

EPEC

Education for Physicians on End-of-life Care

Participant's Handbook

Module 12

Last Hours of Living

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Abstract

The last hours of living are important not only for the comfort of the patient, but for all who are bereaved by, or simply witness, the death. Normal death is explained in this module, as are the key tasks that need to be accomplished before, at, and after the death. Management of the patient's distress is critical, particularly issues associated with feeding and hydration, changes in consciousness, delirium, pain, breathlessness, and secretions. Preparation and education of the family are important. Normal grief and bereavement are discussed as well as complicated grief.

Key words

bereavement, breathing changes, complicated grief, coroner, decreased appetite, decreased mobility, decreased perfusion, decreased thirst, delirium, expectations, eyes, fatigue, imminent death, moving the body, neurological dysfunction, normal grief, pain, rigor mortis, sphincter control, swallowing, tasks of caring

Introduction

Every one of us will die. A few of us (<10%) will die suddenly. Most of us (>90%) will die after a long period of illness with gradual deterioration until an active dying phase at the end. The last hours of our lives may be some of our most significant. They provide the last opportunity to finish our business, create final memories, give final gifts, find spiritual peace, and say good-bye.

Those who provide care have one opportunity to get it right. There is no second chance. If managed well, the last hours can lead to significant personal and family growth. If managed poorly, life closure may be incomplete, suffering may occur unnecessarily, family distress may continue long after the patient's death, and those who watch may worry that their death will be similar.

Most of us have little or no experience with the dying process or death. While many professionals have seen a dead body, lay people rarely have. Most of us have neither watched someone die nor provided care during the last hours of life.

Based on media dramatization and our vivid imaginations, most people have developed an exaggerated sense of what dying and death are like. However, with appropriate management, it is possible to provide smooth passage and comfort for the patient and all onlookers.

Preparing for the last hours of life

During the last hours of their lives, all 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. As changes can occur suddenly and unexpectedly, 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 is 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 provide a sense of final gift giving. For parents of a dying child, confidence can leave a sense of good parenting. If unprepared and unsupported, they may spend excessive energy worrying 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.

Physicians will need to establish in advance whether potential caregivers, including professionals who work in institutions, are skilled in caring for patients in the last hours of life. Do not assume that anyone, even a professional, knows how to perform basic tasks. Those who are inexperienced in this particular area will need specific training including, for instance, knowledge about body fluid precautions. Written materials can provide additional support to caregivers when experts are not present.

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. 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 we may give families or professional caregivers an idea of how long the patient might live, always advise them about the inherent unpredictability of death.

Essential skill for physicians

As virtually all physicians will care for dying patients and their families, the approaches to care in the last hours of life are essential skills for physicians. This module discusses the specialized care required during the last hours of life in 3 parts. These specialized approaches are applicable whether the patient is at home or in an institutional setting:

- part 1 discusses the physiologic changes that occur as patients are dying and approaches to the management of associated symptoms.
- part 2 discusses preparation for expected death and what to do when death occurs.
- part 3 discusses loss and the assessment and management of normal and complicated grief reactions.

Much of the work that can be done to prepare for the last hours of life is covered elsewhere in this curriculum. It is important that physicians know that patients have had the opportunity to prepare for the end of their lives and arrange for the legacies they would like to leave, eg, bequests, organ donation, gifts, etc. (See Plenary 1: Gaps in End-of-life Care; Module 1: Advance Care Planning; Module 2: Communicating Bad News; Module 3: Whole Patient Assessment; and Module 7: Goals of Care.)

Module 12, Part 1: Physiologic changes, symptom management

Objectives

The objective of part 1 of this module is to:

- assess and manage the pathophysiologic changes of dying

Clinical case on trigger tape

Alice is a 79-year-old woman who is in her own home, cared for by her daughter with the help of the home hospice program. Her physician makes a joint home visit with the home hospice nurse in order to assess changes in mental status.

Physiologic changes and symptom management

As a person dies, many different physiologic changes present as signs and symptoms. Each one can be alarming if it is not understood. To control each symptom effectively, physicians need to have an understanding of its cause, underlying pathophysiology, and the appropriate pharmacology to use.

Weakness/fatigue

Weakness and fatigue usually increase as the patient gets closer to death. In the last hours of life, 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 the development of pressure ulcers. These may become painful or odoriferous if they become infected. They are more easily prevented than treated (see Module 10: Common Physical Symptoms).

At the end of life, fatigue need not be resisted and most treatment to alleviate it can be discontinued (see Module 10: Common Physical Symptoms). 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. 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 (eg, 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 erythema or actual skin breakdown.

Decreasing appetite/food intake, wasting

Most patients lose their appetite and reduce food intake long before they reach the last hours of their lives. There are many causes, most of which become irreversible close to death (see Module 10: Common Physical Symptoms).

Families and professional caregivers often interpret cessation of eating as “giving in.” They frequently worry that the patient will “starve to death.” Physicians 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, and that clenching of teeth may be the only way for the patient to express desires.

Educate families about the studies that demonstrate that parenteral or enteral feeding of patients at the end of their lives neither improves symptom control nor lengthens life. Help them to understand that anorexia may be protective, as the resulting ketosis can lead to a greater sense of well-being and diminish pain.

Whatever the degree of acceptance of these facts, it is important for physicians to help families and caregivers realize that food pushed upon the unwilling patient may cause problems such as aspiration and increase tensions (see Module 11: Withholding, Withdrawing Therapy). Above all, help them to find alternate ways to provide appropriate physical care and emotional support to the patient so that they can continue to participate and feel valued during the dying process.

