End of Life II – Clinical Management
Goals and Objectives

Course Description

"End of Life II – Clinical Management" is an asynchronous online text-based continuing education course for physical therapists and physical therapist assistants. This course presents updated information about terminal illness and the last stages of life including sections on symptom management, communication, palliative care, hospice, futile care, life sustaining treatment, and legal and ethical issues.

Course Rationale

The purpose of this course is to present physical therapists and physical therapist assistants with current information about the clinical care issues relating to death and dying. A greater understanding of death and dying will enable physical therapists and physical therapist assistants to provide more effective and efficient care to individuals affected by terminal illness.

Course Goals and Objectives

Upon completion of this course, the participant will be able to:
1. identify and describe common symptomology associated with end-of-life
2. identify clinical interventions available to manage end-of-life symptoms
3. define and explain palliative care.
4. define hospice and differentiate between its levels of care
5. define and summarize futile care
6. list and describe potential sources of conflict
7. define and differentiate the terms associated with life sustaining treatment
8. understand and summarize the common legal and ethical issues relevant to end-of –life care
9. identify the physical signs of impending death
10. list the clinical signs that death has occurred

Course Provider – Innovative Educational Services

Course Instructor - Michael Niss, DPT

Target Audience – physical therapists and physical therapist assistants

Course Educational Level – Introductory / intermediate

Course Prerequisites - None

Method of Instruction/Availability – Online text-based course available continuously.

Criteria for issuance of CE Credits - A score of 70% or greater on the course post-test.

Continuing Education Credits – 3 hours

Determination of Credits - Mergener Formula: $.9 \times [-22.3+(0.00209 \times 63{,}313) + (2.78 \times 15) + (15.5 \times 3)] = 180$ minutes = 3.0 hours

Fees - $29.95

Conflict of Interest – No conflict of interest exists for the presenter or provider of this course.

Refund Policy - Unrestricted 100% refund upon request. The request for a refund by the learner shall be honored in full without penalty or other consideration of any kind. The request for a refund may be made by the learner at any time without limitations before, during, or after course participation.

End of Life II – Clinical Management

Course Outline

Overview

Of all patients who die from disease, only a few (<10%) die suddenly and unexpectedly. Most (>90%) die after a long period of illness with gradual deterioration until an active dying phase at the end. Care provided during those last hours and days can have profound effects, not just on the patient, but on all who participate. At the very end-of-life, there is no second chance to get it right.

During the last hours of their lives, most patients require skilled care around the clock. This can be provided in any setting as long as the professional, family, and volunteer caregivers are appropriately prepared and supported throughout the process. The environment must allow family and friends access to their loved one around the clock without disturbing others and should be conducive to privacy and intimacy. Medications, equipment, and supplies need to be available in anticipation of problems, whether the patient is at home or in a health care institution. As the patient's condition and the family's ability to cope can change frequently, both must be reassessed regularly and the plan of care modified as needed. Changes in the patient's condition can occur suddenly and unexpectedly, so caregivers must be able to respond quickly. This is particularly important when the patient is at home, if unnecessary readmission is to be avoided.

If the last hours of a person's life are to be as rewarding as possible, advance preparation and education of professional, family, and volunteer caregivers are essential, whether the patient is at home, in an acute care or skilled nursing facility, a hospice or palliative care unit, prison, etc. Everyone who participates must be aware of the patient's health status, his or her goals for care and the parents' goals if the patient is a child, advance directives, and proxy for decision making. They should also be knowledgeable about the potential time course, signs, and symptoms of the dying process, and their potential management. Help families to understand that what they see may be very different from the patient's experience. If family members and caregivers feel confident, the experience can be a time of final gift giving. When parents feel confident about providing for the needs of their dying child, their sense that they are practicing good parenting skills is reinforced. If left unprepared and unsupported, they may spend excessive energy worrying about how to handle the next event. If things do not go as hoped for, family members may live with frustration, worry, fear, or guilt that they did something wrong or caused the patient's death.

Although we often sense that death will either come quickly over minutes or be protracted over days to weeks, it is not possible to predict when death will occur with precision. Some patients may appear to wait for someone to visit, or for an important event such as a birthday or a special holiday, and then die soon afterward. Others experience unexplained improvements and live longer than expected. A few seem to decide to die and do so very quickly, sometimes within minutes. While it is possible to give families or professional caregivers a general

idea of how long the patient might live, always advise them about the inherent unpredictability of the moment of death.

Symptom Management

There are a variety of physiologic changes that occur in the last hours and days of life, and when the patient is actually dying. Each can be alarming if it is not understood. The most common issues are summarized here. To effectively manage each syndrome or symptom, health care professionals need to have an understanding of its cause, underlying pathophysiology, and the appropriate pharmacology to use.

Fatigue

Fatigue at the end of life is multidimensional, and its underlying pathophysiology is poorly understood. Factors that may contribute to fatigue include physical changes, psychological dynamics, and adverse effects associated with the treatment of the disease or associated symptoms.

Weakness and fatigue usually increase as the patient approaches the time of death. It is likely that the patient will not be able to move around in the bed or raise his or her head. Joints may become uncomfortable if they are not moved. Continuous pressure on the same area of skin, particularly over bony prominences, will increase the risk of skin ischemia and pain. At the end-of-life, fatigue need not be resisted and most treatment to alleviate it can be discontinued. As the patient approaches death, providing adequate cushioning on the bed will lessen the need for uncomfortable turning.

Cutaneous Ischemia

Patients who are too fatigued to move and have joint position fatigue may require passive movement of their joints every 1 to 2 hours. To minimize the risk of pressure ulcer formation, turn the patient from side to side every 1 to 1.5 hours and protect areas of bony prominence with hydrocolloid dressings and special supports. Do not use "donuts" as they paradoxically worsen areas of breakdown by compressing blood flow circumferentially around the compromised area. A draw sheet can assist caregivers to turn the patient and minimize pain and shearing forces to the skin. If turning is painful, consider a pressure-reducing surface (e.g., air mattress or airbed). As the patient approaches death, the need for turning lessens as the risk of skin breakdown becomes less important.

Intermittent massage before and after turning, particularly to areas of contact, can both be comforting and reduce the risk of skin breakdown by improving circulation and shifting edema. Avoid massaging areas of non-blanching erythema or actual skin breakdown.

Loss of Appetite

Most dying patients lose their appetite. Unfortunately, families and professional caregivers may interpret cessation of eating as "giving in" or "starving to death." Yet, parenteral or enteral feeding of patients near death neither improves symptom control nor lengthens life. Anorexia may be helpful as the resulting ketosis can lead to a sense of well-being and diminish discomfort.

Health care professionals can help families understand that loss of appetite is normal at this stage. Remind them that the patient is not hungry, that food either is not appealing or may be nauseating, that the patient would likely eat if he or she could, that the patient's body is unable to absorb and use nutrients, and that clenching of teeth may be the only way for the patient to express his/her desire not to eat.

Whatever the degree of acceptance of these facts, it is important for clinicians to help families and caregivers realize that food pushed upon the unwilling patient may cause problems such as aspiration and increased tension. Above all, help them to find alternate ways to nurture the patient so that they can continue to participate and feel valued during the dying process.

Decreasing Fluid Intake

Most dying patients stop drinking. This may heighten onlookers' distress as they worry that the dehydrated patient will suffer, particularly if he or she becomes thirsty. Most experts feel that dehydration in the last hours of living does not cause distress and may stimulate endorphin release that promotes the patient's sense of well-being. Low blood pressure or weak pulse is part of the dying process and not an indication of dehydration. Patients who are not able to be upright do not get light-headed or dizzy. Patients with peripheral edema or ascites have excess body water and salt and are not dehydrated.

Parenteral fluids, given either intravenously or subcutaneously using hypodermoclysis, are sometimes considered, particularly when the goal is to reverse delirium. However, parenteral fluids may have adverse effects that are not commonly considered. Intravenous lines can be cumbersome and difficult to maintain. Changing the site of the angiocatheter can be painful, particularly when the patient is cachectic or has no discernible veins. Excess parenteral fluids can lead to fluid overload with consequent peripheral or pulmonary edema, worsened breathlessness, cough, and orotracheobronchial secretions, particularly if there is significant hypoalbuminemia.

To maintain patient comfort and minimize the sense of thirst, even in the face of dehydration, maintain moisture on mucosal membrane surfaces with meticulous oral, nasal, and conjunctival hygiene. Moisten and clean oral mucosa every 15 to 30 minutes with either baking soda mouthwash (1 teaspoon salt, 1 teaspoon

baking soda, 1-quart tepid water) or an artificial saliva preparation to minimize the sense of thirst and avoid bad odors or tastes and painful cracking. Treat oral candidiasis with topical nystatin or systemic fluconazole if the patient is able to swallow. Coat the lips and anterior nasal mucosa hourly with a thin layer of petroleum jelly to reduce evaporation. If the patient is using oxygen, use an alternative nonpetroleum based lubricant. Avoid perfumed lip balms and swabs containing lemon and glycerin, as these can be both desiccating and irritating, particularly on open sores. If eyelids are not closed, moisten conjunctiva with an ophthalmic lubricating gel every 3 to 4 hours, or artificial tears or physiologic saline solution every 15 to 30 minutes to avoid painful dry eyes.

Cardiac and Renal Dysfunction

As cardiac output and intravascular volume decrease at the end-of-life, there will be evidence of diminished peripheral blood perfusion. Tachycardia, hypotension, peripheral cooling, peripheral and central cyanosis, and mottling of the skin (livedo reticularis) are expected. Venous blood may pool along dependent skin surfaces. Urine output falls as perfusion of the kidneys diminishes. Oliguria or anuria usually ensue. Parenteral fluids will not reverse this circulatory shut down.

