

# No one said he was dying: families' experiences of end-of-life care in an acute setting

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## KEYWORDS

death and dying, end-of-life care, communication, advance directives, bereavement, rural nursing

## ABSTRACT

### Objective

To explore the family's experience of end-of-life care for their dying family member during the last few days of life in an acute rural hospital.

### Design

Interpretive design using qualitative methods, including 1:1 semi-structured interviews.

### Setting

The study was undertaken in a large regional health service in Victoria.

### Subjects

Twelve relatives who were next of kin of people who died between 1 January 2012 and 30 June 2013 in an acute ward at the health service agreed to participate in the study.

### Main outcome measure

Families' perceptions of end-of-life care for their dying family member.

### Results

Data analysis identified five themes that were grouped into two general dimensions – communication (guidance for family member's role in end of life care, the family's preparation for death, the dying experience) and care and support (the hospital care experience, follow-up after death).

### Conclusion

A lack of open and candid communication hindered family members' engagement in decision-making and involvement in their loved ones' last days of life. The absence of formal processes for end of life (EOL) care planning resulted in families being unprepared for what they perceived as their family member's 'sudden death'.

## INTRODUCTION

Acute hospitals are increasingly being required to provide care for people at the end of their life (Australian Institute of Health and Welfare 2014, World Health Organization 2014). However, the effective management of people who are dying in acute care environments is challenging. The overall focus of acute hospitals is generally on diagnosis and treatment with a view to cure and discharge. In this context, recognition of the fact that a person may be approaching the end of life and in need of conversations about their goals of care, limitations of treatment, a palliative approach to care, or provision of terminal care are often delayed. Communication and care planning with patients and families may be poor and the dying person's preferences may be neglected. The quality of end of life (EOL) care has important implications for the individual patient and also for their family, whose experience of EOL care will live on long after their loved one dies.

Most research on the quality of EOL care has been conducted in palliative settings, as traditionally EOL care is associated with terminal illness, such as cancer (Australian Institute of Health and Welfare 2014). However, a substantial number of people die from life-limiting illnesses, such as chronic obstructive pulmonary disease and congestive cardiac failure (Murray et al 2013). Hospitals provide episodic care over many years for chronic illness exacerbations and during any of these admissions death can occur (Murray et al 2013). It is estimated that on average nearly 40% of people who die in hospital receive life-sustaining measures that are considered unlikely to be of benefit right up until the moment of death (Cardona-Morrell et al 2016). Decisions about whether it is appropriate to escalate life-sustaining measures for people with a chronic, life-limiting illness are often postponed until there is a sudden deterioration. It is then, that families and health care workers are required to make medical decisions without knowing the dying person's preferences (Winzelberg et al 2005). While there is increasing patient-centred research related to EOL in hospital settings, there has been minimal examination of the quality of EOL care in Australian acute care facilities (Kearns et al 2017; Waller et al 2017).

Policy and program developers are placing increasing importance on listening and responding to the views of patients and their families (Australian Commission on Safety and Quality in Health Care 2015). Listening to people who are dying has been a cornerstone of palliative care since Dame Cicely Saunders and John Hinton pioneered the modern hospice movement in the 1960s (Saunders 2003). Previous studies have typically used satisfaction-based surveys that provide a limited understanding of the patient and families' overall experience of care in hospital (Robinson et al 2014). Only a small fraction of EOL care research has been conducted on how patients and their relatives experience care at the end of life in Australian acute healthcare settings (Kearns et al 2017; Robinson et al 2014).

Even less EOL care research has been conducted in regional settings and there is a need for research exploring rural/regional family member/caregiver experiences of EOL care (Robinson et al 2009). In Australia, people living in regional and remote areas experience death rates between 10-70% higher than in major cities (Australian Institute of Health and Welfare 2008) and also have less access to specialised EOL care services (Wilson et al 2006). That review stated more research is clearly needed to fully understand family caregiver experiences, and what support would be most helpful in these settings.

The aim of this study was to explore the family's experience of EOL care for their relative during the dying process – the care that was provided in the last days and hours of life, in a large regional acute hospital.

