Perceptions of a “good death” in acute hospitals

In this article...

▷ What constitutes a “good death”
▷ Strengths and limitations in end-of-life care in an acute setting
▷ How nurses’ skills and staff support can be improved

Authors

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Abstract


Background

Despite the fact that half of all deaths occur in hospital, there is a lack of literature on general nurses’ experiences of caring for end-of-life patients on general hospital wards.

Aim

To ascertain general nurses’ perceptions and experiences of a good death in an acute hospital setting.

Method

In-depth interviews were conducted with 13 general nurses working in an acute hospital.

Results

Six themes were identified as important in facilitating a good death: good communication/awareness of expected death; time (to care); environment; support; knowledge; symptom management.

Conclusion

Participants felt that failing to communicate a diagnosis of dying adversely affected the quality of death. As such the focus of future end-of-life care education needs to include how general nurses can facilitate communication and handle difficult questions to enable a good death.

Literature review

More than half of the deaths in England (58%) occur in acute hospital settings (Department of Health, 2008) but the patient’s death is not always what may be considered a “good death”.

A good death is dependent on:
» Clear communication around the disease process (Healthcare Commission, 2007);
» Good symptom management;
» Support for the patient and family members;
» Having people important to the patient close by in familiar surroundings, while being treated as an individual with respect and dignity (Office for National Statistics, 2011; Public Health Intelligence Northern England, 2010; DH, 2008; Hughes et al, 2008; Yin et al, 2007)

The DH’s (2008) end of life care strategy for adults sets the standard for a good death, as identified by patients and relatives. The Liverpool Care Pathway was developed to facilitate a good death in any setting (Marie Curie Palliative Care Institute, 2009). After the decision by NHS England in 2013 to phase out the LCP, new guidance identified five priorities for end-of-life care (Box 1) (Leadership Alliance for the Care of Dying People (LACDP), 2014).

Patients who die on general wards in acute UK hospitals receive the most of their care from non-specialist nurses. It is important to know what barriers and fears general nurses experience when delivering end-of-life care in acute hospital settings so current deficits can be improved on. This study aimed to:
» Gain an understanding of the experiences of generalist nurses caring for dying patients in an acute hospital environment;
» Identify factors that generalist nurses believe can facilitate a good death.

5 key points

1 Communication about death and the diagnosis of dying can influence whether a death is “good” or “bad”.
2 More research needs to be done into communicating diagnoses of dying to patients.
3 Working closely with colleagues who are experienced in end-of-life care increases knowledge, skills and confidence in end-of-life care.
4 Nurses want to advocate for patients to prevent medicalisation of death in hospital.
5 General nurses need access to emotional support when caring for patients who are dying.
may raise expectations in patients and family members. Yet, as Murakawa and Nihei (2009) found, general ward nurses already feel unable to meet the expectations of dying patients and their families.

The emphasis on recognising and communicating the likelihood of death in a sensitive and compassionate manner is important because anticipated deaths have been shown to be less disruptive and emotionally demanding for nurses on general wards (Costello, 2006).

The philosophy of holistic care – encompassing empathy and dignity – along with good symptom management is also considered important, but has been reported to be obstructed by the medicalisation of death (Murakawa and Nihei, 2009). In Middlewood et al’s (2001) study, 78% of patients were found to have had diagnostic tests in the last 48 hours of life, showing the acute hospital culture often ignores the emotional and spiritual needs of dying patients in favour of technology.

Hospital patients with end-stage non-malignant disease were even more likely to have aggressive treatments and investigations immediately before death (Murtagh et al, 2004). This affects patient choice, as well as the quality of their death (Willard and Luker, 2006; Proulx and Jacelon, 2004).

Patients who die on general wards receive most of their care from non-specialist nurses, with varying levels of help and advice from specialist palliative and end-of-life practitioners. The Francis report (2013) raised concerns that nurses do not have adequate training or resources to care for complex patients such as those at the end of life.

It is unrealistic to assume that the same level of care can always be delivered in a busy, acute ward as in a hospice, but there is a legal and ethical requirement to ensure that care is as “good” as it can be within the parameters set by the National Institute for Health and Care Excellence (2011) quality standards and the priorities for end-of-life care (LACDP, 2014).

Method

We used a phenomenological approach (Moule and Hek, 2011) to examine, understand and describe participants’ experiences, and purposive sampling to recruit appropriate individuals to the study. Ward managers at a large foundation trust in the south-east of England recruited 13 general nurses who had differing lengths of service (Table 1).

Ethical approval was obtained from the hospital trust and Canterbury Christ Church University. A schedule of open-ended questions was used to collect data through face-to-face, in-depth interviews, which each lasted for an average of 23 minutes. Data was analysed using Nolan’s (2008) analytical framework to group ideas, thoughts and feelings.