Altered Consciousness

The neurologic changes associated with the dying process are the result of multiple concurrent irreversible factors. These changes may manifest themselves in two different patterns that have been described as the "two roads to death" (see below).
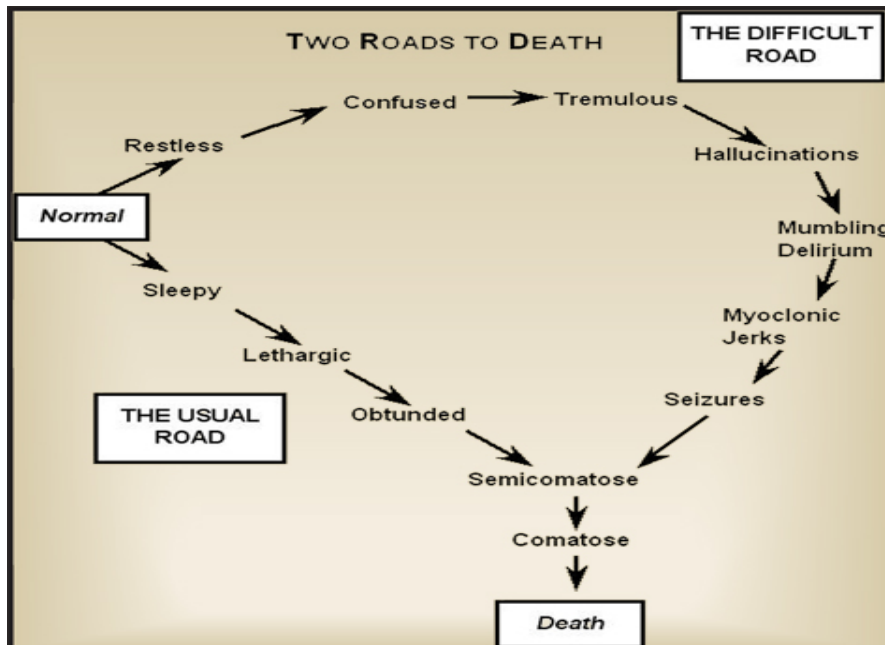
The majority of patients traverse the "usual road to death." They experience increasing drowsiness, sleep most if not all of the time, and eventually become unarousable. Absence of eyelash reflexes on physical examination indicates a profound level of coma equivalent to full anesthesia.

Terminal Delirium
An agitated delirium may be the first sign to herald the "difficult road to death." It frequently presents as confusion, restlessness, and/or agitation, with or without day-night reversal. To the family and professional caregivers who do not understand it, agitated terminal delirium can be very distressing. Although previous care may have been excellent, if the delirium goes misdiagnosed or unmanaged, family members will likely remember a horrible death "in terrible pain" and cognitively impaired "because of the drugs" and may worry that their own death will be the same.

In anticipation of the possibility of terminal delirium, educate and support family and professional caregivers to understand its causes, the finality and irreversibility of the situation, and approaches to its management. It is particularly important that all onlookers understand that what the patient experiences may be very different from what they see.

If the patient is not assessed to be imminently dying, it may be appropriate to evaluate and try to reverse treatable contributing factors. However, if the patient is in the last hours of his or her life, the condition is by definition irreversible. Focus is on the management of the symptoms associated with the terminal delirium in order to settle the patient and the family.

When moaning, groaning, and grimacing accompany the agitation and restlessness, they are frequently misinterpreted as physical pain. However, it is a myth that uncontrollable pain suddenly develops during the last hours of life when it has not previously been a problem. While a trial of opioids may be beneficial in the unconscious patient who is difficult to assess, physicians must remember that opioids may accumulate and add to delirium when renal clearance is poor. If the trial of increased opioids does not relieve the agitation or makes the delirium worse by increasing agitation or precipitating myoclonic jerks or seizures (rare), then alternate therapies should be directed at suppressing the symptoms associated with delirium.

Benzodiazepines are used widely to treat terminal delirium as they are anxiolytics, amnestics, skeletal muscle relaxants, and antiepileptics.

There are two general presentations of delirium: hyperactive and hypoactive.

The hyperactive form of delirium includes agitation, hallucinations, and restlessness.

In hypoactive delirium, the patient is withdrawn and quiet; as a result, this form of delirium may be underdiagnosed. Although the etiology of either form of delirium is poorly understood, metabolic changes (e.g., hypercalcemia, hypoglycemia, opioid metabolites), dehydration, and drug interactions are implicated. Other potential causes of delirium include pathology within the CNS, a full bladder, fecal impaction, dyspnea, or withdrawal from alcohol or benzodiazepines.

Care of the patient with delirium can include stopping unnecessary medications, reversing metabolic abnormalities (if consistent with the goals of care), treating the symptoms of delirium, and providing a safe environment. Agents known to cause delirium include corticosteroids, chemotherapeutic agents, biological response modifiers, opioids, antidepressants, benzodiazepines, and anticholinergic agents.

To limit the potential for drug interactions, medications that are no longer useful or that are inconsistent with the goals of care should be stopped. For example, cholesterol-lowering agents are rarely beneficial at this time of life, but many patients admitted to hospice remain on these medications.

Onset of effect and non-oral modes of delivery should be considered when an agent is being selected to treat delirium at the end of life. Agents that can relieve delirium relatively quickly include haloperidol, 1 mg to 4 mg orally, intravenously, or subcutaneously. The dose is usually repeated every 6 hours but in severe cases can be administered every hour.

Other agents that may be effective include olanzapine, 2.5 mg to 20 mg orally at night (available in an orally disintegrating tablet for patients who cannot swallow). Although benzodiazepines (such as lorazepam) or atypical antipsychotics typically exacerbate delirium, they may be useful in delirium related to alcohol withdrawal and for hyperactive delirium that is not controlled by antipsychotics and other supportive measures.

In intractable cases of delirium, palliative sedation may be warranted. Safety measures include protecting patients from accidents or self-injury while they are restless or agitated. The use of restraints is controversial; other strategies include having family members or sitters at the bedside to prevent harm. 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.

In dying patients, a poorly understood phenomenon that appears to be distinct from delirium is the experience of auditory and/or visual hallucinations that include loved ones who have already died. Although patients may sometimes find these hallucinations comforting, fear of being labeled confused may prevent patients from sharing their experiences with health care professionals. Family members at the bedside may find these hallucinations disconcerting and will require support and reassurance. Consultation with the patient's or family's

minister, rabbi, priest, or imam; the hospital chaplain; or other spiritual advisor is often beneficial.

Respiratory Dysfunction

Changes in a dying patient's breathing pattern may be indicative of significant neurologic compromise. Dyspnea occurs when more respiratory effort is necessary to overcome obstruction or restrictive disease (e.g., tumor or pleural effusions), when more respiratory muscles are required to maintain adequate breathing (e.g., neuromuscular weakness or cachexia), or when there is an increase in ventilatory need (e.g., hypercapnia or metabolic acidosis).

Breaths may become very shallow and frequent with a diminishing tidal volume. Periods of apnea and/or Cheyne-Stokes pattern respirations may develop. Accessory respiratory muscle use may become prominent. A few (or many) last reflex breaths may signal death.

Families and professional caregivers frequently find changes in breathing patterns to be one of the most distressing signs of impending death. Many fear that the comatose patient will experience a sense of suffocation. Knowledge that the unresponsive patient may not be experiencing breathlessness or "suffocating," and may not benefit from oxygen which may actually prolong the dying process, can be very comforting. Low doses of opioids or benzodiazepines are appropriate to manage any perception of breathlessness.

Opioids decrease the perception of air hunger, regardless of the underlying pathophysiology and without causing respiratory depression. This relief is dose related and, experimentally, is reversible by naloxone, an opioid antagonist. Very low doses of opioid, such as morphine 2.5 mg orally, may provide relief in opioid-naïve patients. Higher doses may be indicated in patients who have more intense dyspnea or in patients who are using opioids for pain. As with pain control, gradual upward titration may be needed to provide relief, particularly as symptoms progress.

Some physicians express concern that the use of opioids or benzodiazepines for symptom control near the end-of-life will hasten death. Consequently, they feel they must invoke the ethical principle of double effect to justify treatment. While it is true that patients are more likely to receive higher doses of both opioids and sedatives as they get closer to death, there is no evidence that initiation of treatment or increases in dose of opioids or sedatives is associated with precipitation of death.

Benzodiazepines may be used to treat anxiety commonly associated with dyspnea, but only as an adjunct to opioid therapy. Studies are lacking; however, supplemental oxygen appears to be useful only when hypoxemia is the underlying cause of dyspnea and is not effective in relieving symptoms of

dyspnea in people who do not have hypoxemia. Alternate strategies include positioning a cool fan toward the patient's face and repositioning the patient into an upright posture. Cognitive behavioral therapies such as relaxation, breathing control exercises, and psychosocial support may be effective in relieving dyspnea, although patients in the final hours of life may have limited capacity to participate in these techniques.

Complementary therapies such as acupuncture and acupressure have been demonstrated to be beneficial for relieving dyspnea, although controlled trials are lacking. Antibiotics may provide relief from infectious sources of dyspnea; however, the use of these agents should be consistent with the patient's goals of care. If the patient experiences bronchospasm in conjunction with dyspnea, glucocorticoids or bronchodilators can provide relief. Bronchodilators should be used with caution because they can increase anxiety, leading to a worsened sense of dyspnea. In rare situations, dyspnea may be refractory to all of the treatments described above. In such cases, palliative sedation may be indicated, using benzodiazepines, barbiturates, or neuroleptics.

Coughing

Weakness and decreased neurologic function frequently combine to impair the patient's ability to swallow. The gag reflex and reflexive clearing of the oropharynx decline and secretions from the tracheobronchial tree accumulate.

In some patients, chronic coughing at the end of life may contribute to suffering. Chronic cough can cause pain, interfere with sleep, aggravate dyspnea, and worsen fatigue. At the end of life, aggressive therapies are not warranted and are more likely to cause increased burden or even harm. Symptom control rather than treatment of the underlying source of the cough is warranted at this time of life. Opioids are strong antitussive agents and are frequently used to suppress cough in this setting. Corticosteroids may shrink swelling associated with lymphangitis. Antibiotics may be used to treat infection and reduce secretions leading to cough.

Patients may have comorbid conditions that can lead to cough. For example, bronchodilators are useful in the management of wheezing and cough associated with chronic obstructive pulmonary disease, and diuretics may be effective in relieving cough due to cardiac failure. Additionally, a review of medications is warranted because some drugs (e.g., ACE inhibitors) can cause cough.

Anecdotal evidence suggests a role for inhaled local anesthetics, which should be utilized judiciously and sparingly; they taste unpleasant and inhibit the gag reflex, and anaphylactic reactions to preservatives in these solutions have been documented. In cases of increased sputum production, expectorants and mucolytics have been employed, but the effects have not been well evaluated.

Inhaled sodium cromoglycate has shown promise as a safe method of controlling chronic coughing related to lung cancer.

Once the patient is unable to swallow, cease oral intake. Warn families and professional caregivers of the risk of aspiration. Scopolamine or glycopyrrolate effectively reduce the production of saliva and other secretions. They will minimize or eliminate the gurgling and crackling sounds, and may be used prophylactically in the unconscious dying patient. Anecdote suggests that the earlier treatment is initiated, the better it works, as larger amounts of secretions in the upper aerodigestive tract are more difficult to eliminate. However, premature use in the patient who is still alert may lead to unacceptable drying of oral and pharyngeal mucosa. While atropine may be equally effective, it has an increased risk of producing undesired cardiac and/or CNS excitation.