## METHOD

### Design

An interpretive research methodology was used to explore how the participants made sense of the experience of their loved one dying in the acute setting. Interpretive research is a post-positivist approach to research

that suggests the researcher is not value free but is affected by social, cultural and political points of view (Schneider et al 2013). A critical aspect of interpretative research is listening and observing, with data collection through the use of interviews. This methodology is also useful when previous research has been limited (Adams 2010). Nursing in particular has found this type of inquiry particularly useful as it moves “beyond established qualitative methodologies in order to generate credible and meaningful disciplinary knowledge” (Thorne et al 2004, p3).

### **Setting**

This research was conducted in a large regional health service, located in a large provincial city of 100,000 people and servicing a 48,000 square kilometre area in regional Victoria, Australia.

### **Participants and recruitment**

Participants were recruited using convenience sampling. Written invitations were sent to all next of kin (NOK) of patients who had an expected death (as established by the Health Service’s mortality review) between 1 January 2012 and 30 June 2013 in an acute ward at the health service (n=81). Inclusion criteria included:  $\geq 18$  years of age; English-speaking; able to consent to participate; the participant’s relative’s death was expected i.e. the relative had a life-limiting illness; and the participant’s relative was  $\geq 18$  years of age. Next of kin who were a government appointed entity, such as a carer, guardian or administrator, were excluded.

### **Data collection**

Semi-structured interviews were conducted one-to-one and face-to-face with the participants. Interviews were conducted between three and 12 months following the death of the participant’s relative. Participants were allowed to decide for themselves when to be involved in an interview (Bentley and Connor 2015).

### **Data analysis**

Each interview was audio recorded and transcribed verbatim. Two researchers independently listened to and read the transcripts and then met to agree on identified themes (Rasmussen et al 2012). The themes were then defined with clear descriptions and supported with data from the transcriptions.

### **Ethics**

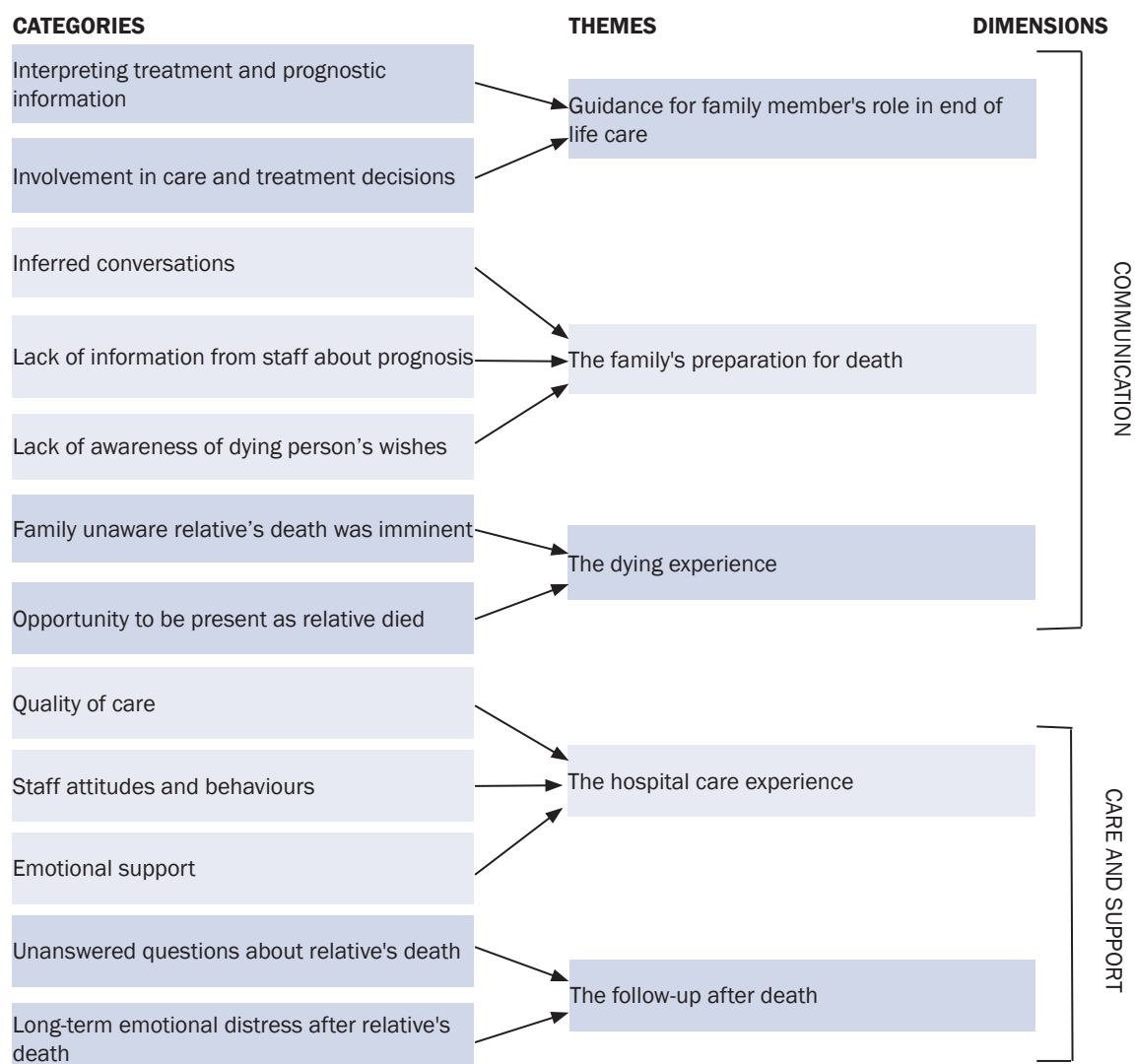
Ethics approval for the study was obtained from the relevant Health Service Human Research Ethics Committees (Ballarat Health Services and St John of God Hospital Ballarat Human Research Ethics Committee LNR/13/BHSSJOG/50).

