How do we deal with the death of a patient?

Although many people say they would like to die at home, only 20% actually do, with the majority dying in hospitals, hospices and care homes. As a student nurse, Ilhan Wardhere found reflection helpful in working through clinical challenges. Here she shares her experiences of dealing with end of life care in the community.

Death is an inevitable and normal process, which everyone faces eventually. However, the subject is still something of a taboo in Western society, with many people unfamiliar with the practicalities of death and dying, despite the fact that nearly half a million people die each year in England alone (Department of Health [DH], 2008).

In modern times, death has been transformed from an event that took place mainly in the home in full view of the whole family, to one that has been shifted into hospitals and witnessed mainly by healthcare professionals. This appears strangely at odds with the wishes of many people — although many individuals state they would like to die at home, only 20% of people actually achieve this, with the majority (60%) dying in hospital and the remaining 20% dying in hospices and care homes (Gomes and Higginson, 2008; Office for National Statistics, 2009). Furthermore, many people — including healthcare professionals — find discussing the topic of death and dying difficult, perhaps because in clinical settings there is a culture of healing and cure, with death perceived as a failure (DH, 2008).

Nevertheless, the process of receiving high-quality end of life care has been the topic of major concern over the last decade, resulting in various policies and legislation and leading to the publication of the first national end of life strategy in 2008 (DH, 2008). The main focus of this strategy was to give an opportunity for patients dying from all conditions access to high-quality end of life care, which includes support for families and carers.

REFLECTIVE PRACTICE

As a student nurse, I have found the use of reflection helpful in working through challenges, particularly during clinical placements. The reflective framework used in this account was designed by Driscoll (2007). The reason why I choose this particular model of reflection is because it is arranged in three sections (‘What’, ‘So what’ and ‘Now what’): firstly questioning what happened, then asking what the point of the reflection is, and finally exploring how the reflection has changed practice (Driscoll, 2007). This helped me to reflect on the situation and explore my feeling afterwards.

The account featured here explores the care provided for an elderly man living at home and facing death from advanced cancer (for confidentiality purposes the patient’s name has been changed to Mr Webb).

CASE STUDY

Throughout my first-year placement I avoided patients who were dying or at the end of life due to fear and anxiety. Dakin (2003) found that student nurses commonly experienced feelings of anxiety and fear in relation to death and the dying patient. However, during my community placement I was convinced I wouldn’t see patients dying, believing this was something that occurred in hospital settings. However, I was shocked to find myself allocated an 88-year-old man, who was predicted to die over the following weeks.

Mr Webb had been diagnosed with advanced bladder cancer and was referred to the community palliative care nurses by the hospital, as doctors believed any invasive treatment would be futile and not in his best interest.

The community palliative care nurses visited Mr Webb at home and set up a syringe driver to provide pain relief and comfort. The driver supplied diamorphine for his pain and cyclizine to control nausea and vomiting. Mr Webb was also referred to the district nursing team as he developed a pressure ulcer on his back.

I was working with the district nurse and visited Mr Webb to keep him comfortable and make sure his pressure areas were intact.

Throughout the next couple of days Mr Webb’s condition deteriorated, and one day as we were about to visit him we received a phone call from his wife informing us that he had died during the previous night. As we were still in the office we collected some leaflets to give to the family about coping with death.
Reflection

Death is a normal process that everyone faces eventually

When we arrived Mrs Webb immediately took us to the bedroom where her husband was lying on the bed. I remember looking at the body, which was pale, cold and clearly showed no signs of life.

Mrs Webb and her daughter and son-in-law were distraught, and explained that they had not known what to do during the night when Mr Webb stopped breathing. Mrs Webb then took us to the living room where the family discussed their concerns about after care. The district nurse and I handed out some informational leaflets about coping with death, provided some contact numbers for funeral services and informed the GP so that the death could be certified.