Death Rattle

Rattle, also referred to as death rattle, occurs when saliva and other fluids accumulate in the oropharynx and upper airways in a patient who is too weak to clear the throat. Rattle does not appear to be painful for the patient, but the association of this symptom with impending death often creates fear and anxiety for those at the bedside. Rattle is an indicator of impending death, with an incidence of approximately 50% in people who are actively dying. There is some evidence that the incidence of rattle can be greatly reduced by avoiding the tendency to overhydrate patients at the end of life.

Two types of rattle have been identified: real death rattle, or type 1, which is probably caused by salivary secretions; and pseudo death rattle, or type 2, which is probably caused by deeper bronchial secretions due to infection, tumor, fluid retention, or aspiration.

The pharmacologic treatment of rattle includes antimuscarinic agents, which antagonize acetylcholine (and are thus termed anticholinergic) to reduce secretions. The most commonly used agents include scopolamine, glycopyrrolate, atropine, and hyoscyamine. Few data exist to support the use of one agent or route over another. Because most patients are unable to swallow at this time, transdermal or parenteral routes are employed most frequently. Scopolamine, also called l-hyoscine or hyoscine, is available in oral, parenteral, transdermal, and ophthalmic formulations. Adverse effects include CNS depression, although paradoxical excitation has been reported.

Glycopyrrolate is less likely to penetrate the CNS, and fewer adverse effects are reported than with other antimuscarinic agents, though this is probably of little In addition to these agents, diuretics such as furosemide can sometimes eliminate excess fluids that build up in the upper airways. Reducing parenteral fluids can help reduce excess secretions. None of these measures appear to be

effective when the underlying cause of rattle is deep fluid accumulation, such as occurs with pneumonia.

If excessive fluid accumulates in the back of the throat and upper airways, it may need to be cleared by repositioning of the patient or postural drainage. Turning the patient onto one side or into a semi-prone position may reduce gurgling. Lowering the head of the bed and raising the foot of the bed while the patient is in a semi-prone position may cause fluids to move into the oropharynx, from which they can be easily removed. Do not maintain this position for more than a few minutes at a time, as stomach contents may also move unexpectedly. Oropharyngeal suctioning is not recommended. It is frequently ineffective, as fluids are beyond the reach of the catheter, and may only stimulate an otherwise peaceful patient and distress family members who are watching.

Incontinence

Fatigue and loss of sphincter control in the last hours of life may lead to incontinence of urine and/or stool. Both can be very distressing to patients and family members, particularly if they are not warned in advance that these problems may arise. If they occur, attention needs to be paid to cleaning and skin care. A urinary catheter may minimize the need for frequent changing and cleaning, prevent skin breakdown, and reduce the demand on caregivers. However, it is not always necessary if urine flow is minimal and can be managed with absorbent pads or surfaces. If diarrhea is considerable and relentless, a rectal tube may be similarly effective.

Pain

While many people fear that pain will suddenly increase as the patient dies, there is no evidence to suggest that this occurs.

Though difficult to assess, continuous pain in the semiconscious or obtunded patient may be associated with grimacing and continuous facial tension, particularly across the fore-head and between the eyebrows. The possibility of pain must also be considered when physiologic signs occur, such as transitory tachycardia that may signal distress. Do not assume it is pain when fleeting forehead tension comes and goes with movement or mental activity (e.g., dreams or hallucinations). Pain should not be confused with the restlessness, agitation, moaning, and groaning that accompany terminal delirium. If the diagnosis is unclear, a trial of a higher dose of opioid may be necessary to judge whether pain is driving the observed behaviors.

Knowledge of opioid pharmacology becomes critical during the last hours of life. The liver conjugates codeine, morphine, oxycodone, and hydromorphone into glucuronides. Some of their metabolites remain active as analgesics until they are renally cleared, particularly morphine. As dying patients experience

diminished hepatic function and renal perfusion, and usually become oliguric or anuric, routine dosing or continuous infusions of morphine may lead to increased serum concentrations of active metabolites, toxicity, and an increased risk of terminal delirium. To minimize this risk, routine dosing or continuous infusions of morphine should be discontinued when urine output and renal clearance stop. The use of alternative opioids with inactive metabolites such as fentanyl or hydromorphone should be considered.

Because consciousness may diminish during this time and swallowing becomes difficult, alternatives to the oral route of opioid delivery are indicated. Both intravenous and subcutaneous routes are effective in delivering opioids and other agents in the inpatient or home setting. For patients who do not have a pre-existing access port or catheter, intermittent or continuous subcutaneous administration provides a painless and effective route of delivery.

Myoclonic jerking can occur at any time during opioid therapy but is seen more frequently at the end of life. Nocturnal myoclonus is common and often precedes opioid-induced myoclonus. The precise cause of opioid-induced myoclonus is unknown.

When opioids are implicated in the development of myoclonus, hydration and rotation to other opioids are the primary treatments. There is great variability in individual response to opioids; thus, different agents may be more likely to produce myoclonus or other adverse effects. Because cross-tolerance between opioids is not complete, empirical evidence suggests that after an equianalgesic dose is calculated, that dose should be reduced by approximately 25%, then titrated upward to meet the patient's analgesic needs.

Loss of Ability to Close Eyes

Eyes that remain open can be distressing to onlookers unless the condition is understood. Advanced wasting leads to loss of the retro-orbital fat pad, and the orbit falls posteriorly within the orbital socket. As eyelids are of insufficient length to both extend the additional distance backward and cover the conjunctiva, they may not be able to fully appose. This may leave some conjunctiva exposed even when the patient is sleeping. If conjunctiva remains exposed, moisture can be maintained by using ophthalmic lubricants, artificial tears, or physiologic saline.

Fever

Terminally ill patients experience a high incidence of fever and infections. A large number of patients who are receiving hospice or palliative care are treated with antibiotics for suspected or documented infections.

The benefits and burdens of the use of antimicrobials in this patient population are topics of much discussion. Symptom control may be the main objective in the

decision to use antimicrobials to treat clinically suspected or documented infections in patients who are receiving palliative or hospice care.

Difficulties in treating symptoms include predicting which patients will obtain symptom relief and which patients will experience only the additional burdens of treatment. Determining the cause of fever (e.g., infection, tumor, or another cause) and deciding which symptoms from suspected infections might respond to various antimicrobial interventions can be difficult clinical judgments, particularly in patients who have multiple active medical problems and for whom the goal of treatment is symptom control.

Hemorrhage

Hemorrhage is an uncommon (6%–10%) yet extremely disturbing symptom that can arise from disease or its treatment. Patients at particular risk include those with head and neck cancers with tumor infiltration into the carotid artery.

Radiation therapy to this region can result in thinning of the walls of the vessels, increasing the risk of bleeding. Slow leakage of blood from eroded areas can signal risk of hemorrhage; however, early signs are frequently not apparent, and bleeding can occur without warning. Other cancers that can lead to sudden hemorrhage include gastric or esophageal cancers that perforate, leading to a rapidly fatal upper gastrointestinal bleed.

Leukemias and other hematologic disorders place patients at risk for hemorrhage. Disseminated intravascular coagulopathy, idiopathic thrombocytopenia, or other platelet abnormalities can lead to sudden hemorrhage.

When chronic bleeding occurs, management may include hemostatic dressings or agents, radiation therapy, endoscopy, arterial embolization, or surgery may be warranted. Systemic interventions include the use of vitamin K or blood products. However, the goals of care are comfort oriented when catastrophic hemorrhage occurs at the end of life.

Optimally, code status has already been discussed; resuscitation is rarely effective. Supportive care is critical, for both the patient and family members at the bedside. Although survival after hemorrhage is very limited (usually a few minutes), patients may be initially aware of events around them. Fast-acting agents such as midazolam may sedate the patient during this distressing event.

The following steps should be taken when bleeding occurs:

- Cover the area with dark-colored (e.g., blue or green) towels to limit visual exposure to the blood.

- Speak calmly and reassure the patient that he or she is not alone (and, if loved ones are in attendance, let the patient know they are there).

- Clean the area rapidly because blood can produce a foul odor that may be distressing to loved ones.

- Provide support to family members.

Oncology, palliative care, and other units that care for patients at risk for hemorrhage should have supplies (towels, sedatives) and standing orders in place for rapid employment. Support is essential for all members of the health care team, including novice clinicians or non-clinical staff who might be in attendance, such as chaplains or social workers. Team members should be encouraged to verbalize their emotions regarding the experience, and their questions should be answered.

Communication

Families will frequently find that their decreasing ability to communicate with their dying family member is distressing. The last hours of life are the time when they most want to communicate with their loved one. As many clinicians have observed, the degree of family distress seems to be inversely related to the extent to which advance planning and preparation occurred. The time spent preparing families is likely to be very worthwhile.

While it is not known exactly what unconscious patients can actually hear, extrapolation from data from the operating room and "near death" experiences suggests that at times their awareness may be greater than their ability to respond. Given our inability to assess a dying patient's comprehension and the distress that talking "over" the patient may cause; it is prudent to presume that the unconscious patient hears everything. Advise families and professional caregivers to talk to the patient as if he or she were conscious.

Encourage families to create an environment that is familiar and pleasant. Surround the patient with the people, children, pets, objects, music, and sounds that he or she would like. Include the patient in everyday conversations.

Encourage family members to say the things they need to say. At times, it may seem that a patient may be waiting for permission to die. If this is the case, encourage family members to give the patient permission to "let go" and die in a manner that feels most comfortable. The physician or other care-givers might suggest to family members other words like:

- "I know that you are dying; please do so when you are ready."

- "I love you. I will miss you. I will never forget you. Please do what you need to do when you are ready."

- "Mommy and Daddy love you. We will miss you, but we will be okay."

As touch can heighten communication, encourage family members to show affection in ways they are used to. Let them know that it is okay to lie beside the patient in privacy to maintain as much intimacy as they feel comfortable with.

Palliative Care

The term palliative care (soins palliatif in French) was first coined by Dr. Balfour Mount, a urologic surgeon working at the Royal Victoria Hospital in Montreal in the mid-1970s. He was looking for a word that would describe the care provided by English hospices but avoid the negative connotations of the word for French-speaking Canada. He piloted his approach beginning in a unit in the Royal Victoria Hospital rather than in a free-standing, separate building. Subsequently, the term palliative care has been associated with the approach to care first developed by hospice programs but made available in hospitals, outpatient clinics, and homecare services.

Various groups have defined palliative care in diverse but related ways. Each of the proposed definitions has in common the focus on relieving suffering and improving quality of life. All of the definitions stress three important features:

1. The multifaceted, multidimensional nature of the experience of living with an acknowledged time-limiting illness

2. The importance of supporting the family and patient as a unit

3. The priority of working as a team to achieve the relief of suffering and facilitate the enhancement of life

The Institute of Medicine defines palliative care as: (Field; 1997)

"Palliative care seeks to prevent, relieve, reduce or soothe the symptoms of disease or disorder without effecting a cure.... Palliative care in this broad sense is not restricted to those who are dying or those enrolled in hospice programs.... It attends closely to the emotional, spiritual, and practical needs and goals of patients and those close to them."