## **FINDINGS**

There were 12 participants (10 females and two males, response rate 14.8%) who agreed to participate in the one-to-one interviews. On average the interviews lasted 35 minutes, with the interview length ranging from 16 minutes to 1.5 hours. Data saturation was achieved. Five themes emerged following analysis of the interview data (table 1): guidance for family member’s role in end of life care; the family’s preparation for death; the dying experience; the hospital care experience; and follow-up after death. These themes were grouped into two general dimensions (figure 1): Communication; and Care and Support.

**Table 1: Definitions of identified themes**

Theme	Definition
Guidance for family member's role in end of life care	Health professionals' communication on the current health status and/or prognosis of their relative. This may have included formal family conferences or bedside conversations.
The families' preparation for death	Health professionals' communication about the dying process. This may also include conversations between family members and their loved one.
The dying experience	Health professionals' communication that relative's death was imminent.
The hospital care experience	Family members' perceptions of the care their relative received, including quality, staff attitudes and emotional support.
The follow-up after death	Any contact from the health service after the relative's death.

**Figure 1: Categories, themes, and dimensions**

## Communication

Families' experience of communication with health professionals in the acute hospital setting was a dominant theme in this study. Family members described positive and negative instances of communication style, content and consistency.

### **Theme 1: Guidance for family member's role in end of life care**

Family members asked for guidance in interpreting what doctors say to them, especially in understanding what treatment means and how treatment can be distinguished from prognosis. Pseudonyms have been used in order to maintain confidentiality of the participants.

*Meg: 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."*

*Jane: We had a couple of meetings, two meetings, on that Friday morning with the doctor that was looking after him and the nursing staff and they didn't actually say, "He is going to die." But in a roundabout way, when they said, "He's going to be severely disabled" [my sister] and I both got the impression that they were sort of softening us up like, "We'll keep the machine on for as long as you like but really, you need to just let him go."*

Family members reported a tension between the need for prognostic information about their relative's changing condition and wanting to hear things from doctors that allow hope.

*Kate: Yeah, so, I don't know. And that's the thing, it's all that I don't know whether people don't want to tell you things or whether they're concerned. I mean you're already in a state of shock and how much, at that stage, would I have been able to cope with? I'm not sure.*

Some family members had clear and open conversations with the health professionals and reported being comfortable with the care decisions made.