Interestingly, before we left, Mrs Webb, who was elderly and physically frail herself, described her husband’s death as a nightmare. She explained that she did not want him to die at home as she believed people were born in hospitals and thus they died in hospitals.

Denial
Mrs Webb expressed major concerns about her husband’s wish to die at home. Kubler-Ross (1989) introduced the now-famous stages of grief:

- Denial
- Anger
- Bargaining
- Depression
- Acceptance.

In this event, I felt that Mr Webb had accepted his condition and knew he was dying. This is not to say he was entirely ‘OK’ with the idea, but to me it seemed like he had come to terms with it, whereas, Mrs Webb was in denial. This was apparent when, following the death of her husband, she said: ‘This does not happen to people like us,’ describing the process as a nightmare.

Kubler-Ross (1989) comments that in the denial stage of the grieving process the initial reaction may be a temporary state of shock, from which the individual will gradually recover. In this stage, the world becomes meaningless and life ceases to make sense. This is certainly the impression that I had from talking with Mrs Webb. However, Kubler-Ross (1989) states that denial helps us ‘pace’ our feelings of grief, so perhaps even in denial Mrs Webb was grieving the death of her husband.

REFLECTION

Looking back over Mr Webb’s death brings back a lot of emotions associated with seeing my first patient die, the experience of looking after relatives of the deceased and my assumption that I would not come across death while on a community placement.

The purpose of returning to this situation is to analyse my experience as a nurse and to examine the ‘good death’ of a patient who fulfilled his wish to die at home. It is also important to explore the affect the patient’s wishes had on the family, specifically Mrs Webb.

Stress
Research indicates (Arber, 2001; Timmins and Kaliszer, 2002) that student nurses find caring for dying patients stress-inducing. This is exactly how I felt as we were escorted to view the dead body — I began to feel cold, goose bumps sprang-up along up my arms, and my eyes filled with tears. However, not wanting to upset Mr Webb’s relatives, Iquickly wiped away my tears.

Dakin (2003) states that student and qualified nurses struggle to cope with death. However, as nurses we are obliged to care for patients before and after they die (Hogston...
and Marjoram, 2007). Nevertheless, we are still human beings and feel the loss even though the public’s expectations are increasing and kindness and compassion at the end of life are expected. Nurses also need support, however.

**The ‘good death’**

There are many definitions of a ‘good death’, and one person’s view of what this means will not be the same as another’s. The government’s *End of Life Strategy* (DH, 2008) illustrates aspects of the good death, including being treated with dignity, being pain- and symptom-free, and being around close family/friends in familiar surroundings.

Mr Webb’s death fits this description as he was in his own home and with his close family. However, being symptom-free was something that needed to be addressed. During the night before Mr Webb died, his wife explained to us that he looked very agitated and distressed and that his breathing changed, becoming noisy. She obviously learnt did not know what to do.

It is clear that communication could have been improved here. Although we do not know what the community palliative care nurses may or may not have told the family, it is clear that they were unaware of the common signs of death.

The Marie Curie Palliative Care Institute Liverpool (MCPCIL, 2010) state that when patients are approaching the end of life they produce signs like those demonstrated by Mr Webb. Therefore, medication such as midazolam and glycopyrronium would have been appropriate to reduce Mr Webb’s agitation and respiratory tract secretions, which were making his breathing noisy (MCPCIL, 2010).

In this case, it appears the district nurse did not know what drugs Mr Webb was prescribed, or what he may have benefitted from, as every time we visited we focused on healing his pressure ulcer rather than observing him holistically.

**“I felt scared without enough knowledge about the nurse’s role”**

Better communication between the community palliative care nurses and the district nurses in this case could have helped the patient and his family to understand the signs that death was imminent.

**Communication**

Communication between healthcare professionals at the end of life is crucial in meeting the needs of cancer patients and their families. Mr Webb’s situation could have been improved if the nurses involved had simply communicated verbally, for example about what they had done each day, the concerns the family had raised, and what information they had been given.

