How nurses can help ease patient transitions to end of life care

Many issues combine to enable an individual to achieve a good death. Kellie Lewis discusses these factors as well as the barriers staff must overcome.

Abstract

Moving from curative to palliative care is often difficult for patients, families and healthcare providers, because hospice or end of life care can be seen as a failure of healthcare teams or as patients having given up. Nurses’ role in this transition is to provide care, educate and advocate for patients, and encourage reflection on the implications of end of life. Providers face challenges in identifying when end of life begins, impaired communication in healthcare teams and feelings of guilt. Patients and families must come to terms with the idea of death while maintaining dignity.

Ensuring older patients are included in discussions can improve their quality of life and sense of dignity. Nurses can help by enabling conversations about the end of life to take place early on, improving communication between staff, and encouraging reflection by healthcare providers.

Keywords
End of life care, palliative care, transition

Terminology

The terms ‘hospice care’, ‘palliative care’ and ‘end of life care’ are often seen as interchangeable, but there are significant differences between them.

Hospice care provides pain relief and comfort, incorporating psychosocial and emotional care in place of curative medical care. It can also include spiritual care and social work consultation (Izumi et al 2012). ‘Hospice’ has evolved as a programme that cares for patients with terminal diagnoses, therefore patients only qualify for this care when it has been determined that they have less than six months to live (Izumi et al 2012).

In contrast, palliative care provides comfort alongside any desired curative care for patients who are experiencing suffering related to a life-threatening illness (Izumi et al 2012). Patients can receive palliation at any time during the disease process to allow pain relief and comfort, and increased quality of life (Izumi et al 2012). Some of the services palliative care provides include ‘assessment and management of pain; psychosocial and spiritual needs; discussion of prognosis and treatment options; management of transition from primarily curative to primarily palliative approach;
decision making around resuscitation and other aggressive treatments; recognition of signs of the end of life; and support for the family before, during, and after death’ (Milligan 2012).

End of life care can incorporate hospice and palliative care services, and treatment varies from patient to patient. Hodo and Buller (2012) defined the goals of end of life care as being to ‘mollify distressing symptoms through the judicious use of comfort measures to enhance quality of life and achieve a peaceful death’. End of life care provides medical, spiritual, emotional and palliative care for anyone who is nearing death (Izumi et al 2012).

Patients in acute care settings often do not receive care that meets all of their end of life needs (Izumi et al 2012, Watts 2012). Rady and Johnson (2004) found that more than two thirds of patients who died after transfer from the general ward to the intensive care unit (ICU) had not been informed of alternative treatment plans, such as palliative care or hospice. Some groups of patients, including older people, those of low socioeconomic status, patients with respiratory illnesses and patients with multiple or complex care needs, tend to be more uninformed about the availability of these treatment options (Milligan 2012).

End of life care decreases the number of unnecessary interventionist treatments. Supportive technologies are often used even when there is limited chance of patients surviving without life support (Vanderspank-Wright et al 2011). Healthcare providers should recognise and understand that interventionist care may not be best for patients who are terminally ill (Gardiner et al 2011). Interventionist care can lead to extended hospital stays and chaotic hospital deaths, rather than allowing patients to spend their last few months with loved ones (Brown 2012). Healthcare teams that focus on curative care and interventionist treatment also tend to postpone the use of palliative care, which can decrease patients’ quality of life (Gardiner et al 2011).

End of life care can provide some of the psychological and emotional support that terminal patients often need. Palliative care can treat the causes of depression related to the end of life, while increasing patients’ hope (Larkin 2010). Similarly, end of life care can address patients’ limited control over the process of dying and the possible loss of dignity that can accompany ageing and symptoms of terminal illness (Brown et al 2011). The transition from curative to end of life care is a complex process that differs for each patient and caregiver. The first step is to identify patients who are nearing end of life. Some people are admitted to hospital after a crisis or surgery and show a steady decline with no improvement from interventions, whereas others have struggled for much longer periods and have had phases of improvement and decline (Long-Sutehall et al 2011). Physicians find it most difficult to identify end of life in patients with chronic illnesses whose symptoms wax and wane over time (Watts 2012). The importance of identifying end of life, especially in long-term care facilities, is summarised by Porock and Oliver (2007): ‘When dying is not recognised, care planning remains focused on the maintenance of physical and cognitive function. Clinical decline and increased dependency are then seen as failures. When diagnosed as dying, expectations for the individual change, and outcomes normally seen as negative become a natural part of the dying trajectory and care changes from fighting those problems to palliating them, ensuring comfort and dignity.’

Once teams have made the decision to initiate end of life care, several steps must occur to ease the transition. Teams must continue discussions with patients and families about what patients’ end of life care might entail (Coombs et al 2012). Most older patients, whether in hospital, long-term care or living independently, are never asked their preferences about end of life care (Jackson et al 2012), so it is important to involve these patients in the planning process.

Nurses who provide good end-of-life care comfort patients, engage in open and frequent communication with patients and caregivers, garner support from co-workers and friends, and reflect on the end of life process; these characteristics are fundamental to satisfactory care (Vanderspank-Wright et al 2011).

