Imminent Death and Loss

HOW TO RECEIVE CREDIT

- Read the enclosed course.
- Complete the questions at the end of the course.
- Return your completed Evaluation to NetCE by mail or fax, or complete online at www.NetCE.com. (If you are a physician, behavioral health professional, or Florida nurse, please return the included Answer Sheet/Evaluation.) Your postmark or facsimile date will be used as your completion date.
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Faculty

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Audience

This course is designed for members of the interprofessional team, including physicians, physician assistants, nurse practitioners, nurses, social workers, marriage and family therapists, and other members seeking to enhance their knowledge of palliative care.

Accreditations & Approvals

In support of improving patient care, NetCE is jointly accredited by the Accreditation Council for Continuing Medical Education (ACCME), the Accreditation Council for Pharmacy Education (ACPE), and the American Nurses Credentialing Center (ANCC), to provide continuing education for the healthcare team.

As a Jointly Accredited Organization, NetCE is approved to offer social work continuing education by the Association of Social Work Boards (ASWB) Approved Continuing Education (ACE) program. Organizations, not individual courses, are approved under this program. Regulatory boards are the final authority on courses accepted for continuing education credit.

A complete Works Cited list begins on page 11.   ***Mention of commercial products does not indicate endorsement.***

AMERICAN PSYCHOLOGICAL ASSOCIATION

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This course is considered self-study by the New York State Board of Mental Health Counseling.

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This course is considered self-study by the New York State Board of Marriage and Family Therapy.

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This activity has been approved for the American Board of Anesthesiology's® (ABA) requirements for Part II: Lifelong Learning and Self-Assessment of the American Board of Anesthesiology's (ABA) redesigned Maintenance of Certification in Anesthesiology Program® (MOCA®), known as MOCA 2.0®. Please consult the ABA website, www.theABA.org, for a list of all MOCA 2.0 requirements. Maintenance of Certification in Anesthesiology Program® and MOCA® are registered certification marks of the American Board of Anesthesiology®. MOCA 2.0® is a trademark of the American Board of Anesthesiology®.

Successful completion of this CME activity, which includes participation in the activity with individual assessments of the participant and feedback to the participant, enables the participant to earn 1 MOC point in the American Board of Pediatrics' (ABP) Maintenance of Certification (MOC) program. It is the CME activity provider's responsibility to submit participant completion information to ACCME for the purpose of granting ABP MOC credit.

This activity has been designated for 1 Lifelong Learning (Part II) credit for the American Board of Pathology Continuing Certification Program.

Through an agreement between the Accreditation Council for Continuing Medical Education and the Royal College of Physicians and Surgeons of Canada, medical practitioners participating in the Royal College MOC Program may record completion of accredited activities registered under the ACCME's "CME in Support of MOC" program in Section 3 of the Royal College's MOC Program.

NetCE designates this continuing education activity for 1 ANCC contact hour.

This activity was planned by and for the healthcare team, and learners will receive 1 Interprofessional Continuing Education (IPCE) credit for learning and change.

NetCE designates this continuing education activity for 1.2 hours for Alabama nurses.

AACN Synergy CERP Category A.

Social workers completing this intermediate-to-advanced course receive 1 Clinical continuing education credit.

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NetCE designates this continuing education activity for 1 CE credit.

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This activity is designed to comply with the requirements of California Assembly Bill 1195, Cultural and Linguistic Competency, and California Assembly Bill 241, Implicit Bias.

About the Sponsor

The purpose of NetCE is to provide challenging curricula to assist healthcare professionals to raise their levels of expertise while fulfilling their continuing education requirements, thereby improving the quality of healthcare.

Our contributing faculty members have taken care to ensure that the information and recommendations are accurate and compatible with the standards generally accepted at the time of publication. The publisher disclaims any liability, loss or damage incurred as a consequence, directly or indirectly, of the use and application of any of the contents. Participants are cautioned about the potential risk of using limited knowledge when integrating new techniques into practice.