In 2002, the World Health Organization (WHO) redefined palliative care as: (WHO; 2002)

"An approach which improves quality of life of patients and their families facing life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."

Over the past decade, to provide the expertise and standards of practice developed by hospice to patients who have needs for symptom control and supportive care earlier in their illness, palliative care programs and consult services have been developing across the United States. They have evolved in response to the success of modern medicine and cancer care to provide relief of suffering and improve the lives of patients who are living longer and dying over a more prolonged time, and their families. The Center to Advance Palliative Care has played a significant role in stimulating their development, particularly in acute care facilities. These programs are designed to improve the quality of patients' lives while they fight their disease, and there is evidence that patients enrolled in such "combined" programs live longer.

Delivering palliative care

Clinical palliative care can be made available at three distinct levels-primary, secondary, and tertiary care-in parallel with current concepts of all medical care.

Primary palliative care refers to the generalist skills and competencies required of all oncologists and other health care professionals. Examples are skills in communication, pain and symptom management, teamwork, and health care system savvy. These are no different than the skills and competencies needed in any of the content areas germane to contemporary cancer care, much as in the realm of infectious disease, which also involves specialist care.

Secondary palliative care refers to the specialist clinicians and organizations that provide consultation and specialty care. By analogy, while not all cancer patients admitted to the hospital require an infectious disease specialist, some do. In palliative care, specially trained clinicians and care delivery models, such as palliative care consultation services, provide care in a variety of settings: the patient's home, nursing homes, outpatient clinics, and hospitals.

Tertiary palliative care refers to the academic centers where specialist knowledge for the most complex cases is practiced, researched, and taught.

Hospice Care

Hospice care represents the initial testing ground for palliative care. Until the last third of the 20th century, hospice was a term to describe places where the dying could be cared for. These facilities were generally run by religious orders. In a remarkable development that stemmed from first listening to one hospitalized

patient with unresectable sarcoma, and then many patients with cancer, Dr. Cicely Saunders founded St. Christopher's Hospice south of London, England, where she could test her hypotheses about the interdisciplinary care of the "whole" patient. St. Christopher's represented a single institution where a team of professionals pursued the medical, emotional, social, and spiritual care of patients and families. Most importantly, it developed as an academic hospice, where education and research were pursued simultaneously with patient care

New approaches and insights were tested and disseminated.

Those who visited St. Christopher's to learn the approaches went on to develop what has been called the modern hospice movement. This movement developed outside of traditional cancer care. The initial response from institutional medicine was perhaps understandable: no conventional system likes to be challenged by a "movement" that is critical of the mainstream.

In order to help families care for patients with advanced life-threatening illness at home, hospice agencies started to appear across the United States during the late 1970s. While volunteers initially ran them, and philanthropy supported them, hospices received a boost in 1982 when the federal government began reimbursing hospice care for Medicare beneficiaries with a prognosis of less than 6 months.

Subsequent decades have seen a marked growth in the number of agencies operating in the United States, primarily providing care at home. However, even with this growth, hospices care for only a minority of dying patients. Of those patients dying of cancer in the United States, only about 40% are ever referred to a hospice agency. (Vernig; 2000) While there is significant regional variation (e.g., 40% of all patients with any diagnosis die with hospice care in Florida), the situation is generally less than ideal for both adult and pediatric patients across the country. Even those patients who are referred to a hospice program generally do not spend enough time in these programs to experience all of the potential benefits. (Christakis; 1996) A 2003 study showed the median survival after enrollment was only 22 days, and 36.9 % of patients died within 7 days of admission. (NHPCO; 2003)

Today, in the United States, the single word hospice is used to describe four different concepts.

- Hospice can be a site of care for the dying, such as a free-standing facility or a dedicated unit within a hospital or nursing home.
- It can be an entity that provides a number of "service lines" in a variety of settings. Some hospice organizations bear little resemblance to their forebears, as contemporary hospitals often do theirs. Hospice organizations differ from one another in the same ways that hospitals and health systems differ.

- The term hospice is also used to describe an approach to care that is integrated into all manner of care sites and practices. In this sense it is synonymous with palliative care.

- Finally, hospice is used to describe a benefit available to Medicare beneficiaries that is subject to the rules and regulations promulgated by the Center for Medicare and Medicaid Services to govern that federal program.

Unfortunately, the use of a single term for all of these meanings has led to confusion. For many patients, the term hospice still means a place to go to die. For many physicians, it means a poorly understood community-based program into which a patient disappears after the physician signs a form certifying a prognosis of less than 6 months. These perceptions persist even though the majority of patients enrolled in hospice programs continue receiving care from their referring physicians and live in their own homes until they die. Surveys of the American public indicate that if they knew they had a life-threatening illness, more than 80% would want to die at home.

Hospice is intended to facilitate: (NHPCO; 1997)

- **Safe and comfortable dying:** to provide the best possible quality of life during the final months of a patient's life, and ensure that the patient dies in the best way possible.

- **Self-determined life closure:** to facilitate closure of business, reminiscence, legacy creation, gift giving (e.g., possessions, money, thoughts), and saying goodbye.

- **Effective grieving:** to help patients and families deal with their losses and grief throughout the illness and bereavement experience; to help families transition through the death of a loved one and rebuild their lives.

Levels of care

Under the Medicare Hospice Benefit, there are four levels of hospice care that can be used to provide care to patients and their families, depending on their need and setting of care:

1. **Routine care** is care provided in the patient's home on a day-to-day basis (i.e., a private residence; a residential, assisted living, or long-term care facility; a jail or prison; on the street; or wherever the patient lives).

2. **General inpatient care** is short-term care provided in an acute care or long-term care facility when 24-hour nursing is required to:

   o Manage pain, other symptoms, or other issues that cannot be controlled at home.

- Provide care during the last hours of life when symptoms may change quickly.
- Provide care when the patient's caregiver is too fatigued or stressed to provide proper care

3. **Continuous care** is enhanced care provided for short periods in the patient's home when the patient needs 8 or more hours of care per day (of which >50% needs to be skilled nursing care provided by a registered nurse (RN) or licensed vocational nurse (LVN).

4. **Respite care** is care provided in an inpatient setting or the patient's home to give the patient's informal caregiver(s) a break from the day-to-day care they provide at home. Respite care is typically preplanned for family events. It is limited to 5 consecutive days at a time. Inpatient respite care requires that a nurse be available 24 hours per day.

Requests for emergency respite care for a suddenly overwhelmed caregiver often result when the patient is sicker and requires more care than was anticipated. These patients should be carefully evaluated by a palliative medicine physician in collaboration with the patient's home hospice team to establish the severity of the underlying issues, appropriate goals, and a suitable plan of care.

Core services

All levels of hospice care must include the following core services:
- Interdisciplinary team care, including:
  - Chaplaincy, nursing care, physician services, medical social services and counseling, and volunteers
  - Dietary counseling
  - Occupational, physical, and speech therapy
  - Home health aide and homemaker services
- Bereavement counseling
- Medical equipment and supplies
- Medications and therapies related to the terminal diagnosis

Futile Care

There are times in every health care professional's career when a patient, family member, or surrogate decision maker (if the patient lacks decision-making capacity) asks for therapy that the clinician believes is not beneficial.

Imagine a case involving a patient with advanced disease whose life is being supported by mechanical ventilation. The family insists that "everything be done."

- How should the clinician approach this type of situation?

- How might the clinician better understand the reasons for the family's seemingly irrational request?

- Are there techniques that are useful for ensuring that both parties feel they have been supported and understood?

- In those rare instances where a mutually acceptable resolution is not possible, how should the clinician balance his or her own concerns with those of the patient and family, and those of the health care system?

- Ultimately, what is the clinician's responsibility in providing futile care?

Requests for futile therapy tend to be frustrating and distressing for everyone involved. Members of the health care team may feel that the family is being unreasonable, wasting scarce economic resources, even causing the patient to undergo increased pain and suffering prior to his or her ultimate demise. In response or self-defense, members of the team may distance themselves from the patient and family, accuse them of ulterior motives, or argue that nonprofessionals should not be allowed to make "medical decisions."

The patient, family, or surrogate decision makers, who are already stressed by the realities of the advanced illness, then feel isolated, misunderstood, and/or abandoned. Some may suggest that the health care team does not care about their loved one, or they impute financial, racial, or other prejudices to the team.

There are many proposed definitions of "medical futility," including:

- Futility exists when a treatment won't achieve the patient's intended goal.

- Treatment is futile when it is ineffective more than 99% of the time.

- Futile treatment is one that does not serve a legitimate goal of medical practice.

- Treatment could be construed as futile when it is outside accepted community standards.

Unequivocal cases of truly futile interventions are rare (e.g., an attempt to resuscitate a patient who is decapitated). In the majority of situations in which death is imminent, consensus is reached and life-sustaining interventions are not provided. In one large study, on the third day of hospitalization of patients whose prognosis for survival was <1%, fewer than 1% did not have a do-not-resuscitate (DNR) order in the medical record. (Halevy; 1996)

More commonly, the concept of medical futility is invoked when there is a conflict over treatment and it is not clear how to reach resolution. Examples of medical interventions in which questions of relative value may be raised include:

- Life-sustaining interventions for patients in a persistent vegetative state.
- Resuscitation efforts for those with life-threatening illness.
- Use of antibiotics, artificial hydration, or chemotherapy in patients with very advanced cancer.

Conflict

Conflict is a disagreement between two or more parties who perceive a threat to their needs, interests, or concerns. It usually arises as a result of misunderstanding, differences in values, personal factors, or problems with the surrogate decision maker.

To minimize the risk of conflict, some have argued that health care professionals should neither offer nor provide therapy that is unlikely to work, or will result only in a poor quality of life. To do otherwise, they believe, would be to violate professional integrity, offer false hope to patients and families, and inflict harm on patients without the possibility of benefit.

Others disagree. They wonder why the clinician's values override patient and family values, especially when those values are religiously based. Many point out the difficulty in differentiating "futile" therapy from "low-yield" therapy. Consequently, an increasing number of groups recommend defining futility on a case-by-case basis. With this approach, emphasis is placed on the need to find a fair process of resolution rather than a final definition of futility.

Unresolved conflicts about treatment goals and specific therapies can lead to misery for the patient, family, and health care professional. Yet, most conflicts about care can be resolved through a process of effective communication and negotiation. It is part of the clinician's role to try to understand and resolve any differences in perception about treatment. This responsibility can be challenging because it calls on important skills involving communication, compassion, and empathy. In negotiating issues of perceived futility, it remains the clinician's obligation to support the patient and family and try to relieve their suffering. To this end, use the principles to guide effective communication, negotiate goals of care and treatment priorities, and facilitate advance care planning to help resolve conflict.