Indeed, when the district nurse handed over what we had done for Mr Webb each day, it was commonly something like: ‘Pressure ulcer washed and dressed for end of life care, which is being provided by the CPCN.’

This statement raises many questions, such as why the district nurse was not observing Mr Webb holistically. More specifically, Hogston and Marjoram (2007), outline that improved handover to other healthcare professionals improves end of life care. The Nursing and Midwifery Council (NMC, 2008) specifically states that nurses should work with other healthcare professionals to promote the health and wellbeing of those in our care and their families. Clearly, the patient is more important than anything else in this situation, and keeping Mr Webb comfortable should have been the main priority (Hjörleifsdóttir and Carter, 2000).

This situation could also have been improved if contact details of funeral directors were provided to the family so that Mr Webb’s body could be taken away immediately after death. This is a clear example of miscommunication, resulting in the family feeling distressed, not knowing what to do or who to call.

Robinson (2007) states that family members are often confused and scared when a loved one dies and require explicit information on what to do. Indeed, the nurse’s contribution during this period cannot be over-emphasised, as relatives often remember poor nursing care at this time (Robinson, 2007).

It is curious that the district nurses did not provide information leaflets before Mr Webb’s death, as these contain a step-by-step guide on what to do and who to call, including the contact details of funeral directors in the area. I felt that we, as healthcare professionals, were avoiding talking about death even though our patient was terminally ill. We were trying to ‘treat’ death instead of delivering high-quality care in Mr Webb’s precious last days.

Again, this brings us back to healthcare professionals not wanting to discuss death, and it is situations like this that may preclude people from considering death as a natural process, contributing to death being taboo in society. This will remain the case until nurses and other healthcare professionals are open in discussing death and dying (Granda-Cameron and Houldin, 2012).

**The fear factor**

Reflecting back on this situation, I realise that I felt scared and did not have enough knowledge about the nurse’s role to identify what was acceptable and unacceptable. Perhaps I should have refused to enter the bedroom where Mr Webb was laid out to avoid seeing his dead body — a fear embedded in me since childhood where death was never spoken about. However, this would have simply delayed exposure to my first body.
Reflection

Having seen my first death, I now feel less anxious about caring for dying patients. Nevertheless, research indicates that student nurses (Dakin, 2003) feel scared when confronted with death and dying patients, although as nurses we have to deal with life and death every time we start a new shift.

Benner (2001) also illustrates that when student nurses enter a new clinical area they are novices, with little understanding of the situations in which they are expected to perform. I definitely felt my lack of knowledge in Mr Webb’s case, although this could have been prevented if I had researched community nursing before my placement instead of assuming that death was something I was unlikely to encounter.

Education

Having access to more education before starting my placement would have enhanced my knowledge about death and dying, as well as the relevant coping methods. Instead, this was avoided throughout my first year of training.

There are differing opinions on the effects of education in preparing people to deal with death. For example, Matzo et al (2003) found that education promoted confidence and decreased anxiety, whereas other studies demonstrate inconclusive results, with some even indicating that education could potentially increase anxiety among junior nurses or those with personal experience of death (Coombs, 1981; Yarber et al, 1981; Johansson and Lally, 1990).

In my case, some pre-placement education on end of life care would have been beneficial, as my knowledge and skills were insubstantial. Thus, there is a need to restructure nursing programmes to ensure that end of life care is taught throughout the undergraduate level.

CONCLUSION

I hope that I have used this paper to analyse a troubling incident, partly through self-criticism. I hope you have been taken through Mr Webb’s journey as he approached his final days of life.

I have aimed to show the importance of communication between healthcare professionals and family members, and I would like to think that education and training are essential in preventing scenarios like this from arising.

Additionally, to modify my own practice, I aim to make communication and patient education my main priority, particularly when dealing with sensitive areas such as end of life care. Finally, the government’s End of Life Care Strategy (DH, 2008) represents a huge step in providing dignity in death, although the role of family members and caregivers must not be forgotten.

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REFERENCES


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