Disclosure Statement

It is the policy of NetCE not to accept commercial support. Furthermore, commercial interests are prohibited from distributing or providing access to this activity to learners.

Course Objective

The purpose of this course is to bridge the gap in knowledge of palliative care at the time of imminent death and in skills necessary to support patients and families in the moments before death.

Learning Objectives

Upon completion of this course, you should be able to:

1. Develop a strategy for providing care to patients and their families over the last days and hours of life.

2. Support appropriate grief and mourning.

3. Discuss how culture impacts end of life care and death.

Sections marked with this symbol include evidence-based practice recommendations. The level of evidence and/or strength of recommendation, as provided by the evidence-based source, are also included so you may determine the validity or relevance of the information. These sections may be used in conjunction with the course material for better application to your daily practice.

INTRODUCTION

In the last days, the goals of the healthcare team are to ensure a peaceful death for the patient and to support the family during the dying process and throughout grief and mourning. The focus for the patient is management of symptoms and emotional and spiritual ease, and the focus for the family is education to prepare them for the dying process.

THE PATIENT'S NEEDS

During the last days, all care should be directed at comfort, and the National Comprehensive Cancer Network (NCCN) has listed several interventions for imminently dying patients (*Table 1*) [1]. The physician should minimize the number of medications by reassessing the need for each one. The symptoms that occur most commonly during the last days are pain, noisy breathing, dyspnea, and delirium, and medications to manage these symptoms should be maintained or initiated [2]. In addition, medication may be required to reduce the risk of seizures. Medications should be prescribed for the least invasive route of administration (oral or buccal mucosa), but patients may lose the ability to swallow, making a subcutaneous, transdermal, or intravenous route necessary.

Treatment of pain should continue, and knowledge of opioid pharmacology becomes critical during the last hours of life [2; 3]. The metabolites of morphine and some other opioids remain active until they are cleared through the kidneys. If urine output stops, alternative opioids, such as fentanyl or methadone, should be considered, as they have inactive metabolites [4; 5].

Anticholinergic medications can eliminate the so-called "death rattle" brought on by the build-up of secretions when the gag reflex is lost or swallowing is difficult. However, it is important to note that results of clinical trials examining various pharmacologic agents for the treatment of death rattle have so far been inconclusive [6]. Despite the lack of clear evidence, pharmacologic therapies continue to be used frequently in clinical practice [3]. Specific drugs used include scopolamine, glycopyrrolate, hyoscyamine, and atropine (*Table 2*) [2; 3; 7]. Glycopyrrolate may be preferred because it is less likely to penetrate the central nervous system and with fewer adverse effects than with other antimuscarinic agents, which can worsen delirium [3]. For patients with advanced kidney disease, the dose of glycopyrrolate should be reduced 50% (because evidence indicates that the drug accumulates in renal impairment) and hyoscine butylbromide should not be used (because of a risk of excessive drowsiness or paradoxical agitation) [4]. Some evidence suggests that treatment is more effective when given earlier; however, if the patient is alert, the dryness of the mouth and throat caused by these medications can be distressful. Repositioning the patient to one side or the other or in the semiprone position may reduce the sound. Oropharyngeal suctioning is not only often ineffective but also may disturb the patient or cause further distress for the family. Therefore, it is not recommended.

Terminal delirium occurs before death in 50% to 90% of patients. It is associated with shorter survival and complicates symptom assessment, communication, and decision making. It can be extremely distressing to caregivers and healthcare professionals alike [3]. Safety measures include protecting patients from accidents or self-injury. Reorientation strategies are of little use during the final hours of life. Education and support for families witnessing a loved one's delirium are warranted [3]. There are few randomized controlled trials on the management of terminal delirium. Agents that can be used to manage delirium include haloperidol, which is frequently the first choice for its relatively quick action [3; 8]. Other drugs may include olanzapine, chlorpromazine, levomepromazine, and benzodiazepines [3; 8]. For terminal delirium associated with agitation, benzodiazepines, including clonazepam, midazolam, diazepam, and lorazepam may be helpful [3; 8; 9].