Most disagreements about futile care are actually the result of misunderstandings or inattention to the family's or care team's emotional reaction to the fact that the patient is dying. Thus, the critical issue is to understand why there is

disagreement. Typically, the conflict can be resolved in a manner that is respectful of the point of view of both the health care provider and the patient/family. Moreover, by concentrating on understanding points of view, one often can initiate interventions that help with adjustment and/or bereavement.

Approaching issues of futility from the point of view of resolving conflict will lead to resolution in the majority of cases.

Among cases in which futility is claimed, most can be attributed to misunderstanding, differences in values, personal factors, or problems with the surrogate decision maker.

Misunderstandings

Diagnosis/prognosis: Conflict is frequently the result of misunderstanding on the part of the patient, family, or surrogate decision maker about diagnosis or prognosis, because:

- No one informs the parent or surrogate of the diagnosis or prognosis.

- The language used to inform them is not understandable. This can happen when clinician's use jargon or technical terms that have meaning only to the health care team, or when the listener lacks the cognitive ability to understand the information.

- The patient or family members receive different or conflicting information.

- Members of the health care team "hedge" regarding the patient's prognosis in the interest of not wanting to sound too pessimistic.

- Stress, sleep deprivation, and/or emotional distress decrease the listeners' comprehension.

- The patient or family members are not psychologically prepared to hear the bad news (e.g., when they are in denial).

"Do everything": Misinterpretation of the phrase "do everything" is another source of misunderstanding. In medical jargon this phrase is frequently used to connote maximal medical attempts to save or prolong life, whether or not they are expected to be of benefit. Mistaken notions of legal requirements sometimes propel its use in this manner. In contrast, families may use the same phrase to communicate that they don't want their loved one to be abandoned or to die. This difference in perspective can be the cause of considerable misunderstanding.

Differences in Values

Some requests for therapies that others characterize as ineffective or futile are genuinely a reflection of differing values between the patient/family/surrogate and the health care team. What is futile to one may be worthwhile to another. Genuine value conflicts (i.e., not based on misunderstandings) are typically of two types:

1. **Parties differ over goals.** For example, one party wishes to preserve life at all costs while the other party concludes that preserving life is not a worthwhile goal.

2. **Parties differ over benefit.** For example, one party wishes to pursue a therapy that is highly unlikely to achieve the agreed-upon goal (i.e., a miracle), while the other party does not believe the chances of success are high enough to continue treatment.

Whichever type of conflict, it is important to explore the root of the value difference. Health care professionals need to know their own disposition and work to avoid imposing their views on the patient, family, or surrogate decision maker. Whenever possible, anticipate decisions that go against your own values. If they are likely, arrange for transfer of the patient's care to someone else before the conflict arises.

Religious beliefs: Many people have a religious foundation for their lives and the decisions they make. This extends to decisions about medical treatments and life-sustaining therapies. When these are not recognized by the health care team, differences can lead to significant conflict.

Miracles: Patients, families, and surrogate decision makers may believe in miracles. While their beliefs may have a formal religious connotation, they are more likely to be an expression of hope that a supernatural or paranormal force will intervene to change the course of the illness.

Value of life: Some people believe in life at all cost. These beliefs may or may not be religiously based. These "fighters" need to know they tried everything possible. They may even choose to die receiving ventilatory support. Any suggestion that a possible therapy will not be beneficial leads to conflict.

Personal Factors

There are multiple ways that interpersonal issues can manifest as conflict.

Distrust: Comments from patients, families, or surrogates may suggest that they do not trust the information they are being given. These comments may be subtle, particularly when they are being polite and respectful. Statements that might indicate distrust include:

- "The previous doctor(s) was wrong."

- "The last doctor(s) was only interested in money."

- "The previous hospital wasn't very good."

- "The nurses never answered the call lights."

- "The nurses administered the wrong treatments."

- "We suspected racial or ethnic prejudice."

Grief: Grief is a natural human response to loss. Conflict may be an extension of anticipatory grief that is overwhelming. Comments like, "I can't live without him!" or "What will I do if she doesn't get better?" are markers of overwhelming grief.

Guilt: Guilt over relationship issues with the patient is a powerful motivator of human behavior. It can be a source of considerable conflict. It is often subtly present in decision-making discussions. When it is associated with a sense of shame, it may remain invisible to the health care team for a long time.

Intrafamily issues: Health care decision making is frequently influenced by family dynamics. Lack of communication or considerable conflict between family members can lead to significant conflict in decision making. These conflicts may not be initially apparent to the oncologist or the cancer care team, particularly if they don't see the family as a group.

An archetypal, not-so-subtle situation is the arrival of the long-estranged or distanced relative at the bedside urging something divergent from the prior plan for care. For instance, if the plan has been to cease curative attempts, the distanced relative may say, "You must do everything; you can't give up." As frustrating as this may be to the care team, avoid making assumptions about such family dynamics; each member of the family probably has an understandable background behind the position they have taken and little-informed opinions from the professional team are unlikely to help.

Secondary gain: Occasionally, discussions regarding futility are influenced by other implications of a patient's death that lead to a conflict of interest. For example:

- Income to a family member or surrogate decision maker may be lost when the patient dies.

- The patient's death may influence where the family member may live, or whether he or she will have access to savings or social status.

- Conversely, the decision maker may stand to benefit financially from the patient's death if he or she is named in the patient's will.

Problems with Surrogate Decision Makers

A problem with implementation of the surrogate's role can lead to requests for futile therapy and related conflicts when:

- There has been no advance planning and no surrogate appointed by the patient.

- The surrogate does not know the patient or his or her wishes well.

- There is a conflict of interest and the surrogate's own biases/goals are guiding decision making, not the patient's (with or without secondary gain).

Conflict Within the Care Team

Physicians and other members of the health care team bring their own personal feelings about end-of-life care and benefits and burdens of specific interventions to every case. Some push for interventions because of their belief that death is worse than any other state. Others push because they feel it is a failure of their care if they do otherwise. Still others have strong personal desires to avoid aggressive intervention and project this on the patient and family.

Less commonly acknowledged, but of equal importance, are those situations in which the health care professional persists in recommending therapy when the patient or family does not think it is beneficial, or evidence does not support any benefit to the patient.

This inclination to provide "futile therapy" may be out of a desire to maintain hope, a personal belief that it is the professional's job to maintain life at all costs, or a need to avoid feeling failure or shame for not helping the patient. Physicians and other members of the health care team, as well as patients and families, may need to feel that "everything possible" was done so that, after the death, they will feel no regret or guilt.

At all times, it is helpful to ask, "Who are we doing this for?" Center care on the patient's values and goals for care. After all, it is the patient's life and body that are in jeopardy. To minimize the risk of conflict, maintain an open and ongoing process to listen to the patient, family, and surrogate; share information carefully; facilitate their decision making; and support their choices. Strive to resolve differences in a manner that avoids showing disrespect for the professionals' expertise and knowledge yet fully respects the centrality of the patient.

Life-Sustaining Treatments

There is a wide range of life-sustaining treatments that might be considered for an individual patient and family. These include cardiopulmonary resuscitation, elective intubation and mechanical ventilation, surgery, dialysis, blood transfusions or administration of blood products, artificial nutrition and hydration, diagnostic tests, antibiotics, other medications and treatments, and future hospital or intensive care unit admissions.

Considerations

Culture

Culture plays a role in decisions to withhold or withdraw care. For example, many studies have shown that nonwhite patients are less likely than white patients to agree to "Do Not Resuscitate" (DNR) orders or to withhold or withdraw care and are less likely to have advance care directives. (Blackhall; 1999) In Asian cultures, filial piety, the obligation of children to care for their parents in gratitude for the parent's caring and sacrifice, is a central value. Making a decision to withhold or withdraw life support from a parent may be seen as unfilial. If the integrity of the family as a whole is valued more than the wishes of an individual family member, even the patient who would not want life support may expect the family to do everything possible to prolong his or her life. To do otherwise would bring dishonor on the family.

Different cultures may have varying views of the role of suffering. Although many nurses and doctors may support withholding life support at the end-of-life as a compassionate act that prevents unnecessary suffering, not all patients share this value. Some cultures view suffering as redemptive and something to be endured as a test of faith rather than avoided. The idea that only God, not doctors, knows when it is time to die may also affect how patients view the use of life-sustaining therapies.

Religion

Various religions have espoused specific opinions about the use of artificial hydration and nutrition. Most teach that when death is inevitable and not due to the absence of hydration or nutrition, withholding both can be appropriate. However, some religious leaders teach that human beings must do all in their power to prolong life. In situations of conflict, it is wise to engage leaders or teachers of the religious faith in question.

Artificial Nutrition

It is "ordinary care" to provide oral nutrition to the patient who wants to eat. That includes bringing food to the mouth even if the patient is too weak to do so. For the patient who needs assistance, special attention to appearance, color, smell,

and consistency may be needed to make food appetizing. However, it is unethical and illegal to force the patient to eat if the patient declines to do so.

Administration of nutrition by an alternate route is indicated if the patient is hungry and cannot eat (i.e., when there is a neurological abnormality affecting swallowing or an obstructing esophageal cancer). The gastrointestinal tract should always be the route of intake if it is functional.

There is no evidence that artificial nutrition alone improves functional ability or energy, relieves fatigue, or improves survival or symptom control (except hunger) if it is the disease that is responsible for the anorexia and weight loss.

Enteral Nutrition

There are two common reasons cited for instituting enteral nutrition in patients: to improve fatigue or "strength" and to avoid "starving to death." Patients, family, and some clinicians erroneously believe that the patient is weak because he or she is not eating. Further, they erroneously believe that if the patient does not eat, he or she will die.

In contrast with conventional wisdom, there is no evidence that enteral nutrition improves energy level or survival in the patient with end-stage disease.

Parenteral Nutrition

The weight of scientific evidence has shown no general benefit for parenteral nutrition in patients with end-stage disease. This has even turned out to be the case in the surgical and intensive care settings. Parenteral nutrition has been shown to be of benefit in the limited circumstances where the gastrointestinal tract suffers prolonged toxicity (e.g., bone marrow transplant), or in the perioperative setting where there is preexisting malnutrition. In fact, even in the setting of bone marrow transplant, there only appears to be a role when there is prolonged, demonstrable inability to eat. This surprising conclusion is drawn from studies performed over the past 30 years. In fact, meta-analysis suggests that patients with cancer who receive parenteral nutrition die faster than patients who do not. (ACP; 1989)

Artificial Hydration

One of the most common treatments associated with medical care is an intravenous infusion of fluids. The indication is the maintenance of fluid and electrolyte balance when the patient is temporarily unable to drink adequate volumes. The administration of isotonic fluids subcutaneously (hypodermoclysis) is an underutilized, equally efficacious way to administer fluids without the risk of intravenous access (infection, clot, bleeding) or the skills needed to locate a vein.