Results

Six themes were identified:

- Communication/expected death;
- Time to care;
- The care environment;
- Staff support;
- Staff knowledge;
- Symptom management.

Communication/expected death

When a patient is clearly dying, communication was important to all participants so that all concerned could prepare for the death:

“The patient knew that he had cancer, the family knew and they had support from the doctors and everybody… the family were informed of what’s going on, so there is a big communication thing going” (Nurse 7).

“Things that make a death better are things like communication” (Nurse 2).

Failure to diagnose that a patient would die had an adverse effect:

“There are certain consultants who do not want to make a ‘do not resuscitate’ decision or ‘for end-of-life care’… Patients and their relatives’ end-of-life experiences are often affected by a lack of decision” (Nurse 8).

Most participants thought patients and their family members were given an unrealistic prognosis by the doctor:

“[The family] had completely false hope… the doctors didn’t even speak to the family… and they really thought we were going to save him, and it was just false” (Nurse 6).

However, despite criticism of doctors’ poor communication skills, participants did not regard it as their role to communicate any bad news:

“It should be initiated by the doctors because they are the ones that are giving the treatment” (Nurse 4).

“However experienced or qualified they are, you’re not a doctor… information has to come from a doctor” (Nurse 1).

Participants deemed handling difficult questions to be challenging:

“I’ve been there when the doctor has spoken to the family that the patient is going to die, and I found that really hard to deal with… I was trying to support them. It was really difficult” (Nurse 11).

“Breaking bad news and talking about those sorts of things are just… that’s probably one of our weakest [areas]” (Nurse 1).

Time to care

Difficulty in dividing one’s time between patients who were acutely ill and those who were dying was acknowledged by both senior and junior nurses:
As a pragmatic nurse, I have to say you have to focus on that person who we can keep alive and give another 20, 30 years of life but it’s a horrible call to have to make” (Nurse 1).

“You always seem to cope with it... you always seem to figure out how to do it, no matter how short-staffed you are” (Nurse 2).

Although participants did not want a patient to die alone, it was acknowledged that this sometimes happened:

“You would want somebody with them, but it’s not always possible and that’s quite sad that you have all this hubbub and bubble going on around you, and someone dies alone” (Nurse 11).

The care environment

Seven participants identified hospital as the wrong place to die. The constant struggle to free up beds for patients who were acutely ill was partly to blame and affected nurses’ morale:

“I think a lot of them [nurses] are just getting really fed up with the constant barrage of ‘the bed is more important than the patient’” (Nurse 6).

However, there were perceived advantages over dying at home:

“Sometimes it’s better to be in hospital. I don’t know... it’s my feeling we can access drugs and help and all kinds of things [more] quickly” (Nurse 2).

It was generally acknowledged that a side room affords greater privacy for final conversations and facilitates family visits around the clock, if necessary. With relatives present, there was an assumption that they would call nurses if needed but one participant was concerned relatives may not feel supported:

“it’s really important... if they [relatives] are in a side room, they still feel supported” (Nurse 11).

Support for staff

Although one participant referred to gaining support from the matrons, another said they failed to understand the pressures nurses are under when caring for patients who are dying. The main support came from ward nurse colleagues:

“Getting support from other ward staff [nurses] helps as well, and if you’ve got good support you can balance it [acute versus dying patient] OK” (Nurse 11).

“The nurses were here for me after [the death] and said ‘come and have a talk about it’, which is really nice and I let all my emotions out” (Nurse 3).

One participant commented that it was not always recognised that nurses may have had a death to deal with – this was a concern, and particularly so in the case of junior and student nurses:

“Sometimes we forget, as a group on the ward, that actually the nurse has just had a death to deal with. She needs some time to think about it, to go away, she might be upset, she might be a student with a first death. We don’t seem to think about that in the equation any more” (Nurse 2).

However, good communication is often lacking, so patients are prevented from being able to make decisions about their end-of-life care (Willard and Luker, 2006).

Participants did not want to communicate bad news, despite being critical of doctors’ failings – a finding similar to those of White et al’s (2001) in oncology nurses. Participants’ concern about handling difficult questions and feeling that experiencing communication issues first hand on the ward may help develop better skills than can be taught in the classroom were notable.

Although nurses moved patients to a side room to offer privacy, this risks the patient being isolated (Pease and Finlay, 2002). There is also a risk that patients may die alone because nurses do not have the time to sit with them when they are caring for other patients who are acutely unwell (O’Hara, 2011; Murakawa and Nihei, 2009).