INTERVENTIONS FOR PATIENTS WHO ARE IMMINENTLY DYING
Intensify ongoing care.
Try to ensure privacy (if not at home, arrange for private room if possible).
Discontinue diagnostic tests.
Reposition for comfort as appropriate.
Avoid unnecessary needle sticks.
Provide mouth care (e.g., hydrogen peroxide/water solution).
Treat for urinary retention and fecal impaction.
Ensure access to medication even when oral route is not available.
Prepare to meet request for organ donation and autopsy.
Allow patient and family uninterrupted time together.
Ensure the patient and family understand the signs and symptoms of imminent death and are supported through the dying process.
Offer anticipatory bereavement support.
Provide support to children and grandchildren.
Encourage visits by children if consistent with family values.
Support culturally meaningful rituals.
Facilitate around-the-clock family presence.
Ensure that caregivers understand and will honor advance directives.
Provide respectful space for families.
Facilitate closure.

Source: [1]   *Table 1*

TREATMENT OF EXCESSIVE RESPIRATORY SECRETIONS CAUSING "DEATH RATTLE"	
Drug	**Dose**
Scopolamine (transdermal patch)	One (1.5-mg) patch applied behind the ear and changed every 72 hours Onset of action may be delayed several hours, so other anticholinergic treatment should be provided until effective.
Glycopyrrolate	0.2–0.4 mg SC, repeat at 30 minutes, then every 4 to 6 hours, as needed; or 0.6–1.2 mg/day CSCI
Hyoscyamine	0.4 mg SC, repeat at 30 minutes, then every 2 to 4 hours, as needed; or 0.6–1.2 mg/day CSCI
Atropine	0.4–0.8 mg SC, repeat every 2 to 4 hours
CSCI = continuous subcutaneous infusion, SC = subcutaneously.	

Source: [8]   *Table 2*

Depending on which drug is used, administration may be intravenous, subcutaneous, or rectal, and the dose can be titrated until effective.

Seizures at the end of life may be managed with high doses of benzodiazepines. Other antiepileptics such as phenytoin (administered intravenously), fosphenytoin (administered subcutaneously), or phenobarbital (60–120 mg rectally, intravenously, or intramuscularly every 10 to 20 minutes as needed) may become necessary until control is established.

A calm and peaceful environment should be maintained for the patient. Family and spiritual leaders should be allowed to carry out traditional rites and rituals associated with death.

PALLIATIVE SEDATION

Palliative sedation may be considered when an imminently dying patient is experiencing suffering (physical, psychologic, and/or spiritual) that is refractory to the best palliative care efforts. Terminal restlessness and dyspnea have been the most common indications for palliative sedation, and thiopental and midazolam are the typical sedatives used [1; 10; 11]. For patients who have advanced kidney disease, midazolam is recommended, but the dose should be reduced because more unbound drug becomes available [1; 4]. Before beginning palliative sedation, the clinician should consult with a psychiatrist and pastoral services (if appropriate) and talk to the patient, family members, and other members of the healthcare team about the medical, emotional, and ethical issues surrounding the decision [1; 2; 9; 12; 13]. Formal informed consent should be obtained from the patient or from the healthcare proxy.

