Life’s Final Journey: The Oncology Nurse’s Role

Cheryl A. Fairbrother, RN, BSN, MHA, OCN®, and Judith A. Paice, PhD, RN, FAAN

Despite advances in technology and science, many people diagnosed with cancer are likely to die from the disease. Because of the long-term relationships that oncology nurses develop with patients and their families during lengthy treatment periods, they are the most appropriate clinicians to provide care across the continuum and through the final journey. Care of patients in the final days of life requires a comprehensive knowledge of common syndromes, skillful assessment, and adept clinical management. Nurses cannot focus solely on the needs of patients; family members often are unaware of the dying process. Oncology nurses are uniquely qualified to provide education and support to families at the bedside witnessing the final days and hours of their loved ones. Finally, oncology nurses involved in the care of dying patients are at risk for burnout and need to provide care for their own needs to find balance between their professional and personal lives.

Nursing Management of Signs and Symptoms in the Final Hours of Life

Symptoms common at the end of life include rattle, delirium, myoclonus, and seizures. In a study of 200 patients with cancer, noisy breathing or rattle, pain, and urinary dysfunction were the most frequent symptoms during the last 48 hours of life (Lichter & Hunt, 1990). Other studies have confirmed that pain, delirium, dyspnea, and other symptoms are common in the final days (Hall, Schroder, & Weaver, 2002; Morita, Tsunoda, Inoue, & Chihara, 1999; Ng & von Gunten, 1998; Potter, Hami, Bryan, & Quigley, 2003). Oncology nurses who can manage the symptoms improve quality of life for patients and facilitate positive memories for patients’ loved ones at the bedside.

Rattle

One of the most difficult symptoms for family members to observe during the final hours is what is referred to as “the death rattle,” or rattle. The term refers to the sound of saliva and other fluids that accumulate in the oropharynx and upper airways when individuals are too weak to clear their throats (Hall et al., 2002; Wildiers & Menten, 2002). Although the symptom is not painful for patients, its association with impending death often creates fear and anxiety for those at the bedside.

Some evidence exists that avoiding the tendency to overhydrate patients at the end of life's final days (Field et al., 2000; Field, Cassel, & Institute of Medicine, 1997). Less attention is placed on the communication skills and procedures and products to maintain youthfulness (Zimmermann & Rodin, 2004). Discussing death and the dying process requires excellent communication skills and a thorough knowledge of the physical and psychological changes common during that time of life.

Finally, oncology nurses must be able to care for themselves by identifying signs of burnout or abnormal coping that may result from the unresolved grief of caring for so many patients who are in pain, suffering, and dying (Ferrell, 1999). Oncology nurses must examine their own beliefs and biases about death as well as find balance between the professional and personal components of life.
life can prevent rattle (Bennett et al., 2002). The treatment of rattle includes medications to reduce secretions as well as repositioning. Scopolamine patches placed behind the ear are indicated primarily for the management of motion-induced nausea and vomiting; however, the anticholinergic effects of the drug also serve to reduce secretions (Bennett, 1996). One or two scopolamine patches are placed behind the ear and changed every 72 hours. Noticeable reduction in secretions usually occurs within one or two hours. In some cases, a scopolamine infusion is necessary, with a starting dose of 50 mcg per hour via IV or subcutaneously and upward titration to 200 mcg per hour or more.

Other drugs that can assist with reducing secretions are atropine, glycopyrrolate, and hyoscymamine (Bennett et al., 2002; Spiess & Scott, 2003). In addition to these agents, diuretics such as furosemide can eliminate excess fluids that build up in the upper airways. Reducing parenteral fluids can help decrease excess secretions. None of the measures appears to be effective when the underlying cause of rattle is deep fluid accumulation, such as occurs with pneumonia (Morita et al., 2000).

Other comfort measures can be instituted by oncology nurses, such as repositioning patients by elevating the head of the bed or turning them to either side. A more complicated intervention, because of the meaning of food in culture, involves the reduction of oral or enteral feeding. Oncology nurses may educate families about the rationale behind slowing or discontinuing feeding. Rather than starving patients, reducing or eliminating additional fluids and feedings alleviates fluid accumulation in the body.

Oncology nurses should help families understand that rattle is a strong indicator that patients are actively dying. Studies indicate that rattle typically occurs within 16–57 hours before death (Kass & Ellershaw, 2003; Morita et al., 2000; Wildiers & Menten, 2002). Family members also may request suctioning, but this can be traumatic and cause bleeding or stimulate the gag reflex. If suctioning truly is indicated, do not suction beyond the oral cavity.

Delirium

Delirium is common during the final days of life (Hall et al., 2002; Lawlor & Bruera, 2002). Two general presentations of delirium exist. Most clinicians are aware of the hyperactive form of delirium, in which patients appear agitated, hallucinate, or try to climb out of bed (Breitbart, Gibson, & Tremblay, 2002). Hypoactive delirium, in which patients are withdrawn and quiet, often is overlooked (Lawlor & Bruera; Lawlor et al., 2000). The underlying cause of either form of delirium is poorly understood, yet metabolic changes, dehydration, and drug interactions can contribute to the phenomenon (Lawlor et al.). Other potential causes of delirium include a full bladder, fecal impaction, dyspnea, anxiety, and nausea.