*Dom: He said "Your father's back in hospital because his breathing's not good, and his cough, and he's not coping. I've had a discussion with your father... he wants no more treatment. He said doesn't want anything and he's finished with it." I said, "Okay." ... we respected dad's wishes.*

Some family members felt peripheral to important discussions between the doctor and their family member.

*Meg: A couple of times they made her cry and I felt so awful for her. I know down the track you've got to do this, but sometimes I wish they'd just take the family aside and say to the family, "This is what your mum or your dad might have to do." Let us break the horrible news. They're our parents*

### **Theme 2: The families' preparation for death**

Some family members received very little explicit communication from staff about the dying process. Many family members reported that health professionals used euphemisms – "he'll go tonight" and "her time is near". Family members were forced to make inferences when interventions or services were withdrawn.

*Julie: ... 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.*

In the absence of clear communication, the realisation that their relative's death was imminent was unexpected and upsetting for these family members.

*Betty: Then the nurse said, "The doctor wants to see you." I thought, "Oh yeah, the doctor's going to tell me 'Lance's really crook'. The doctor just sat there. He didn't say anything. I just said, "He's gone has he?" And he said, "Yes."*

*Dom: So he said, "Okay, in that case you'll need to come now." And that sort of shocked me. Because dad's been limping along for so long. He said, "You'll need to come, it'll be in a few hours, or, it'll be tonight."*

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

The ability of families to prepare for the death of their relative relied not only on good, timely communication from health care staff, but also on the communication within the family. Some family members reported feeling well prepared for their relative's death and were aware of their wishes.

*Mary: She didn't want any intervention. Every time she went in there she said, "You're not doing anything to me, if anything happens." She had already signed a form thank God, before she was diagnosed with Alzheimer's, that she didn't want to be resuscitated.*

Other family members felt they did not have a clear idea of their relative's wishes for care at the end of their life.

*Jill: ... he never actually said, "If I have a massive heart attack I just want to be left to die"... they said, you know, "What do you think he would want?" My sister said "It's really hard to choose for someone else, when you're ending their life"*

### **Theme 3: The dying experience**

Some family members expressed that they knew or had a sense that their family member was dying, however, many were not aware when their relative's death was imminent. Several family members were distressed and disappointed that they were not present at the actual moment of death. Some family members described their relative's death as a sudden event or traumatic death.

*Julie: So we've just gone in thinking they've either shut it [the curtain] to give him a wash and as I've pulled it back I've just gone, "Oh my God, what's wrong with [husband]?" My daughter said, "Mum, he's gone."*

*Betty: 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,*

Where families were made aware that their relative was close to death, they reported being grateful for the opportunity to make the most of that time with their relative.

*Dom: ...but that was really his last cognisant evening and we all stayed at the hospital with our partners and we just sort of sat round the bed and he had a lovely time. He chatted, I mean his words were a bit slurred sometimes or he'd forget words.... He just had a lovely time that last night.*

## **Care and support**

### **Theme 4: The hospital care experience**

The care received from members of the health care team varied in quality. Some family members perceived that their relative received "good" care.

*Dom: The staff were brilliant. They explained things that they were doing for dad. They'd come in and say, "Okay, we're just checking out this or that."*

Other family members perceived the attitudes and behaviours of staff towards their dying relative as demeaning and unacceptable.

*Meg: A lot of that care was just not right. She even knew that herself. You don't have to be told to "Do it in bed" rather than going to the toilet. 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, "Meg, we're old. They don't care about us anymore." I just think to myself, "You guys, you're going to be there yourself one day." When someone doesn't treat you with dignity .... The dignity just isn't there.*

Several family members perceived a lack of emotional care from health professionals, both for themselves and their dying relative.

*Meg: That woman in ED, I couldn't believe it. She nearly tackled us to the ground. Like we were in a rugby team. We've just been told mum is dying and we're going out to see her and she said, "Two at a time."*

The option of dying at home was discussed with some family members and their dying relative. However, there was often a lack of practical support to make it happen, particularly for people who came from rural and regional areas.

*Kerrie: I first heard news that 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."*

### **Theme 5: Follow-up after death**

In addition to the care experienced while their relative was dying, many family members commented on the need for support following the actual death.

