Understanding the subjective experiences and needs of patients as they approach death

Acknowledging and validating the spiritual needs and experiences of patients who are dying can help nurses better support them at the end of their lives

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When patients are approaching the end of life their spiritual as well as physical needs should be considered. This article considers how nurses can best support patients who are dying and work to ensure they experience a peaceful transition to death. Attending to their spiritual needs is shown to be of utmost importance; the near death and end of life experiences that some patients may have are also taken into consideration.

INTRODUCTION

Nurses are in a unique position to administer to the spiritual needs of patients who are dying. However, some nurses lack experience in caring for these patients and some lack confidence in providing spiritual support.

A number of factors need to be taken into consideration if patients’ spiritual needs are to be met as they near the end of life (Sartori, 2010a; Sartori, 2010b). Daaleman et al (2008) identified three essential aspects of spiritual care at the end of life:

- Being present: interacting with the patient, paying attention to emotional and social needs;
- Opening eyes: becoming aware of and understanding the patient’s individualised experience of illness;
- Cocreating: planning holistic care between patient, family and caregiver to maintain dignity and humanity.

These aspects of care are best achieved by getting to know the patient and building up a rapport with him or her, as patients are usually more willing to confide in nurses they know and with whom they feel comfortable. Where possible, therefore, it is best if patients nearing the end of life are cared for by nurses who have already established a relationship with them and who have an understanding of their ongoing needs or any others that may develop.

BALANCING PHYSICAL AND SPIRITUAL NEEDS

No one should suffer as they approach death, so it is essential that patients’ physical pain is well controlled. An infusion of diamorphine or a syringe driver is often necessary to ensure relief from physical pain, respiratory distress or other symptoms. However, not all patients will require such drugs or develop symptoms that are physically distressing. It is vital to consider individual needs; if physical distress develops, medication can be administered.

Although the physical aspects of patient care remain important, as patients approach death it is vital to consider their spiritual needs as well. Caring solely for physical needs may cause patients to be deprived of the support they need while they are dying. Spiritual needs should be considered as paramount when death is imminent.

The greatest spiritual need for most patients is for their family to be present and, if possible, to be in a quiet, private environment. For patients on busy hospital wards this may involve moving them to a cubicle or side room.

Some hospital routines may be detrimental to and even violate patients’ spiritual needs. For example, it is necessary to disturb a dying patient every three hours for pressure area relief just to adhere to protocol, if this causes discomfort? Considering such a matter is not to encourage the neglect of important physical aspects, but to ensure nurses remain mindful of their actions in relation to each individual patient (Box 1).

It must be emphasised that this article does not in any way advocate withholding physical care or medication from patients who are approaching death. However, it does encourage nurses to be aware of the wider picture and to see beyond the usual ritualistic or routine care – spiritual care is not prescriptive.

PRACTICE POINTS

- Nurses caring for patients who are dying need to balance spiritual and physical needs.
- Some patients who are dying may be in spiritual pain, which can be addressed through active listening.
- Caregivers’ acknowledgement of subjective experiences can ease patients’ transition into death and give comfort to relatives.

SPIRITUAL PAIN

Some patients may display signs of agitation or even aggression as they approach death. Sometimes sedation may be required, but it is important to explore other solutions before resorting to this. Nurses should ask themselves whether the agitation could be addressed in any way.

Patients may be in spiritual pain, which can be due to an inability to find a meaning for their existence. They may feel that their life’s purpose has not been fulfilled, or their feelings may relate to a fear of death, pain, loneliness, the unknown, becoming a burden, unpleasant experiences, judgement at death or death as extinction (Deeken, 2008; Penson et al, 2005).

To address spiritual pain, Elias et al (2008) developed a therapeutic intervention which they called relaxation, mental images and spirituality therapy (RIME). This approach explored the transcendental aspects of the dying process, encouraging patients to reflect on the positive aspects of their life and to complete any unfinished business.