**Role of the nurse**

Physicians may not regularly interact with patients and families after teams have decided to implement end of life treatment, so nurses must guide patients through transition to this stage (Ranse et al 2012). Nurses must act in four ways; as care providers, educators, advocates and facilitators.

The main role of nurses is to provide for patients’ comfort and care. Ranse et al (2012) noted that nurses can offer fundamental services such as ‘bathing, hair care, mouth care, pressure area care, spiritual care, and the administration of analgesics, sedatives, and antimucolytics’. Acute care nurses must also perform regular nursing interventions,
including maintaining intravenous pumps, assessing pain and arranging for discharge to a hospice or home setting while providing emotional support to patients and families (Milligan 2012).

Other nursing interventions that can help patients achieve their desired comfort include changing hospital sheets and blankets for linens from patients’ homes, arranging pictures around the bedside and removing any loud monitoring equipment from the room (Ranse et al 2012). The location of patients’ death should be carefully considered before it occurs; a calm, quiet, single room is best, with family or loved ones present as patients desire (Long-Sutehall et al 2011, Ranse et al 2012).

When providing care for the terminally ill, nurses are responsible for educating patients about options available at end of life, as well as about specific care needed for patients’ conditions (Borowske 2012). Educating patients and caregivers about symptom management, medication regimens and how to seek help out of hours is valuable (Brown et al 2011). Nurses can provide a wealth of information about patients’ conditions and possible outcomes of treatment plans and can steer treatment towards a comfort care model by guiding discussion from interventionist care to palliative care (Borowske 2012). Nurses should also be prepared to explain the prognosis to patients and families in a sensitive, yet honest, way (Hodo and Buller 2012).

Nurses advocate for patients by providing them and their families with information about the options and rights to treatment (Borowske 2012). Nurses can help promote communication between caregivers and healthcare teams and co-ordinate the treatment plan. This can be achieved by asking about the goals of each party and uniting these, while ensuring physicians are sharing relevant treatment information with patients (Long-Sutehall et al 2011). Older patients need to be encouraged to discuss their wishes and views on end of life care with nurses so that they can peacefully transition into end of life (Jackson et al 2012). Nurses can empower patients to advocate for themselves by encouraging them to convey their wishes to the healthcare team (Borowske 2012).

Lastly, patients should be given time to contemplate their end of life situation. Transitions into intensive care or palliative care can happen within hours, so patients may not have had time to reflect on what transfer means (Marsella 2009). Patients may find speaking with a chaplain or participating in spiritual activities valuable experiences (Hayden 2011). By asking open-ended questions nurses can guide this reflection and allow patients to become more aware of any emotional or spiritual care they may be seeking (Hayden 2011).

**Challenges**

**For nurses** Identifying end of life can be difficult (Coombs et al 2012). Older patients often present with multiple chronic conditions and, with the lack of a clear prognosis and trajectory, there is rarely one major indication that they are declining (Schonfeld et al 2012). Healthcare providers do not want to upset patients and families by raising the issue, and they are afraid of suppressing hopes of recovery (Dalgaard et al 2010, Brown 2012). Providers also find that conversations about the end of life are longer than other care-related conversations (Waterworth and Gott 2010).

By suggesting hospice care, physicians may think the ‘six months to live’ prognosis is concrete and that they have failed to provide adequate care (Borowske 2012). However, diagnosing patients as ‘actively dying’ helps families and caregivers to accept that the treatment plan has changed (Coombs et al 2012).

Nurses who provide end of life care may feel guilty when patients die, because they may perceive their care as failing to treat (Ranse et al 2012). Nurses new to the ICU may even believe their role in the withdrawal of treatment caused the death (Vanderspank-Wright et al 2011). Physicians are often absent after deciding to withdraw treatment, so nurses feel deserted, adding to the feelings of culpability when patients die. Most nurses working in intensive care or end of life settings lack a support system (Ranse et al 2012).

Nurses who work in long-term care or nursing homes with older patients have their own challenges in transitions to end of life care. Nursing homes have set standards for quality so there are many requirements for patients’ care (Waldrop and Nyquist 2011). Nurses and nursing assistants are required to reposition patients every two hours to prevent pressure ulcers and circulation difficulties, but older frail patients who might die within days can find these frequent repositionings painful and no longer part of the optimal plan of care (Waldrop and Nyquist 2011).

Providers struggle with weighing the ‘need for individualised care of residents who are at life’s end with the need for comprehensive care in a highly
regulated environment’ (Waldrop and Nyquist 2011). Long-term care providers acknowledge that the most difficult part in transitioning patients from routine to end of life care is losing their connections and bonds with residents they have been working with for years (Waldrop and Nyquist 2011).