*Mary: Probably I think, perhaps that follow-up phone call, particularly considering the circumstances around Peter's death. I felt that perhaps that could have been explained to me a little bit better.*

Some of the family members expressed long-term grief issues and emotional distress following the death of their relative.

*Judy: You've looked after them for years and years and years and then all of a sudden they're gone. It's like someone closing the door and it's bang. There's nothing behind it. You're on your own. I just want to end everything.*

*Interviewer: So you are having suicidal thoughts?*

*Judy: Yeah, I did.*

## **DISCUSSION**

As the number of people dying in acute hospitals grow, family members will increasingly participate in decisions for medical procedures and the withdrawal of treatments. The findings of this study describe how next of kin (NOK) experienced the end of life care for a family member who died in a large acute hospital in a rural setting. These experiences provide important information on how families perceived communication from health professionals and their own role in EOL care. Understanding family members' perceptions and involvement in hospitalisation at the end of life is essential to providing quality EOL care in acute hospitals (Swerissen and Duckett 2014).

The lack of open and clear communication from health professionals was a major issue raised by family members. This finding is consistent with previous research, including a review of integrated care pathways for end of life (Neuberger et al 2013), in which failure to communicate was clearly one of the most serious concerns raised by relatives and carers (Swerissen and Duckett 2014). Family members in this study highlighted problems with communication that reflected a lack of recognition of their role in EOL care for their family member. In this study family members clearly expressed their desire for different kinds of information and engagement with EOL care and decision-making. The families' comments suggested they not only wanted the 'facts', but also needed help interpreting those details in order to be able to recognise death was imminent. This finding is similar to that of the study by Russ and Kaufman (2005) involving 26 family members of patients who had

died in a California community hospital. That study found that families' feedback indicated they often 'knew' in retrospect, but couldn't 'hear' at the time, suggesting families did not need more information, rather, they needed more interpretation of details and facts. Helping families understand information about prognosis and its implications is important to prepare them for the decision-making that precedes death.

A lack of open and transparent communication made some of the NOK feel marginal to important communication and decision-making related to EOL care for their dying relative. Higher levels of shared decision-making during EOL care have been associated with higher levels of family satisfaction with care (Young et al 2009), and poor communication is a major factor in complaints relating to EOL care (Australian Commission on Safety and Quality in Health Care 2013). Health professionals need high-level communication skills and need to be able to provide guidance to NOK around their responsibilities surrounding their family member's dying.

Many of the NOK felt they were unprepared for their family member's death. Next of kin reported difficulty with changing their mindset from hoping for the best to having to face their family member's imminent death. They also reported feeling unprepared for the decisions demanded of them very near the time of death, such as the withdrawal of treatment or emergency resuscitation. This finding is consistent with previous research related to surrogate decision making, where discordant expectations about prognosis were found to be common between patients' physicians and surrogate decision makers (White et al 2016). Family members in the study by Russ & Kaufman (2005) reported similar experiences. In that study, family members accustomed to interventions and discussions of how to "turn this around" reported experiencing the final decline as a "death without dying" (p. 117).

Several factors may be related to NOK's perception of their family member's 'sudden' death. Firstly, there is often a delay in identifying patients whose imminent death could have been anticipated (Gott et al 2011). Of the people in Australia who died in an acute hospital, 70 per cent received treatment aimed at cure up until the time of death, suggesting that health professionals did not recognise that the person was dying (Hillman 2010). General practitioners and hospital specialists have previously reported difficulties with timely recognition of patients at risk of dying (Gott et al 2011). Tools, such as the Supportive & Palliative Care Indicators Tool (SPICT™) (Highet et al 2013) and the "surprise question" (Moss et al 2008), may prompt identification of patients at risk of deteriorating and dying.