The most common inappropriate reason to consider intravenous fluids in the setting of symptom control is to prevent or treat thirst and to prevent "dehydrating to death."

Symptoms of dehydration differ between those who are ambulatory and those who are bed-bound. Whereas an otherwise healthy person will experience reversal of severe thirst, fatigue, or malaise with rehydration, a seriously ill patient will not. There is no evidence that IV fluids relieve thirst in the patient with advanced illness. The same is true for fluids given via an enteral feeding tube. In contrast, stopping medications with anticholinergic side effects and administering good lip and mouth care has been shown to relieve thirst.

Dehydration appears to be associated with endorphin release resulting in an associated improvement in mood.

Addressing Family Concerns

Family members frequently feel helpless in the face of end-stage illness. Their advocacy for artificial nutrition or hydration may be a response to this feeling. The advocacy may come from a misunderstanding of the situation (e.g., she'll be stronger if only she eats more; he won't die if he eats; her mouth won't be so dry if she has an IV), or as an emotional response (e.g., it's important to fight back).

As part of the discussion, identify the emotional need that is met by providing food and water, particularly for families. Help the family find ways to demonstrate their caring in the face of "letting nature take its course," and teach them the skills they need to be effective. A major goal is to permit the family and professionals to feel helpful rather than helpless. Examples include:

- Eat for pleasure.
- Plan social interactions that don't center on meals.
- Read or watch movies together.
- Look at photo albums together.
- Participate in mouth care.
- Massage the extremities or feet with unscented oil.
- Do chores such as housecleaning, gardening.
- Reminisce and tell stories.

Loss of appetite and diminished fluid intake are a part of the normal dying process. Trying to counteract these natural trends may lead to more discomfort for the patient without affecting the outcome.

Near the end-of-life, patients and families may be concerned that there will be suffering from thirst or hunger if the patient is not taking any fluids or nutrition. Help the patient and caregiving family to understand that dehydration is a natural part of the dying process. It does not affect the dying patient in the same way as a healthy person who feels thirsty on a hot day or becomes dizzy on standing.

Let family members know that if the patient is not hungry, artificial fluids and hydration will not help him or her feel better. Badgering the patient to eat or drink will only increase tension and may cause the patient to become angry, depressed, or withdrawn if he or she cannot comply.

In addition, make sure family members and caregivers know that artificial fluids and nutrition may make edema, ascites, pulmonary and other secretions, and dyspnea worse, particularly if there is significant hypoalbuminemia.

Ensure that family and caregivers know that a state of dehydration in a patient who is bed-bound and imminently dying may have some benefits. Pulmonary secretions, vomiting, and urinary incontinence may be less severe. Dehydration may actually stimulate the production of endorphins and other anesthetic compounds that help contribute to a peaceful, comfortable death for many patients.

Legal and Ethical Issues

All states in the United States have statutes covering issues related to withholding or withdrawing life-sustaining treatments. The Quinlan case (1976) established that artificial nutrition could be withdrawn even from a patient in a persistent vegetative state. In 1983, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research found that no treatments, including artificial nutrition and hydration, were obligatory. This was confirmed in the United States Supreme Court decision on the Cruzan case (1990), which established that artificial hydration and nutrition are like other life-sustaining treatment. It was upheld again in Florida courts in the case of Schiavo (2005).

It is also legal and ethical to withhold or withdraw nutrition and hydration for the patient who lacks decision-making capacity. States may differ in the degree of evidence that is required if the patient lacks decision-making capacity. For example, in New York and Missouri, there must be "clear and convincing evidence." In the other states, substitute decision makers can make the decision.

Institutional policies of many hospitals or other health care institutions tend to include considerations, perhaps drafted by ethics committees, to protect patients' rights and interests and considerations, or possibly crafted by risk management officers to protect the institution from risk. Institutional policies are often written in

response to the general perceived legal imperative to, when in doubt, provide treatment to prolong life. Institutional policies may or may not be in the best interest of a particular patient. If the appropriate goals of care are other than "life at all costs," then the physician needs to write orders that are specific enough to accomplish the intended goals.

All too often, patients are transferred to the acute care setting, where inappropriate life-sustaining measures are administered because the appropriate treatment plan and physician's orders have not been completed and placed in the patient's chart. One study demonstrated that fewer than 25% of advance directive orders were carried from the nursing home to the acute care hospital. The fact that physician's orders may not transfer across settings (e.g., nursing home, ambulance, acute care hospital) also exacerbates the problem.

Nutritional Supplementation

Providing nutrition to patients at the end of life is a very complex and individualized decision. Ideally, the options for nutrition support for end-of-life care should be discussed in advance, and information on all nutritional choices and their consequences should be provided to the patient and family. Patients are best able to make decisions if they are well informed about the possible risks and benefits of artificial nutrition. Considerations of financial cost, burden to patient and family of additional hospitalizations and medical procedures, and all potential complications must be weighed against any potential benefit derived from artificial nutrition support. Supplemental nutrition may be beneficial in the treatment of advanced cancer, where quality of life would otherwise suffer and death would be caused by malnutrition rather than the underlying disease, such as in mechanical obstruction or malabsorption resulting in intolerance of oral intake.

The rationale for providing artificial nutrition at the very end of life is less clear. One study has concluded that artificial nutrition—specifically, parenteral nutrition—neither influenced the outcome nor improved the quality of life in terminally ill patients. (Morita; 1999)

The controversial nature of providing artificial nutrition at the end of life has prompted the American Academy of Hospice and Palliative Medicine (AAHPM) to recommend that individual clinical situations be assessed using clinical judgment and skill to determine when artificial nutrition is appropriate. Recognizing that the primary intention of nutrition is to benefit the patient, AAHPM concludes that withholding artificial nutrition near the end of life may be appropriate medical care if the risks outweigh the possible benefit to the patient.

The goal of end-of-life care is to relieve suffering and alleviate distressing symptoms. The patient's needs and desires must be the focus, with their best

interests being the guide for decision making, influenced by religious, ethical, and compassionate issues.

Resuscitation

Broadly defined, resuscitation includes all interventions that provide cardiovascular, respiratory, and metabolic support necessary to maintain and sustain the life of a dying patient. It is important for patients, families, and proxies to understand that choices may be made specifying what supportive measures, if any, should be given preceding death and at the time of death. People often believe that there is plenty of time to discuss resuscitation and the surrounding issues. However, many dying patients do not make choices in advance or have not communicated their decisions to their families, proxies, and the health care team. If these issues are unresolved at the time of end-of-life events, undesired support and resuscitation may result.

Narrowly defined, a Do Not Resuscitate (DNR) order instructs health care providers that, in the event of cardiopulmonary arrest, cardiopulmonary resuscitation (CPR, including chest compressions and/or ventilations) should not be performed and that natural death be allowed to proceed. DNR orders must be made before cardiac arrest and may be recommended by physicians when CPR is considered medically futile or would be ineffective in returning a patient to life.

A DNR order may also be made at the instruction of the patient (or family or proxy) when CPR is not consistent with the goals of care. It is advisable for a patient who has clear thoughts about these issues to initiate conversations with the health care team (or appointed health care agents in the outpatient setting) and to have forms completed as early as possible (i.e., before hospital admission), before the capacity to make such decisions is lost. Although patients with end-stage disease and their families are often uncomfortable bringing up the issues surrounding DNR orders, physicians and other health care professionals should tactfully and respectfully address these issues appropriately and in a timely fashion.

Ventilator Withdrawal

Fewer patients with advanced illness will undergo resuscitation and ventilatory support when discussions regarding goals of care and advance directives begin early in the course of the disease. However, when advance directives are not available or when the directives are not adequately communicated, intubation may occur despite low likelihood of survival.

When ventilatory support appears to be medically futile or is no longer consistent with the patient's (or family's or proxy's) goals of care, ventilator withdrawal to allow death may take place. Extensive discussions must first take place with patients (if they are able) and family members to help them understand the

rationale for and process of withdrawal. When no advance directive is available and a patient can no longer communicate, it is helpful to reinterpret in a more realistic light, or reframe for family members, that they are not making a decision to "pull the plug" for their loved one. Rather, they are helping the health care team interpret their loved one's wishes or discontinuing a treatment that is no longer considered effective. Such reframing is essential to help family members and significant others understand that the underlying disease process, and not ventilator withdrawal, is the cause of the patient's death.

Two methods of withdrawal have been described: immediate extubation and terminal weaning. Immediate extubation includes providing parenteral opioids for analgesia and sedating agents such as midazolam, suctioning to remove excess secretions, setting the ventilator to "no assist" and turning off all alarms, and deflating the cuff and removing the endotracheal tube. Gentle suctioning of the oral cavity may be necessary, but aggressive and deep suctioning should be avoided. In some cases, patients may appear to be in significant distress. Analgesics and sedatives should be provided even if the patient is comatose. Family members and others who are present should be warned that some movements may occur after extubation, even in patients who are brain dead. Such movements are probably caused by hypoxia and may include gasping, moving extremities, or sitting up in bed.

Immediate extubation is generally chosen when a patient is brain dead, when a patient is comatose and unlikely to experience any suffering, or when a patient prefers a more rapid procedure.

Terminal withdrawal entails a more gradual process. Ventilator rate, oxygen levels, and positive end-expiratory pressure are decreased gradually over a period of 30 minutes to a few hours. A patient who survives may be placed on a T-piece; this may be left in place, or extubation may proceed. There is some evidence that the gradual process in a patient who may experience distress allows clinicians to assess pain and dyspnea and to modify the sedative and analgesic regimen accordingly. In a study of 31 patients undergoing terminal weaning, most patients remained comfortable, as assessed by a variety of physiologic measures, when low doses of opioids and benzodiazepines were administered. The average time to death in this study was 24 hours, although two patients survived to be discharged to hospice. (Campbell; 1999)

Paralytic agents have no analgesic or sedative effects, and they can mask patient discomfort. These neuromuscular blockers should be discontinued before extubation. Guidelines suggest that these agents should never be introduced when the ventilator is being withdrawn; in general, when patients have been receiving paralytic agents, these agents should be withdrawn before extubation. The advantage of withdrawal of the neuromuscular blocker is the resultant ability of the health care provider to better assess the patient's comfort level and to allow possible interaction between the patient and loved ones. One notable

exception to withdrawal of the paralytic agent is when death is expected to be rapid after the removal of the ventilator and when waiting for the drug to reverse might place an unreasonable burden on the patient and family.