For patients Transition to end of life care forces patients to face the diagnosis of impending death (Marsella 2009). Misconceptions about hospice care play on patients’ fears of death, and patients are reluctant to enrol in a hospice because they fear they will die within days (Borowske 2012). Patients are often unwilling or unprepared to abandon curative treatment (Dalgaard et al 2010). Older patients report that they fear losing their independence, becoming bedridden, becoming a burden to their caregivers and being admitted to a long-term care facility (Waterworth and Jorgensen 2010).

Problems that may seem inconsequential to younger patients become challenges for ageing patients, who may not have access to an adequate social support system or transportation (Hanratty et al 2012). Older patients have more concerns about how they will die and the symptoms that will accompany their death rather than concerns about when or where they will die (Waterworth and Gott 2010). Also, they tend to be more concerned about loss of dignity than the quality of their care; Hanratty et al (2012) imply that while medical staff do not see losing patients’ false teeth or sending them for an X-ray wearing only a hospital gown as poor quality care, these kinds of situations cause older patients much stress.

To avoid suffering, dependency and the ‘loss of dignity and personhood’ that accompanies ageing and longer death trajectories, patients older than 65 commonly prefer sudden deaths (Waterworth and Gott 2010).

Easing transition

Earlier implementation of palliative care can lead to increased survival time even with less aggressive treatments (Temel et al 2010). If nurses were to ask for a palliative care consultation earlier, the psychological transition to end of life care for patients, as well as the transition between healthcare teams, would be easier (Marsella 2009).

Hickey and Quinn (2012) found that 87 per cent of patients would prefer to discuss end of life options when they are well or recently diagnosed rather than when severely ill. Nurses can begin discussing end of life care options in outpatient clinics and settings so that patients have time to think about their preferences before their quality of life declines (Rady and Johnson 2004).

Rather than experiencing an abrupt change from curative to purely non-intervention-based care, patients can be transitioned gradually into supportive care that focuses on enhancing quality of life (Brown 2012). Patients who have rapid transitions will have limited time to reflect on the implications of end of life care (Marsella 2009). By increasing the length of the transition, which means discussing end of life sooner, patients have more time to reflect. Nurses and medical staff would also have more opportunities to discuss possible options and treatment plans with patients if the transition to end of life stage was longer (Vanderspank-Wright et al 2011).

Ethical issues

Providers may be reluctant to speak with patients about end of life decisions. Waterworth and Gott (2010) state: ‘It has been recognised that older people’s care and treatment choices are not stable and that decision making can be further complicated by changing mental and cognitive state.’ If providers begin end of life discussions earlier, while patients still have their cognitive abilities, this ethical situation can be avoided.

Individual beliefs and values of staff can cause conflict when deciding to transition care (Coombs et al 2012). Even if patients are ready to accept a terminal diagnosis, members of the team may be unwilling to, which often causes tension between medical and nursing staff (Coombs et al 2012). Providers must remember that they have a moral responsibility to follow the wishes of patients and families (Kirk 2007).

Noncompliance by patients or families can cause ethical dilemmas for nurses. In one case study, a family refused to administer pain medication to a hospice patient, disregarding the non-verbal 74 year old’s obvious discomfort (Kirk 2007). Caregivers are considered to be patients as well in hospice care, and nurses have a moral obligation to respect the wishes of caregivers; therefore, nurses must work with patients and caregivers to come up with a plan of care that is acceptable for everyone (Kirk 2007).

Lastly, Badger (2005) acknowledges the ethical decisions that accompany treating older patients in critical care. While nurses want to provide the best care possible for patients and their families, it is difficult to subject older patients to aggressive interventions that may be futile, especially when there is no advance directive to reassure staff that patients want aggressive treatment (Badger 2005).
Nurses play an important role in aiding communication during transitions. Nurses should ensure that patients understand the treatment, present all information in patients’ native language and at the correct health literacy level, and allow for open discussion of all possible treatment options (Ngo-Metzger et al 2008). Decreased communication about treatment plans leads to more doubt and confusion for patients and medical staff; without knowing patients’ detailed wishes for end of life care, staff will not know whether to use mechanical interventions such as ventilators (Dalgaard et al 2010). By acting as mediators or facilitators supporting communication between family members and healthcare professionals, nurses contribute to patients’ feelings of social support (Brown et al 2011).

New nurses who plan to work with dying patients need to be educated about the reality of end of life work and equipped with coping methods before starting their jobs (Vanderspank-Wright et al 2011, Waldrop and Nyquist 2011). Novice nurses should feel that their unit acknowledges death as a difficult event and that discussion of death is acceptable in their workplace (Vanderspank-Wright et al 2011). Comprehensive end of life education should be provided for nursing home workers as death is an inevitable part of their job (Waldrop and Nyquist 2011).

**Conclusion**

The transition from curative to end of life care can cause anguish and suffering for patients and their families, but also for healthcare teams. Barriers to palliative and end of life care exist such as healthcare teams that do not recognise when end of life begins, lack of knowledge about end of life treatment and inability to agree on a course of treatment. Older patients can benefit from earlier implementation of end of life care. If implemented at an earlier stage, end of life care can greatly improve the quality of life and dignity of patients’ remaining time and should be used whenever possible.

**References**