The palliative care team was recognised as supportive:

“[The palliative care team] are there for expertise in what the most appropriate amount of medication is... and a resource for teaching... there are staff who want to talk to you about the process and what to expect... what happens during and after [dying]” (Nurse 12).

“I think it’s good if [the palliative care team] come in and make suggestions... just for peace of mind that we are not missing anything as well” (Nurse 11).

The possibility that a person may die within the next few days or hours is recognised and communicated clearly, decisions made and actions are taken in accordance with the person’s needs and wishes, and are regularly reviewed and revised accordingly:

Sensitive communication takes place between staff and the dying person, and those identified as important to them:

The dying person, and those important to them, are involved in decisions about treatment and care to the extent that the dying person wants:

The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible:

An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, coordinated and delivered with compassion.

Source: Leadership Alliance for the Care of Dying People

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Staff knowledge

Six participants said education helped in relation to symptom management and communication skills, and most participants concluded that the most effective way to learn was by observation and first-hand experience:

“I think it’s good to go on a study day, but the way I’ve learnt is from experiencing it” (Nurse 10).

“It’s almost like a life skill, you’re not able to pick it up from college; you’re only going to pick it up from experiences on the ward” (Nurse 8).

Three experienced and one newly qualified participant felt their formal training lacked any focus on end-of-life care.

Symptom management

All participants felt a good death was one in which the patient was free from pain and distress. Most believed the last hours of their patients’ lives were comfortable:

“She went very peacefully and all the care she got... we were happy she was comfortable” (Nurse 3).

“He was calm and settled and died peacefully an hour later with his wife sitting with him” (Nurse 13).

Discussion

Communication around the diagnosis of dying has an impact on the death experience for the patient, family and the nurses caring for them (Neuberger et al, 2013; Murtagh et al, 2004). The nurses in this study said that, if done well, communication can facilitate a good death in an acute hospital setting.

However, good communication is often lacking, so patients are prevented from being able to make decisions about their end-of-life care (Willard and Luker, 2006).

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All the nurses in this study, and junior
nurses in particular, found communicating with a dying patient’s relative stressful. However, some of this stress can be alleviated if nurses are supported. This support was said to come from ward nurses and the palliative care team, which participants identified as assessing that drugs and care were appropriate.

Hopkinson (2002) highlighted the positive effect of support in reducing anxiety. Although it appears senior nurses are mindful that junior nurses need support, this study revealed a gap in the awareness of structured emotional support that is available via the chaplaincy service, clinical supervision, the hospital counsellor attached to the palliative care team and counsellors accessible through occupational health.

Patients who are dying want to be cared for by competent staff (Neuberger et al, 2013) and we know from previous studies (Graham et al, 2005), as well as this research, that confidence increases with knowledge, which, in turn, often derives from experience. However, even experienced nurses requested that the palliative care team see all dying patients to clarify appropriate care.

The results of this study indicate that symptom management was not seen as an issue once there was an acceptance the patient was dying. Although some participants identified delays in getting the appropriate drugs prescribed in a timely manner, generally the hospital environment allows ready access to comfort drugs.

Limitations

Only one hospital in the trust was involved in the study and, although unlikely, results from the other two hospitals or a larger sample may differ. The risk of the Hawthorne effect, in which people improve an aspect of their behaviour in response to awareness of being observed, should be acknowledged and the fact that the interviewer was known to participants may have influenced their responses.

Conclusion

This study confirms that many nurses believe the acute hospital is not a good place to die. Timely diagnosis and communication of dying prevented medicalisation of death and made caring for the patient less time consuming, less demanding and more rewarding. Participants felt supported by their nurse colleagues on the ward, enabling them to better cope with the stresses of caring for patients who are dying. The palliative care team also offered support with symptom management and raising concerns with the doctor.

In terms of communication, participants considered it to be the doctor’s role to break bad news. They also felt uncomfortable handling difficult questions directed at them by patients and relatives. However, nurses need to be able to communicate with dying patients and their families to facilitate important discussions around end-of-life care. This study, therefore, highlights the need for communication to be the key element of future end-of-life care education in acute hospitals. Formal education on communication skills may be best delivered by observing and teaching, which could be achieved through ‘shadowing’ experienced nurses.

TABLE 1 PARTICIPANTS’ CHARACTERISTICS

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*Has worked as a Marie Curie nurse in the community


Leadership Alliance for the Care of Dying People (LACPD) (2014) One Chance to Get it Right. Improving People’s Experience of Care in the Last Few Days and Hours of Life. Bit.ly/LACPDOneChance


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Quick Fact

78% Percentage of patients who have diagnostic tests in the last 48 hours of their life

References


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Starting end-of-life conversations in hospital

Bit.ly/NTEOLConversations

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