Regardless of the technique employed, the patient and setting must be prepared. Monitors and alarms should be turned off, and life-prolonging interventions such as antibiotics and transfusions should be discontinued. Family members should be given sufficient time to make preparations, including making arrangements for the presence of all loved ones who wish to be in attendance. They should be given information on what to expect during the process; some may elect to remain out of the room during extubation. Chaplains or social workers may be called to provide support to the family.

Palliative Sedation

Palliative sedation to relieve pain and physical symptoms is widely practiced and accepted. However, the use of palliative sedation for psychosocial and existential symptoms can be particularly controversial.

The Principle of Double Effect (PDE) provides that an action with both a good and a bad effect is ethically permissible if the following conditions are met:

1. The action itself must be morally good or at least indifferent.

2. Only the good effect must be intended (even though the bad or secondary effect is foreseen).

3. The good effect must not be achieved by way of the bad effect.

4. The good result must outweigh the bad result.

Under the principle of double effect, the intended effect (relieving psychological suffering) would be considered allowable as long as any risks or negative effects (i.e., shortened survival) are unintended by the health care professional.

The difficulty arises because the principle only discusses the professional's intention, when it is the patient's intention that can be unclear and potentially problematic. Is the depressed patient who no longer wants to suffer depressive symptoms asking only for that relief, or does the patient also intend to ask the professional to shorten his or her life? A clinician who feels uncomfortable in such situations may wish to seek guidance from his or her ethics committee.

Other difficult questions can arise from the potentially negative value that is culturally assigned to detaching oneself, or "zoning out," as a lower form of coping. Should the anxious patient who no longer wants to face the anxiety associated with the end of life and who wants to be sedated be encouraged to work through such issues? Or is it allowable for these patients to have sedation for dealing with their anxiety? How many alternatives should be tried before anxiety is considered unacceptable? When dealing with such requests,

professionals should consider their own cultural and religious biases and the cultural and/or religious backgrounds of patients and their families.

Legal/Ethical FAQs

There are several common concerns that impact decisions about life-sustaining treatments in general and withdrawal of hydration and nutrition in particular.

Are physicians legally required to provide all life-sustaining measures possible?
No. Physicians are required to provide care that will accomplish treatment goals within the bounds of accepted medical practice. No physician is required to provide care that is futile (e.g., total parenteral nutrition for a dying patient). Conversely, even when a treatment might prolong life (e.g., intravenous antibiotics for pneumonia), patients have a right to refuse, and the physician has an obligation not to provide or coerce.

Is withdrawal or withholding of artificial hydration and nutrition euthanasia?
After decades of discussion in society, there is strong general consensus that withdrawal or withholding of artificial hydration and nutrition is a decision/action that allows the illness to progress on its natural course. It is not a decision/action actively to seek death and end life. By contrast, euthanasia actively seeks to end the patient's life.

Can the treatment of symptoms associated with withdrawal of hydration and nutrition constitute euthanasia?
The intent of the physician and the means used to accomplish the intent are important. Opioids for pain, sedatives for restlessness, and other treatments to control symptoms are not euthanasia when accepted dosing guidelines are used. Symptom treatment alleviates symptoms; it does not intentionally cause death.

Is it illegal for a physician to prescribe large doses of opioids to relieve symptoms of pain, breathlessness, or other symptoms after artificial hydration and nutrition have been withdrawn?
Even very large doses of opioids or other drugs are both permitted and appropriate, if the intent and doses given are titrated to the patient's needs.

The Final Hours

Although the signs of approaching death may appear obvious to health care professionals, many family members have never observed the death of a loved one as death has become more institutionalized. As a result, most people are not familiar with the signs of impending death. Educating family members about these signs is critical.

In the final days to hours of life, patients often experience a decreased desire to eat or drink, as evidenced by clenched teeth or turning from offered food and fluids. This behavior may be difficult for family members to accept because of the meaning of food in our society and the inference that the patient is "starving." Family members should be advised that forcing food or fluids can lead to aspiration. Reframing will include teaching the family to provide ice chips or a moistened oral applicator to keep a patient's mouth and lips moist. Massage is another strategy through which family members can provide care and demonstrate love.

Patients may withdraw and spend more time sleeping. When patients respond slowly to questions, are somewhat confused, and have a decreased interest in their environment, family should be encouraged to touch and speak to them. Professionals can model these behaviors.

A patient's extremities may become mottled, cold, or cyanotic. The heart rate may increase or decrease and may become irregular; blood pressure usually drops as death approaches. Urine output may decrease dramatically or cease. Respiration often takes on an abnormal pattern called Cheyne-Stokes respiration, which ranges from very shallow breaths to alternating periods of apnea and deep, rapid breathing. These changes should be explained to family members at the bedside or when they are preparing to care for a loved one at home

It is important for health care professionals to explore with families any fears associated with the time of death and any cultural or religious rituals that may be important to them. Such rituals might include placement of the body (e.g., the head of the bed facing Mecca for an Islamic patient) or having only same-sex caregivers or family members wash the body (as practiced in many orthodox religions). When death occurs, expressions of grief by those at the bedside vary greatly, dictated in part by culture and in part by their preparation for the death. Chaplains should be consulted as early as possible if the family accepts this assistance. Health care providers can offer to assist families in contacting loved ones and making other arrangements, including contacting a funeral home.

When Death Occurs

Signs that Death Has Occurred

- The heart stops beating
- Breathing stops
- Body color becomes pale and waxen as blood settles
- Body temperature drops

- Muscles and sphincters relax (muscles stiffen 4-6 hours after death as rigor mortis sets in)
- Urine and stool may be released
- Eyes may remain open
- The jaw may fall open
- Observers may hear the trickling of fluids internally, even after death

Pronouncing Death

In teaching hospitals, medical students and residents are typically called to "pronounce" death. In non-teaching settings, the attending physician or nursing staff may be the ones to do it. When a patient dies at home with hospice care, it is usually a nurse who confirms the absence of vital signs. Although local regulations differ, if an expected death occurs at home without hospice care and the patient has a physician willing to sign a death certificate, then transportation to a hospital for a physician to confirm death may not be needed.

After Death

No matter how well families and professional caregivers are prepared, they may find the time of death to be challenging. Families, including children, and caregivers may have specific questions for the health care providers.

Basic information about death may be appropriate (e.g., the heart stops beating; breathing stops; pupils become fixed; body color becomes pale and waxen as blood settles; body temperature drops; muscles and sphincters relax, and urine and stool may be released; eyes may remain open; the jaw can fall open; and observers may hear the trickling of fluids internally).

There are no universally applicable rules that govern what happens when the patient dies (in any setting). If the patient dies an expected death at home, there is no need to call for emergency assistance. If a hospice program is involved, have the family call the hospice. If a hospice program is not involved, determine in advance who should be notified. Unless death is unexpected, or malice is suspected, involvement of the coroner's office is usually not required (State and local regulations vary. Health care professionals will need to familiarize themselves with the regulations in the areas where they practice).

When an expected death occurs, the focus of care shifts from the patient to the family and those who provided care. Even though the loss has been anticipated for some time, no one will know what it feels like until it actually occurs, and indeed it may take hours to days to weeks or even months for each person to realize the full effect.

Many experts assert that the time spent with the body immediately after death will help people deal with acute grief. Those present, including caregivers, may need the physician's permission to spend the time to come to terms with the event and say their good-byes. There is no need to rush, even in the hospital or other care facility. Encourage those who need to touch, hold, and even kiss the person's body as they feel most comfortable (while maintaining universal body fluid precautions). As a visually peaceful and accessible environment may facilitate the acute grieving process, a few moments spent alone in the room positioning the patient's body, disconnecting any lines and machinery, removing catheters, and cleaning up any mess will allow the family closer access to the patient's body.

Spiritual advisors or other interdisciplinary team members may be instrumental in orchestrating events to facilitate the experience of those present. Those who have not been present for the death may benefit from listening to a recounting of how things went leading up to the death and afterward. Grief reactions beyond cultural norms suggest a risk of significant ongoing or delayed grief reactions.

When letting people know about the death, follow the guidelines for communicating bad news. Try to avoid breaking unexpected news by telephone, as communicating in person provides a much greater opportunity for assessment and support. If additional visitors arrive, spend a few moments to prepare them for what they are likely to see.

Once family members have had the time they need to deal with their acute grief reactions and observe their customs and traditions, then preparations for burial or cremation and a funeral or memorial service(s) can begin. Some family members may find it therapeutic to help bathe and prepare the person's body for transfer to the funeral home or the hospital morgue. For many, such rituals will be their final act of direct caring.

Depending on local regulations and arrangements, some funeral directors will insist on the completed death certificate being present before they pick up the body. All will require a completed death certificate to proceed with any body preparation and registration of the death.

For many, moving the body is a major confrontation with the reality of the death. Some family members will wish to witness the removal. Others will find it very difficult and will prefer to be elsewhere. Once the body has been removed and family members are settled, professional caregivers can offer to assist them with some of their immediate tasks. They may notify other physicians and caregivers that the death has occurred so that services can be stopped and equipment removed. Local regulations governing the handling of medications and waste disposal after a death vary. When family members are ready, professional caregivers can let the family know how to reach them, and then leave them to have some privacy together.

Supplemental Information

Conceptual foundations of a palliative approach: a knowledge synthesis
Sawatzky, R., Porterfield, P., Lee, J., Dixon, D., Lounsbury, K., Pesut, B., ... & Stajduhar, K. (2016). Conceptual foundations of a palliative approach: a knowledge synthesis. *BMC Palliative Care*, *15*(1), 1. CC BY 4.0

Communication tools for end-of-life decision-making in the intensive care unit: a systematic review and meta-analysis
Oczkowski, S. J., Chung, H. O., Hanvey, L., Mbuagbaw, L., & You, J. J. (2016). Communication tools for end-of-life decision-making in the intensive care unit: a systematic review and meta-analysis. *Critical Care*, *20*(1), 1. CC BY 4.0

Sometimes we can't fix things": a qualitative study of health care professionals' perceptions of end of life care for patients with heart failure
Glogowska, M., Simmonds, R., McLachlan, S., Cramer, H., Sanders, T., Johnson, R., ... & Purdy, S. (2016). "Sometimes we can't fix things": a qualitative study of health care professionals' perceptions of end of life care for patients with heart failure. *BMC palliative care*, *15*(1), 1. CC BY 4.0

Patient Perspectives of Dignity, Autonomy and Control at the End of Life: Systematic Review and Meta-Ethnography
Rodríguez-Prat, A., Monforte-Royo, C., Porta-Sales, J., Escribano, X., & Balaguer, A. (2016). Patient Perspectives of Dignity, Autonomy and Control at the End of Life: Systematic Review and Meta-Ethnography. *PloS one*, *11*(3), e0151435 CC BY 4.0

Conceptual foundations of a palliative approach: a knowledge synthesis
Sawatzky, R., Porterfield, P., Lee, J., Dixon, D., Lounsbury, K., Pesut, B., ... & Stajduhar, K. (2016). Conceptual foundations of a palliative approach: a knowledge synthesis. *BMC Palliative Care*, *15*(1), 1. CC BY 4.0

Context, mechanisms and outcomes in end of life care for people with advanced dementia
Kupeli, N., Leavey, G., Moore, K., Harrington, J., Lord, K., King, M., ... & Jones, L. (2016). Context, mechanisms and outcomes in end of life care for people with advanced dementia. *BMC palliative care*, *15*(1), 1. CC BY 4.0

Expert views on the factors enabling good end of life care for people with dementia: a qualitative study
Lee, R. P., Bamford, C., Exley, C., & Robinson, L. (2015). Expert views on the factors enabling good end of life care for people with dementia: a qualitative study. *BMC palliative care*, *14*(1), 32. CC BY 4.0

Living with and dying from advanced heart failure: understanding the needs of older patients at the end of life
Klintworth, K., Oster, P., Hager, K., Krause, O., Bleidorn, J., & Schneider, N. (2015). Living with and dying from advanced heart failure: understanding the needs of older patients at the end of life. *BMC geriatrics*, *15*(1), 1. CC BY 4.0

References

Alonso, A., Ebert, A. D., Dörr, D., Buchheidt, D., Hennerici, M. G., & Szabo, K. (2016). End-of-life decisions in acute stroke patients: an observational cohort study. *BMC palliative care*, *15*(1), 1.

