Methods

- In 2013 we invited NOK whose loved one had died on our acute wards between January 1 and September 30, 2013.
- A qualitative interpretative design was adopted and data was collected via semi-structured open-ended individual interviews.

Methods

- Interviews were recorded, transcribed and a thematic analysis undertaken. Data analysis was undertaken by x2 researchers.
- Thirteen participants shared their very private thoughts and memories of the death of their loved one and five key themes emerged following analysis of data

Key Themes

- Preparation for death
- The care experience
- The dying experience
- Follow up after death
- Communication

Preparation for death

Sue: The Dr said “your father’s back in hospital because his breathing’s not good ... and he’s not coping. I’ve had a discussion with your father ... he wants no more treatment. He said he doesn’t want anything, he’s finished with it.” I said, “Okay.” he said, “I respect his wishes.” And I said to him, “and we respect dad’s wishes too.”

Sue: So it kind of didn’t surprise us that he didn’t want anymore treatment. What surprised me was that people agreed to it.

Preparation for death

Kell: ... the doctor there thought that he would die in hospital within weeks. I said, "Well, I'd like to take my grandfather home." That was completely dismissed by that doctor and in an arrogant way too. He basically said, "I'm not going to talk about that at this point."

Kell: Pop had his own money and I was willing to do whatever to have him die where he loved to be. He had said to me within prior weeks, "Kell, you know where I want to be love, it's at Waterloo." And that's where I lived.

The care experience

Ann: And they said, "Oh, just have a seat and we'll let you know when he arrives." And I sat there for almost an hour and nobody came ... I just thought, oh, he's died. But nobody came and said anything, and I went to the window and said, "I'm waiting for my husband to arrive" and they said, "they have taken him to 'somewhere' to do an operation." And I said, "So he's still alive" and they said, "Oh, yes, he's okay."

The care experience

Jude: I called the nurse in and I said, to the nurse, "He keeps twitching his shoulder and lifting his feet." She said, "Oh, he's in pain. When he does that you must come and tell us. We need to give him some pain killer." And I thought "Well, nice of you to tell me that now."

The care experience

Marg: She buzzed and buzzed to go to the toilet. Our younger brother, he said, she ended up pooing her bed. He buzzed them. He could hear them talking. He ended up going up to them and saying, "Get up there and clean up my mum." You don't want anyone to be incontinent. And they were telling her to 'just do it in the bed.'

The dying experience

Gerri: She never wanted us to complain. I don't know whether she got afraid that if we complained that they might be nasty to her. I would go to see her every morning and every night and she would say, "Geraldine, we're old. They don't care about us any more."

The dying experience

Jo: I think probably the other thing that quietly sat in my mind through that shock was the information given to me on the phone when the doctor rang me to tell me that Paul had passed away, was that they had commenced resuscitation but then became aware of a NFR order that was in place and they ceased immediately.... He was terminally ill, that's what I understood. He was terminally ill, he was NFR

The dying experience

Fran: I had about fifteen minutes with him. I was really cheesed off with the hospital that they didn't ring me and tell me how desperately ill he was,

Follow up after death

Judy: I was with the nurse at the time and I felt that she had treated me with respect. But I don't think she really knew what to do, as in what advice to give us ... I think probably I was a little disappointed that the hospital in no way actually followed up, social worker or anybody.

Fran: They said to me, "Someone will give you a call tomorrow" and I never heard a thing from anyone until I wrote to them and I got a letter back from them they would have rung me if I had asked.

Follow up after death

- Ina: We'd been married for such a long time. When you've been together that many years, the only time you've been apart is when you're in hospital. I hate it when I'm on my own, because I've always had Don there and it's very, very hard
- Kell: I actually ended up having a breakdown after Pop's death. So, it's been a pretty long road.

Communication

Lyn: I'll be honest, no-one ever mentioned that it was getting near. No-one

Jude: ... we just guessed...with everything disconnected, like Saturday he was connected to glucose or some clear stuff and he had oxygen and yet when we got there Sunday morning he was connected to nothing

Communication

Jude: The nurse who kept spraying the perfume said to us in the corridor one time, "We don't know, it could be three days, three weeks, we don't know." Which is crap. It's crap. My daughter said, "Mum, we know."

Fran: I said to them, if he was that sick, why wasn't he in ICU? They said, because he's next to the nurses station. He was wired. So they knew he was really, really ill, but no-one rang us

Communication

Ann: There was a family conference on the Thursday night where they told us what had happened,
Yeah, they were helpful because they gave us a chance to ask any questions that we wanted to ask...they kept us informed as to what was going on

Arle: ...so I met my brother at the hospital at 10.00 am. As I got there they were moving him into a single room. I know what that means.

Recommendations from the families

Fran: My main gripe was that I wasn't called to say how sick he was.

Arle: ...no one sat me down and said, "This is it."

Kell: I don't think it was acknowledged that I was the next of kin. I think I could have had more phone calls to let me know what was going on. Often I would just turn up and have to ask whoever was around.



Recommendations from the families

Fran: My main thing was, “Why didn’t they ring me?” I just naturally thought they would. I thought they really would.

The doctors would come in and see him and there was never much communication about what was happening. Sometimes he was going to have a CT and other times he wasn’t. Half the time it seemed like they had no idea what was happening

Recommendations from the families

Gerri: You need somewhere to go where you can ask, can you explain what's going on? Why can't they say, "Today the doctor came and this is what happened."

Kell: ...It was just so much losing control, not being able to help him and I know that is a process of letting go but the system didn't help either.



Framework elements

- Advance Care Planning
- Identifying patients at risk of deteriorating or dying
- Establishing medical goals of care
- Caring for patients who are actively dying
- **Communication skills training for staff**

You know that place between sleep and awake, the place where you can still remember dreaming? That's where I'll always love you. That's where I'll be waiting.

Tinker Bell, *Hook*