PHYSICIAN-ASSISTED DEATH

Physician-assisted death, or hastened death, is defined as active euthanasia (direct administration of a lethal agent with a merciful intent) or assisted death (aiding a patient in ending his or her life at the request of the patient) [2]. The following are not considered to be physician-assisted death: carrying out a patient's wishes to refuse treatment, withdrawal of treatment, and the use of high-dose opioids with the intent to relieve pain. The American Medical Association Code of Ethics explicitly states, "Physician-assisted suicide is fundamentally incompatible with the physician's role as healer, would be difficult or impossible to control, and would pose serious societal risks" [14]. Position statements against the use of physician-assisted death have been issued by many other professional organizations, including the National Hospice and Palliative Care Organization and the American Academy of Hospice and Palliative Medicine (AAHPM) [15; 16]. The AAHPM states that their position is one of "studied neutrality" [15]. The basis for these declarations is that appropriate hospice care is an effective choice for providing comfort to dying patients.

In 2010, in a first-of-its-kind comprehensive consensus statement, the Heart Rhythm Society in collaboration with the major cardiology, geriatrics, and palliative care societies, emphasized that deactivation of implantable cardioverter-defibrillators is neither euthanasia nor physician-assisted death [17]. The organizations urged clinicians to respect the right of patients to request deactivation.

The 2024 NCCN guidelines advise that a request for hastened death often has important meanings that should be explored, beginning with an assessment to ensure palliative care needs are being met. This may enlarge the range of useful therapeutic options and might reduce the patient's wish to die. It is recommended clinicians explore the reasons for the request for a hastened death and determine the precipitating conditions in a joint discussion with patient, family, and caregivers [1]. During discussion, issues to consider include individual values, purpose, and meaning; worries about caregiver burden and abandonment; and views of spiritual/existential suffering (with consideration of spiritual care consultation). It is important to reassess symptom management and whether there are unrecognized patient issues, such as depression, anxiety, and delirium. It may be helpful to clarify the legal/ethical distinctions among assisted death, treatment withdrawal, and aggressive symptom management [1]. Some states have enacted assisted death statutes. State laws vary, and knowledge of your local statutes is necessary.

THE FAMILY'S NEEDS

Ongoing communication with family members is essential to ensure their well-being as their loved one dies. The healthcare team should discuss what will happen over the course of dying so the family can be better prepared for symptoms such as altered breathing patterns and sounds, terminal delirium, and unconsciousness [1; 3; 18]. The family should be reassured that what they may think the patient is experiencing is not the patient's actual reality.

The altered breathing patterns that are present as death is imminent are distressful for family members, as they believe that the patient is experiencing a sense of suffocation. Also distressful to family is the sound of the death rattle. The healthcare team should assure family that these signs do not indicate that the patient is suffering and explain that additional therapy will not be of benefit.

Families often misinterpret the early signs of terminal delirium as signs of uncontrollable pain. However, if pain has been adequately managed throughout the delivery of palliative care, such pain will not begin during the last hours. As the patient slips in and out of consciousness, family members may become increasingly distressed about not being able to communicate anymore with their loved one. Although it is unknown what a dying patient can hear, other experiences in medicine suggest that awareness may be greater than the ability to respond. Family members should be encouraged to continue talking with their loved one to help them attain a sense of closure.

Despite the best efforts to prepare the family, reactions are unpredictable when death occurs. The clinician should take time to answer questions from family members, including children, and perhaps provide information on the physiologic events associated with death [2]. For family members who were not present during the death, the clinician should describe the event, while reassuring them that the patient died peacefully.

Many experts believe that people can handle grief better if they spend time with a loved one immediately after death. Family members should be allowed to touch, hold, and kiss their loved one as they feel comfortable. The healthcare team should respect the needs of the family to conduct personal, cultural, or religious traditions, rites, and rituals.

GRIEF, MOURNING, AND BEREAVEMENT

Palliative care extends beyond the patient's death, with the focus shifting to support of the family during bereavement and mourning. Although the terms "grief," "mourning," and "bereavement" are often used interchangeably, their definitions are different. Grief is a normal reaction to a loss; mourning is the process by which individuals adjust to the loss; and bereavement is the period of time during which grief and mourning occur [2; 19]. Psychosocial support of the family is essential throughout the duration of palliative care and can help to decrease the risks of morbidity, substance abuse, and mortality that have been found among spouses and other loved ones of patients who have died [18].

