## "No one told me he was dying":

End of life care in the acute hospital environment, family members' perspectives.

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# Background and methodology

Ballarat Health Services (BHS) is a regional health service providing acute, sub-acute, residential aged care and community based services. This poster reports the experiences of family members in relation to the end of life care their loved ones received at BHS. This research is part of a larger project that will inform the development of an end of life framework to be implemented by the health service. A qualitative interpretive design was adopted and data was collected via semi-structured open-ended individual interviews.

Following this approval 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.

### The Themes

#### Five key themes emerged following analysis of data

- Conversations and communication
- The families' preparation for death
- Follow-up after death
- The care experience
- The dying experience

This poster will report on the family members' perspectives of the conversations and communication with members of the health care team.

Conversations and communication was a key theme and several sub themes emerged from the data. They consisted of overt conversation, inferred conversation and no conversation.

**Literature.** Effective communication skills are considered a key point in providing high quality end of life care. Nurses should be able to recognise that death is approaching and be prepared to have discussions with the family about future care needs (Hayes, 2010). When a person who is dying and their family are actively involved in end of life decision making it encourages positive relationships to be formed between the family, their loved one and nursing staff (Frank, 2009).

**Data.** According to the participants, the degree and quality of the communication about their loved one's wishes and care needs was variable.



#### **Overt conversations**

**Adam**: I remember saying to the doctor ...he said to me, "You know, look this is really not good". And then we had this discussion about how long, you know you don't expect a direct answer but [he said] maybe a week.

**Peter**: [The doctor said] "Your father's back in hospital because his breathing is not good, and his cough, and he's not coping." He said "I have 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."

#### **Inferred conversations**

**April**: I thought they sound like they're letting me know gently that the end is in sight. So it wasn't a big surprise.

**Ralph**: ...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.

#### No conversations

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

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

#### Participants' recommendations

**Tina**: You do need to hear it, you do, I think. You need to start prepping yourself and the rest of the family. To say, well this is it.

**April**: Just more information in that initial stage, you know, you're in a panic because you don't know what's going on.



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