Interventions to reverse delirium include reducing unnecessary medications, reversing metabolic abnormalities (if this is consistent with the goals of care), treating the delirium with medications, and providing a safe environment. Oncology nurses should review medication profiles for agents known to cause delirium, including corticosteroids, neuroleptics, and anticholinergic agents. Because drug interactions can occur, medications that no longer are useful or consistent with goals of care should be discontinued. For example, cholestero- lowering agents rarely are of benefit at the end of life. Agents that can relieve delirium include haloperidol 1–4 mg orally, via IV, or subcutaneously. The dose usually is repeated every six hours but in severe cases can be administered every hour. Other agents that may be effective include olanzapine 2.5–20 mg orally at night (it also is available in an orally disintegrating tablet for patients unable to swallow) (Breitbart, Tremblay, & Gibson, 2002). Lorazepam and risperidone also have been reported to be of use. Chlorpromazine can be used, but IV administration can lead to severe hypotension and, therefore, should be used cautiously (Cowan & Palmer, 2002).

Protecting patients from harm is critical. A quiet environment, with protection from accidents and self-injury, is essential. Reorientation used to be part of the treatment plan but no longer is considered to be useful and may contribute to patient agitation.

At the end of life, patients may have auditory or visual hallucinations about loved ones who have died before them (Callanan & Kelley, 1992). Often, such hallucinations may bring comfort and joy to patients because they see those who died before them or places they once were (Callanan & Kelley). Family members in attendance may find such hallucinations to be disconcerting. Oncology nurses need to offer support and reassure families that the phenomenon is common in those who are dying. Consultation to a minister, rabbi, priest, imam, hospital chaplain, or other spiritual advisor may be beneficial.

Myoclonus

Myoclonus is another complication that can occur in the final phases of life. Myoclo-
Sudden death usually occurs within one hour of symptoms but may occur within seconds or minutes. In the general population, the primary reason of sudden death is related to heart disease. In patients with cancer, sudden death often is related to hemorrhage, either as a result of complications of the disease or treatment (Drake, 2000; Labovich, 1994). Patients at particular risk include those with head and neck cancers with tumor infiltration into the carotid artery. Radiation therapy to the region increases risk because it can cause thinning of the walls of the vessels. Other cancers that can lead to sudden hemorrhage include gastric or esophageal cancers that perforate, leading to a rapidly fatal upper gastrointestinal bleed (Drake; Labovich). Regardless of the origin of hemorrhage, oncology nurses must recognize that rapid response is necessary. Oncology nurses must know the code status of patients. If a patient is a full-code, resuscitation must follow. If a patient has indicated that he or she wishes to allow a natural death by electing “do not resuscitate,” then supportive care is critical, both for the patient and loved ones. Discuss the use of a standing order for midazolam or another agent to sedate patients during this distressing event of the dying process (Hanks-Bell, Paice, & Krammer, 2002).

Supportive care is important not only for families but also for other team members who assisted with caring for patients. Clean the area rapidly because blood can produce a foul odor that may be distressing. Cover the area with dark towels or cloths to reduce visual exposure to blood. Speak calmly to patients during the process, reassuring them that you will not leave them and, if they are in attendance, that their loved ones are with them. Support for other members of the team, including novice clinicians and nonclinical staff who might be in attendance such as chaplains and social workers, includes allowing them to verbalize about the experience and to ask questions.

**Family Teaching About Signs of Death**

Although the ability to prognosticate is poor, several signs suggest that death is near (Glaré et al., 2003). Unfortunately, because death has become more institutionalized, many people never have observed the death of a loved one. As a result, most people who work outside of health care have no idea about the signs of impending death. Education is critical. Oncology nurses often are the most appropriate professionals to provide education to family members.

Although great variability exists in response during the final days and hours of life, patients often have decreased desire to eat or drink (Ferrell, 2004). Clenched teeth or turning from offered food and fluids are strong indicators that patients do not want oral intake. Yet, because of the meaning of food and eating in society, refusal of food and fluids often is difficult for family members to accept. Families should be instructed that forcing food or fluids can lead to aspiration. Reframing their efforts includes teaching families to provide flavored ice chips or a wet, clean washcloth to keep the mouth and lips moist.

Patients often withdraw and spend more time sleeping. Oncology nurses can instruct families to simply sit and be present with patients, hold their hands, and talk gently to them (Ferrell, 2004). Families needs to know that, of the five senses, hearing may remain strong, even when patients appear to be sleeping.

As a result of changes in circulation, patients’ arms and legs may become cold or cyanotic. Families should be advised that pulse and blood pressure might change as a result of metabolic changes and that urine output may cease. Respirations may take on abnormal patterns from very shallow to alternating periods of apnea and deep, rapid breathing. Oncology nurses should explain to families the unusual patterns of breathing that occur as patients enter the final phases of life.