Despite understanding that a person with a life-limiting illness is dying, families often do not recognise when death is imminent (Australian Commission on Safety and Quality in Health Care 2014). Many family members reported that health professionals used euphemisms – "he'll go tonight" and "her time is near". Family members were forced to make inferences when interventions or services were withdrawn. Previous research has shown that health professionals are often uneasy discussing death and dying with patients and their families and do not feel they have the required skills to have difficult conversations (Noble et al 2015). Inadequate role preparation for the provision of high quality EOL care has been identified as a significant problem, particularly in rural settings (Robinson et al 2009). Only a small number of studies have explored rural health professionals' perspectives on providing EOL care and further research is needed to evaluate if specific health care delivery issues exist in these settings. Problems with talking about and planning for death is one of the most significant obstacles to improving the quality of EOL care (Swerissen and Duckett 2014; Australian Commission on Safety and Quality in Health Care 2013).

Finally, some NOK were not clear about their family member's wishes for EOL care and felt unprepared for the decisions they were asked to make close to their family member's death. Very few families were aware of the concepts of advance care planning or had discussed the goals of care approach with the treating doctor. Advance care planning has been shown to be an effective approach for improving communication between



patients who are dying, their families and health professionals (Brinkman-Stoppelenburg et al 2014). An advance care plan (ACP) is the plan for future health and personal care whereby a person's values, beliefs and preferences are made known so they can guide clinical decision making at a future time when that person cannot make or communicate their decisions because they no longer have capacity (Detering et al 2010). An ACP can provide clarity for health professionals who provide treatment and services and for family members who may be involved in the decision-making (Brinkman-Stoppelenburg et al 2014).

The quality of the care and support experienced by NOK and their dying family member varied considerably. While some NOK were happy with the care provided, others perceived their family member did not receive basic care and was not treated with respect or dignity. Similar findings in which health professionals stopped engaging with the dying person's clinical needs in acute settings, almost as though these needs were no longer relevant, have been previously reported (Neuberger et al 2013). Most medical and nursing staff are motivated to provide quality care, however, factors such as feeling under-prepared and under-educated strongly influence the cultures and attitudes towards caring for dying patients (Aleksandric and Hanson 2010). Caring for the dying is important and doing it well requires health professionals to have high-level skills in clinical care, compassion and communication.

Family members also expressed the need for support and follow-up after their relative's death. Some family members reported significant grief resulting in negative consequences for their health. The detrimental effects of long-term, unresolved grief are well documented (Fauri et al 2000). In the palliative care setting it is well recognised that care does not end until the family has been supported with their grief responses and those with complicated grief responses have been helped to get care (Street et al 2004). Further work is needed to explore the availability and quality of bereavement services in acute settings, particularly in rural areas.

## **LIMITATIONS**

This study explored the experiences of 12 family members in one hospital in regional Australia. The findings are local and particular to the area, however, may be relevant to similar hospitals in similar rural/regional settings. As the sample size is small it is not clear that findings are representative of the experiences of family members of people who have died in this rural setting. The use of family members as patient proxies, while providing a limited understanding of patient experience, still provides important information on the quality of EOL care in this setting.

## **IMPLICATIONS FOR CLINICAL PRACTICE**

This study identified key actions for nurses and doctors in providing a best practice approach to caring for the dying person. Firstly, allowing families time to prepare for their loved ones death by identifying that the person is dying and family as soon as possible. Families need to be involved in the conversations, and have information, including prognosis, explained to them. Clinicians should be sensitive, use plain language and avoid euphemisms, with follow up to ensure the family understands. Secondly, there is potential for ambiguity and uncertainty at the end of life. Clinicians should explain the prognosis and that the dying process varies between individuals. This must be honestly and openly acknowledged, and discussed with patients, substitute decision-makers, families and carers. Finally, families of people who are dying also need care from the treating team, both during the dying process and following the death. There is a need to ensure there is support for the family with their grief responses and to identify those that are at risk of complicated grief.

In order to address these priorities all members of the interdisciplinary team should receive education and training to prepare them for having conversations about EOL care (Australian Commission on Safety and

Quality in Health Care 2014). Results from this study have informed an EOL framework, providing guidance and direction for staff at a large regional health service, for the delivery of best practice EOL care.

## CONCLUSIONS

Families are seeking guidance from health professionals for their role in end of life care for their dying relative. End of life care planning in acute hospitals needs to incorporate strategies, such as health professional communication skills training and advance care planning, to ensure end of life discussions take place. These discussions need to take into account the preferences of both the patient and their family and provide guidance for them through the dying process.

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