Becker, R. (2008). Palliative care 1: principles of palliative care nursing and end-of-life care. *Nursing times*, *105*(13), 14-16.

Bee, P. E., Barnes, P., & Luker, K. A. (2009). A systematic review of informal caregivers' needs in providing home-based end-of-life care to people with cancer. *Journal of clinical nursing*, *18*(10), 1379-1393.

Bonin-Scaon, S., Sastre, M. T. M., Chasseigne, G., Sorum, P. C., & Mullet, E. (2009). End-of-life preferences: A theory-driven inventory. *The International Journal of Aging and Human Development*, *68*(1), 1-26.

Breen LJ, Aoun SM, O'Connor M, Johnson AR & Howting D. (2020). Effect of caregiving at end of life on grief, quality of life and general health: A prospective, longitudinal, comparative study. *Palliative Medicine*, *34*, 145-154.

Bruinsma, S. M., van der Heide, A., van der Lee, M. L., Vergouwe, Y., & Rietjens, J. A. C. (2016). No Negative Impact of Palliative Sedation on Relatives' Experience of the Dying Phase and Their Wellbeing after the Patient's Death: An Observational Study. *PloS one*, *11*(2), e0149250.

Cohen AB, Benjamin AZ & Fried TR. (2019). End-of-Life Decision Making and Treatment for Patients with Professional Guardians. *Journal of the American Geriatrics Society*, *67*, 2161-2166.

Fox, C. R. (2007). What health care providers know (and need to know) about palliative care. *Journal of allied health*, *36*(4), 209-215.

Gerrard, R., Campbell, J., Minton, O., Moback, B., Skinner, C., McGowan, C., & Stone, P. C. (2011). Achieving the preferred place of care for hospitalized patients at the end of life. *Palliative medicine*, *25*(4), 333-336.

Gill TM, Gahbauer EA, Leo-Summers L & Murphy TE. (2019). Taking to Bed at the End of Life. *Journal of the American Geriatrics Society*, *67*, 1248-1252. https://doi.org/10.1111/jgs.15822, 10.1111/jgs.15822

Glogowska, M., Simmonds, R., McLachlan, S., Cramer, H., Sanders, T., Johnson, R., ... & Purdy, S. (2016). "Sometimes we can't fix things": a qualitative study of health care professionals' perceptions of end of life care for patients with heart failure. *BMC palliative care*, *15*(1), 1.

Klindtworth, K., Oster, P., Hager, K., Krause, O., Bleidorn, J., & Schneider, N. (2015). Living with and dying from advanced heart failure: understanding the needs of older patients at the end of life. *BMC geriatrics*, *15*(1), 1.

Kupeli, N., Leavey, G., Moore, K., Harrington, J., Lord, K., King, M., ... & Jones, L. (2016). Context, mechanisms and outcomes in end of life care for people with advanced dementia. *BMC palliative care*, *15*(1), 1.

Lee, R. P., Bamford, C., Exley, C., & Robinson, L. (2015). Expert views on the factors enabling good end of life care for people with dementia: a qualitative study. *BMC palliative care*, *14*(1), 32.

Liao, S., & Ackermann, R. J. (2008). Interdisciplinary end-of-life care in nursing homes. *Clinical Gerontologist*, *31*(4), 83-96.

Lowe, S. S., Tan, M., Faily, J., Watanabe, S. M., & Courneya, K. S. (2016). Physical activity in advanced cancer patients: a systematic review protocol. *Systematic reviews*, *5*(1), 1.

Mathew C, Hsu AT, Prentice M, Lawlor P, Kyeremanteng K, Tanuseputro P, et al. (2020). Economic evaluations of palliative care models: A systematic review. *Palliative Medicine*, *34*, 69-82.

Murali KP. (2020). End of Life Decision-Making: Watson's Theory of Human Caring. *Nursing Science Quarterly*, *33*, 73-78.

National Cancer Institute. (2013, June). Education in Palliative and End-of-Life Care for Oncology (EPEC-O) Self-Study: Original Version. Available at: http://www.cancer.gov/resources-for/hp/education/epeco/self-study.

Oczkowski, S. J., Chung, H. O., Hanvey, L., Mbuagbaw, L., & You, J. J. (2016). Communication tools for end-of-life decision-making in the intensive care unit: a systematic review and meta-analysis. *Critical Care*, *20*(1), 1.

Pattison, N. (2011). End of life in critical care: an emphasis on care. *Nursing in critical care*, *16*(3), 113-115.

Pooler, J. (2009). Patients need to be provided with real choice in end-of-life care. *Nursing times*, *105*(25).

Rodríguez-Prat, A., Monforte-Royo, C., Porta-Sales, J., Escribano, X., & Balaguer, A. (2016). Patient Perspectives of Dignity, Autonomy and Control at the End of Life: Systematic Review and Meta-Ethnography. *PloS one*, *11*(3), e0151435

Sawatzky, R., Porterfield, P., Lee, J., Dixon, D., Lounsbury, K., Pesut, B., ... & Stajduhar, K. (2016). Conceptual foundations of a palliative approach: a knowledge synthesis. *BMC Palliative Care*, *15*(1), 1.

Sheikh A & Dhami S. (2020). Ethnicity and "aggressive" end-of-life care. *CMAJ Canadian Medical Association Journal*, *192*, E287-E288.

Sinclair, S., Raffin, S., Pereira, J., & Guebert, N. (2006). Collective soul: the spirituality of an interdisciplinary palliative care team. *Palliative & supportive care*, *4*(01), 13-24.

Tucker, K. L. (2009). Ensuring informed end-of-life decisions. *Journal of palliative medicine*, *12*(2), 119-120.

Tyacke MH, Guttormson JL, Garnier-Villarreal M, Schroeter K & Peltier W. (2020). Advance directives and intensity of care delivered to hospitalized older adults at the end-of-life.

Vachon, M., Fillion, L., & Achille, M. (2009). A conceptual analysis of spirituality at the end of life. *Journal of palliative medicine*, *12*(1), 53-59.

Viola, D., Leven, D. C., & LePere, J. C. (2009). End-of-life care: an interdisciplinary perspective. *American Journal of Hospice and Palliative Medicine*, *26*(2), 75-78.

Wasserman, L. S. (2008). Respectful death: A model for end-of-life care. *Clinical journal of oncology nursing*, *12*(4), 621.

End of Life II – Clinical Management

Post-Test

1. More than 90% of the people who die from disease have a long period of illness with gradual deterioration. (p. 3) A. True B. False

2. Patients who are too fatigued to move should have a "donut" cushion placed around areas that show signs of pressure induced cutaneous ischemia. (p. 4) A. True B. False

3. Central cyanosis and oliguria are commonly seen in individuals close to death. (p. 6)
    A. True B. False

4. Terminal delirium is _____. (p. 7)
    A. Rarely caused by the sudden onset of uncontrolled pain during the last hours of life
    B. Relieved by opioids in patients with poor renal clearance
    C. Effectively managed with patient reorientation strategies
    D. Defined as "hypoactive" if the patient experiences auditory and/or visual hallucinations

5. Changes in a dying patient's breathing pattern may be indicative of significant neurologic compromise. (p. 9) A. True B. False

6. Approximately half of all people who are nearing death experience _____. (p. 11)
    A. Rattle
    B. Pain
    C. Myoclonic jerking
    D. Hemorrhaging

7. Restlessness, agitation, moaning, and groaning are all signs that the patient is in considerable pain. (p. 12) A. True B. False

8. Palliative care seeks to cure underlying disease as well as prevent, relieve, reduce, and soothe symptoms. (p. 16) A. True B. False

9. All levels of hospice care must include which of the following core services? (p. 20)
    A. Chaplaincy
    B. Occupational, physical, and speech therapy
    C. Homemaker services
    D. All of the above

10. Which of the following is NOT one of the proposed definitions of medical futility? (p. 21)
    A. A treatment that won't achieve the patient's intended goal
    B. A treatment whose costs are unjustified relative to intended outcomes
    C. A treatment that is ineffective more than 99% of the time
    D. A treatment that does not serve a legitimate goal of medical practice

11. Value conflicts between the patient/family/surrogate and the health care team are typically focused on goals and/or benefits. (p. 24) A. True B. False

12. There is strong evidence that _____ improves energy levels and prolongs survival in patients with end-stage disease. (p. 27-29)
    A. enteral nutrition
    B. parenteral nutrition
    C. artificial hydration
    D. none of the above

13. Resuscitation includes all interventions that provide cardiovascular, respiratory, and metabolic support necessary to maintain and sustain the life of a dying patient. (p. 32) A. True
    B. False

14. A terminally ill patient is given opioid medication to alleviate severe pain. The unintended consequence of this action may be the shortening of the patient's life. This is an example of _____. (p. 34)
    A. Euthanasia
    B. The Principle of Double Effect
    C. The Doctrine of Unintended Consequences
    D. Errare humanum est

15. Which of the following is TRUE? (p. 35)
    A. Physicians are required to provide all life sustaining measures possible.
    B. Patients have a right to refuse treatment; even when treatment might prolong their life.
    C. Physicians are legally required to provide futile care if the patient (or their legal proxy) specifically request it.
    D. None of the above is true.

C11g52913r41820t31317