### Self-Care for Oncology Nurses

Oncology nurses who repeatedly observe dying patients in unrelieved pain or experiencing other suffering are at risk for burnout and stress (Barrett & Yates, 2002). The problem is compounded by other factors, such as heavy workloads, inadequate staffing, and conflicts with other staff (Kash et al., 2000). Adding to stress are the personal stressors of life, such as caring for children or elderly parents (Nevijon, 2004). Finding balance in life, through honest appraisal of beliefs about death and dying, support from colleagues, and integration of healthy lifestyle behaviors, is critical. Some physical signs of burnout are included in Table 1.

Oncology nurses first need to identify the behaviors that lead to burnout, then develop coping activities to change the behaviors. Individual professional counseling may be necessary in situations when nurses have difficulty with interpersonal relationships, work performance decline, physical illness, and difficulty finding pleasure in daily living. Oncology nurses also can develop their own support structures in their work environments, as well as outside of work such as at their churches, at fitness clubs, or with family and friends. When people appear to be heading into a burnout mode, they must have somewhere safe to express their needs.

Oncology nurses can overcome and manage early burnout. The first step in understanding burnout is getting in touch with the inner feelings and physical symptoms that occur when signs of stress are happening. Seeking supportive relationships during stressful times is important. Supportive people can be family members or friends. Oncology nurses tend to be very caring and compassionate individuals who also are used to taking on several tasks at one time. Overloading can occur and further contribute to burnout. Nurses must learn to say no and prioritize the tasks that are important. Exercise routines and quiet relaxation periods are important to the overall well-being of the minds, bodies, and spirits of oncology nurses. Relaxation and rest restore and provide a sense of well-being.

Oncology nurses provide spiritual care in a variety of ways that often are personal and private. Oncology nurses experience spiritual distress when dealing with job, personal, and value conflicts in their lives. They should realize that experiencing feelings of conflict with emotions, values, and profession when dealing with end-of-life issues daily in their careers is normal. They should not ignore the feelings when they present themselves.

Nurses tend to be the eternal caregivers and may not look after themselves. The first step in recognizing that taking care of oneself is acknowledgement. Nurses must admit when they are overcommitted (Miller, 2003.)

### Conclusion

Oncology nurses play a significant role in providing care to patients and family members during the final journey. To do so requires knowledge and skill related to symptoms and syndromes unique to the end of life. More than any other time of care, the focus is on patients and their families, and education is essential. Finally, oncology nurses involved in the care of dying patients are at risk for burnout. Knowledge of the signs of burnout and strategies to address stressors are critical. Striving for professional and personal balance allows oncology nurses to continue to provide excellent care for suffering patients and families.
**Table 1. Physical Symptoms of Burnout**

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Comments</th>
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<tr>
<td>Heart palpitations</td>
<td>Feeling of tightness, rapid heart rate, and rapid pulse</td>
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<tr>
<td>Headaches</td>
<td>Frontal lobe and temporal that lasts longer than 20 minutes feeling of thickness in the throat and ready to vomit at any time</td>
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<tr>
<td>Nausea</td>
<td>Forgets to eat; can go days and not care about food; eats things that normally are not eaten, as well as volume of food, especially at night</td>
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<td>Loss of appetite or increased appetite</td>
<td>Not able to fall asleep or only for a four-hour time period; sleeping more than usual hours and not caring if the day is slept away</td>
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<tr>
<td>Changes in bowel patterns</td>
<td>Diarrhea several times a day; constipation and days of not realizing or knowing when the last bowel movement was</td>
</tr>
<tr>
<td>Sleep-pattern disturbances</td>
<td>Not able to fall asleep or only for a four-hour time period; sleeping more than usual hours and not caring if the day is slept away</td>
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<tr>
<td>Irritability and mood-pattern changes</td>
<td>Snaps at anything that is not what is wanted; usually can tolerate certain situations but disagrees quickly and without cause</td>
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<td>Depression</td>
<td>Feelings and actions as if life does not matter and there is no reason to continue functioning</td>
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<tr>
<td>Withdrawing from people and activities</td>
<td>Makes excuses for not attending functions; prefers to be in a self-care mode; no pleasure from being with people</td>
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<tr>
<td>Smoking, drinking, or gambling</td>
<td>Starts or resumes smoking and increases drinking without thought to consequences</td>
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while attending to their own needs. This will allow nurses to have very meaningful and long careers in oncology.

**References**


**Rapid Recap**

**Life’s Final Journey: The Oncology Nurse’s Role**

- Oncology nurses must be skilled in the assessment and management of symptoms common during the final days of life.
- Pain, rattle, delirium, myoclonus, and seizures may occur at the end of life, and available pharmacologic and nonpharmacologic treatments usually are effective.
- Oncology nurses are at risk for burnout and need to develop self-care strategies.