PATIENTS’ SUBJECTIVE EXPERIENCES AS THEY APPROACH DEATH

For many patients, surviving a life threatening illness can lead to a spiritual awakening and transformation (Vachon, 2008).

An aspect that is rarely acknowledged, especially in UK research journals, is the subjective experience of some patients as they approach death. Metaphysical aspects of spirituality do not sit well within the
research-based scientific nursing profession. However, a number of authors have conducted research into near death experiences (NDEs) (Sartori, 2008; Greyson, 2003; Schwaninger et al, 2002; Parnia et al, 2001; Van Lommel, 2001) and end of life experiences (ELEs) (Fenwick and Brayne, 2010; Fenwick et al, 2009; Brayne et al, 2008; Brayne et al, 2006). This research shows that subjective experiences close to death can no longer be dismissed; they can give great meaning to patients and act as a catalyst for spiritual transformation.

ELEs were documented as early as 1926 (Barrett. Osis and Haraldsson, 1977) conducted a large cross-cultural survey in the US and India. In the UK, palliative care hospice workers and nursing home healthcare workers have been interviewed about deathbed phenomena they had witnessed (Fenwick et al, 2009; Brayne et al, 2008; Brayne et al, 2006).

As death approaches, many patients have been observed communicating with people who are not physically present. These communications are usually dismissed as hallucinations, but some caregivers argue that these experiences are different from drug-induced hallucinations and occur during clear consciousness (Fenwick et al, 2009; Brayne et al, 2008; Brayne et al, 2006). While hallucinations can result in anxiety or confusion, ELEs can result in the acceptance of death and peace (Brayne et al, 2008).

NDEs and ELEs have previously been attributed to the administration of painkilling or sedative drugs. However, many caregivers disagree with this view (Fenwick et al, 2009; Brayne et al, 2008), and both phenomena have been shown to occur in the absence of such drugs (Sartori et al, 2006; Sartori, 2008).

In one study, strong painkilling medication appeared to contribute to unpleasant, confusing experiences and patients who had received large doses of these drugs were less likely to report an NDE or ELE (Sartori, 2008).

It is possible therefore that large doses of painkilling or sedative drugs may inhibit or deny patients’ opportunity to experience valid spiritual aspects of the dying process. It is therefore important that caregivers bear in mind the importance of not over sedating patients as they approach death.

TYPES OF END OF LIFE EXPERIENCE

Brayne and Fenwick (2008) distinguished two types of ELEs: transpersonal and final meaning ELEs.

Transpersonal ELEs

These ELEs are deathbed phenomena reported by healthcare workers and relatives who have been in the presence of patients who are dying. They include:

- Seeing patients have conversations with dead family members;
- Seeing light around the body just before death;
- A change in temperature at the bedside of the patient;
- The appearance of the dying person to a relative who is not present at the deathbed;
- Malfunctioning of electrical equipment;
- Clocks stopping at the time of death.

Patients may use symbolic language and talk about going on a journey or packing a case (Sanders, 2007; Callanan and Kelley, 1992) and may report having vivid dreams about dead relatives (Brayne et al, 2006). Patients who report deceased relatives, friends or pets coming to meet them with the purpose of leading them into death usually die within two to five days of the onset of such visions (Fenwick et al, 2009; Osis and Haraldsson, 1977).

Final meaning ELEs

Final meaning ELEs refer to the patient’s motivation to complete unfinished business and resolve complex family relationships. Sometimes confused patients experience a moment of lucidity that enables them to communicate farewells to relatives.

SHARED DEATH EXPERIENCE

A lesser reported phenomenon is the shared death experience (Moody, 1999). Two separate cases of shared death experiences were reported to the author by relatives present at the deathbed of a dying person. In both cases, the family members also experienced visions and participated in part of the journey of the patient who was dying. In the visions, the relatives were only allowed to go a certain amount of the journey; the patient then went on alone into the light, which coincided with the time of death. The family members reported that they were left with feelings of bliss, elation and happiness at knowing that their loved one was at peace.