EVIDENCE-BASED PRACTICE RECOMMENDATION

The National Hospice and Palliative Care Organization recommends that patient and family/caregiver feelings, strengths, goals, and needs related to loss, grief, and bereavement be assessed. Then, interventions should be developed based on the assessment and are incorporated into the interdisciplinary plan of care.

(https://www.nhpco.org/wp-content/uploads/Standards_of_Practice.pdf. Last accessed October 19, 2024.)

Strength of Recommendation/Level of Evidence: Expert Opinion/Consensus Statement

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GRIEF

Grief comprises a range of feelings, thoughts, and behaviors that fall in the realm of the physical, emotional, and social domains [2]. Individuals may have trouble sleeping, changes in appetite, or other physical symptoms or illness. Emotions can include sadness, anxiety, guilt, and anger. Return to work, activities with friends, and taking care of family can be beneficial.

Grief counseling for the family and patient should begin when the patient is alive, with a focus on life meaning and the contributions from the patient's family. An understanding of the mediators of the grief response can help physicians and other members of the healthcare team recognize the family members who may be at increased risk for adapting poorly to the loss [8; 20]. These mediators are:

- Nature of attachment (how close and/or dependent the individual was with regard to the patient)
- Mode of death (the suddenness of the death)
- Historical antecedents (how the individual has handled loss in the past)
- Personality variables (factors related to age, gender, ability to express feelings)
- Social factors (availability of social support, involvement in ethnic and religious groups)
- Changes and concurrent stressors (number of other stressors in the individual's life, coping styles)

Prolonged grief disorder was added to the DSM-5-TR in 2022, after several decades of studies that suggested many people were experiencing persistent difficulties associated with bereavement that exceeded expected social, cultural, or religious expectations [31]. It is defined as "intense yearning or longing for the deceased (often with intense sorrow and emotional pain) and preoccupation with thoughts or memories of the deceased. In children and adolescents, this preoccupation may focus on the circumstances of the death" [31]. In adults, this intense grief must still be present one year after a loss to be considered prolonged grief disorder; in children, the timeframe is six months. Additionally, the individual with prolonged grief disorder may experience significant distress or problems performing daily activities at home, work, or other important areas [31]. Clinical assessment should be carried out for individuals at risk of prolonged grief. Distinguishing between prolonged grief disorder and major depression can be challenging, as many signs and symptoms are similar. However, the characteristic symptoms of prolonged grief disorder are [31]:

- Identity disruption (e.g., feeling as though part of oneself has died)
- A marked sense of disbelief about the death
- Avoidance of reminders that the person is dead
- Intense emotional pain (e.g., anger, bitterness, sorrow)
- Difficulty reintegrating (e.g., unable to engage with friends, pursue interests, plan for the future)
- Emotional numbness
- Feeling that life is meaningless
- Intense loneliness and feeling of being detached from others

MOURNING

Satisfactory adaptation to loss depends on "tasks" of mourning [20]. Previous research referred to "stages" of mourning, but the term "task" is now used because the stages were not clear-cut and were not always followed in the same order. The tasks include:

- Accepting the reality of the loss
- Experiencing the pain of the loss
- Adjusting to the environment in which the deceased is missing (external, internal, and spiritual adjustments)
- Finding a way to remember the deceased while moving forward with life

After the patient's death, members of the palliative care team should encourage the family to talk about the patient, as this promotes acceptance of the death. Explaining that a wide range of emotions is normal during the mourning process can help family members understand that experiencing these emotions is a necessary aspect of grieving. Frequent contact with family members after the loved one's death can ensure that the family is adjusting to the loss. Referrals for psychosocial and spiritual interventions should be made as early as possible to optimize their efficacy.

BEREAVEMENT

Bereavement support should begin immediately with a handwritten condolence note from the clinician. Such notes have been found to provide comfort to the family [21; 22]. The physician should emphasize the personal strengths of the family that will help them cope with the loss and should offer help with specific issues. Attendance at the patient's funeral, if possible, is also appropriate.

How bereavement services are provided through a hospice/palliative care program vary. Programs usually involve contacting the family at regular intervals to provide resources on grieving, coping strategies, professional services, and support groups [1; 9]. When notes are sent, family members should be invited to contact the physician or other members of the healthcare team with questions. Notes are especially beneficial at the time of the first holidays without the patient, significant days for the family (patient's birthday, spouse's birthday), and the anniversary of the patient's death. Bereavement services should extend for at least one year after the patient's death, but a longer period may be necessary [9; 18].

CULTURAL CONSIDERATIONS

Cultural sensitivity consists of promoting trust and mutual respect for cultural differences between providers and patients [23]. In end-of-life care, an understanding of cultural differences in beliefs about grieving is necessary. In Western culture, grieving is expected to be time-limited, and extended grieving can be considered pathologic [24]. However, in other cultures, extended periods of grieving are socially sanctioned.

Cultural groups adhere to culturally laden beliefs about death rituals, death symbols, language, gender roles, advanced care planning, end-of-life directives, and bereavement and grief. As a result, a provider's level of cultural competence will influence how he or she interacts with patients and family members during the end of life, ultimately influencing how patients and families perceive the end-of-life experience [25]. In traditional Asian families, for example, the eldest son may be designated to make key health and end-of-life decisions [26]. Various cultural groups will have specific norms about the expression of emotion during funerals. White Protestant individuals, for example, may value stoicism, while the Chinese equate the amount of wailing to the amount of respect paid to the deceased [27]. Crying that involves shaking of the body is considered cathartic and a normal reaction in some cultures [28].

It is also important to consider intersectionality in discussions of cultural competence. Individuals do not belong in one category in terms of their identity. Often, patients have overlapping identities (e.g., sex/gender, socioeconomic status, religion, class, sexual orientation, racial/ethnic minority group). This contributes to discrimination and marginalization, which influences how one experiences death and dying [29]. Some experts assert that the word "competence" in cultural competence is a misnomer, because it implies that providers can obtain a "rational mastery and application of knowledge" [30]. End-of-life care planning is complex, and cultural competence entails being reflective and accessing one's intuition.

CONCLUSION

When patients and their families are confronted with a terminal illness and issues of death and dying, it is undoubtedly a time of grief and stress. Although patients and families require support during this period, practitioners may be uncomfortable witnessing grief, as it may raise personal issues about their own mortality. Palliative care eases the burden of suffering experienced by patients approaching life's end and provides for grief counseling and bereavement services for a family adjusting to loss.

Implicit Bias in Health Care

The role of implicit biases on healthcare outcomes has become a concern, as there is some evidence that implicit biases contribute to health disparities, professionals' attitudes toward and interactions with patients, quality of care, diagnoses, and treatment decisions. This may produce differences in help-seeking, diagnoses, and ultimately treatments and interventions. Implicit biases may also unwittingly produce professional behaviors, attitudes, and interactions that reduce patients' trust and comfort with their provider, leading to earlier termination of visits and/or reduced adherence and follow-up. Disadvantaged groups are marginalized in the healthcare system and vulnerable on multiple levels; health professionals' implicit biases can further exacerbate these existing disadvantages.

Interventions or strategies designed to reduce implicit bias may be categorized as change-based or control-based. Change-based interventions focus on reducing or changing cognitive associations underlying implicit biases. These interventions might include challenging stereotypes. Conversely, control-based interventions involve reducing the effects of the implicit bias on the individual's behaviors. These strategies include increasing awareness of biased thoughts and responses. The two types of interventions are not mutually exclusive and may be used synergistically.

FACULTY BIOGRAPHIES

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