ACKNOWLEDGING DEATHBED EXPERIENCES

People who have witnessed or undergone deathbed experiences are often reluctant to discuss them for fear of being considered crazy or weird (Fenwick et al, 2009). Patients are more likely to report them to nurses than to doctors (Brayne et al, 2006).

Dismissal of such transcendent, spiritual experiences by those who have not experienced such a state is insulting to patients. Such behaviour can be detrimental to them and could even make the dying process more difficult or stressful. Patients who are met with a negative response when confiding their NDE rarely mention it again, which inhibits integration of the experience into their life (Sartori, 2008).

Nurses who observe patients having deathbed experiences could usefully share this information with their colleagues by documenting it in the patient’s care plan.

**BOX 1. PHYSICAL VERSUS SPIRITUAL NEEDS**

Sam Green* was in the end stages of cancer. He was at home, being cared for by his wife and family with the help of district nurses.

The day before he died, his pain was increasing and a syringe driver was commenced. Mr Green’s daughter, who lived in France, arrived shortly after this.

Mr Green was comfortable, conversant and very happy to see his daughter. They were able to have a brief chat, which was interrupted by the arrival of the evening district nurse team.

It was the first time this team had met Mr Green. As they attempted to reposition him, he cried out in pain as the syringe driver had not had time to take full effect. The family suggested that Mr Green be left undisturbed as his sheets were clean, he did not have a pressure ulcer and was on a pressure relieving mattress.

The nurses said that they would not be able to return later and had to change Mr Green’s position. They came out of his room five minutes later and explained that they had given him a strong painkiller and “something to settle him”.

Mr Green had been given midazolam and was no longer able to communicate. As a result, his daughter did not have the opportunity to finish her conversation with her father. Unfortunately, the nursing team had no way of providing continuity of care and did not know Mr Green.

This was unavoidable but had the nurses not repositioned him, it is unlikely that he would have experienced more pain or cried out. He certainly would not have medicalised. In all likelihood, Mr Green would have been able to continue his conversation with his daughter, and she would not have been left with the burden of unexpressed emotions during her grieving process.

* Name has been changed
and mentioning it on handover. It is important to allow patients to express their ELEs and give them the validation they need by reassuring them that such experiences are common. ELEs have a healing quality (Betty, 2006), bring comfort, allow patients time to review their life and give great meaning at the end of life. Patients who experience visions usually have a peaceful transition into death (Fenwick et al, 2009).

Approximately 14% of all NDEs are frightening in nature. Recalling the experience can evoke great emotion (Box 2) as, in some cases, patients believe that they have experienced hell (Sartori, 2008). It is therefore imperative that NDEs and ELEs are taken seriously and further research is undertaken to gain greater understanding so that better psychological support can be provided in such cases.

Elias et al (2008), using a relaxation, mental images and spirituality intervention, discovered that when patients’ negative spiritual experiences were treated as actual experiences as opposed to hallucinations, their spiritual pain was relieved.

DEATH EDUCATION
Brayne et al (2008) found that nurses felt they were lacking in knowledge and understanding of ELEs. They also found that caregivers lacked support to deal with personal or professional issues arising from caring for patients who experience ELEs.

REFERENCES

Box 2. Frightening near death experiences

As a student nurse, I cared for a dying patient who was terrified at the prospect of her impending death because of a previous negative spiritual experience. She fiercely clung on to the uniforms and arms of all nurses, digging her nails into their skin while looking straight into their eyes and begging them not to let her die. She kept repeating that she had died before and it was a terrible experience and she did not want to go back there. Having spoken to the family at the time and on reflection — with the benefit of having undertaken research into near death experiences — I have since concluded that this patient may have experienced a negative NDE during a cardiac arrest five years previously.

At the time, however, myself and my colleagues had never heard of this type of experience.

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