Decreasing fluid intake, dehydration

Most patients also reduce their fluid intake, or stop drinking entirely, long before they die. If they are still taking some fluid but are not eating, salt-containing fluids such as soups, soda water, sport drinks, and red vegetable juices can help to maintain electrolyte balance and minimize the risk of nausea from hyponatremia.

Decreased fluid intake usually heightens onlookers’ distress as they worry that the dehydrated patient will suffer, particularly if he or she becomes thirsty. As with feeding, families and professional caregivers will need support to understand that this is an expected event. It may help families to understand that most experts in the field feel that dehydration in the last hours of living does not cause distress and may stimulate endorphin release that adds to 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 move off the bed do not get lightheaded or dizzy. Patients with peripheral edema or ascites have excess body water and salt and are not dehydrated.

Parenteral fluids, 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. Moving the angiocatheter can be uncomfortable, particularly if the access site needs to be changed frequently and the patient is cachectic or has no accessible 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. They also have the potential to prolong the dying process, which may be undesirable.

Mucosal/conjunctival care

To maintain patient comfort and minimize the sense of thirst, even in the face of dehydration, maintain moisture in mucosal membranes 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 lips and anterior nasal mucosa hourly with a thin layer of petroleum jelly to reduce evaporation. 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.

Decreasing blood perfusion, renal failure

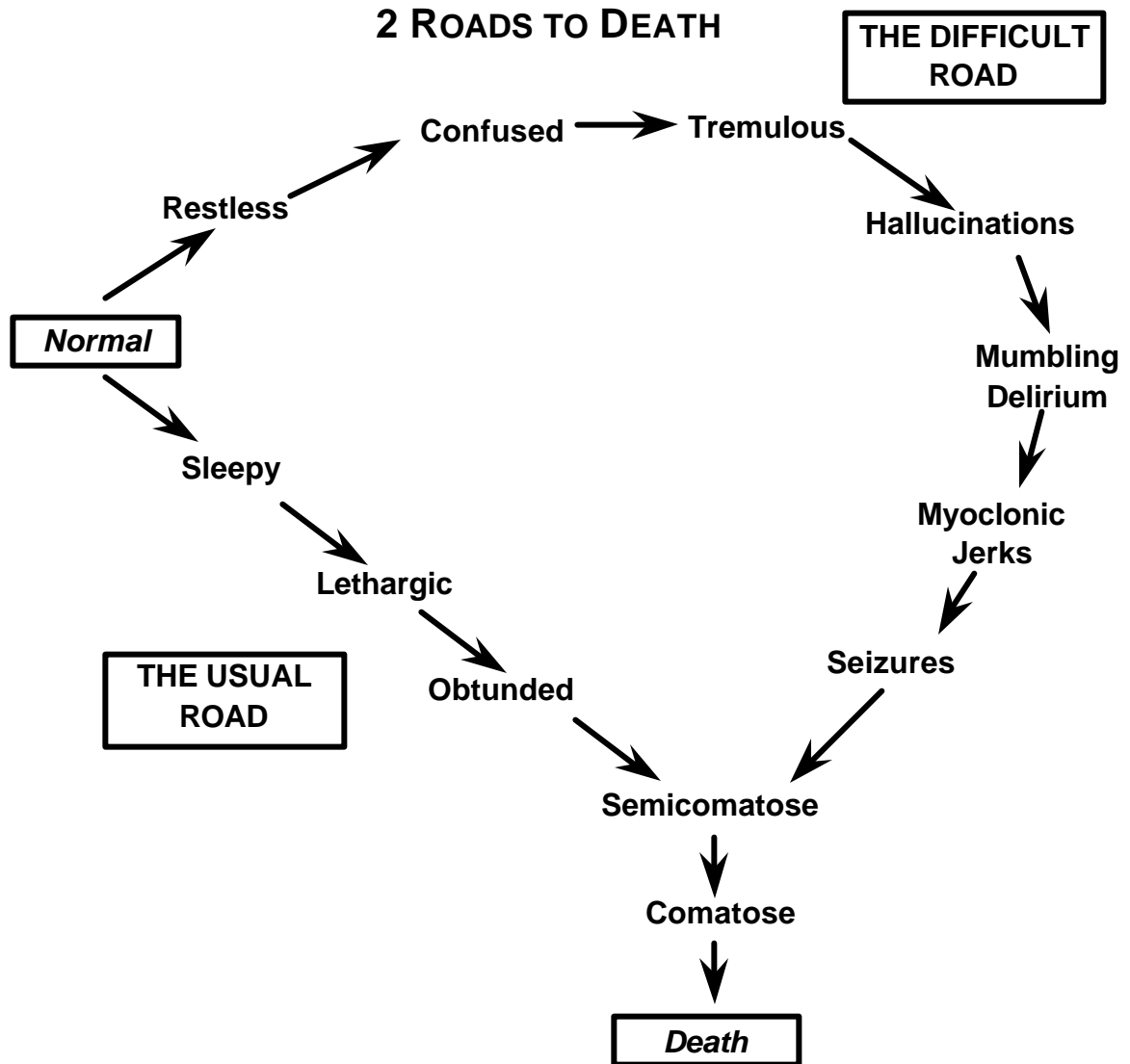
As cardiac output and intravascular volume decrease toward the end of life, there will be evidence of diminished peripheral blood perfusion. Tachycardia, hypotension, peripheral cooling, peripheral and central cyanosis, and mottling of the skin (livedo reticularis) are normal. Venous blood may pool along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

Neurologic dysfunction

The neurologic changes associated with the dying process are the result of multiple concurrent nonreversible factors, including hypoxemia, metabolic imbalance, acidosis, toxin accumulation due to liver and renal failure, adverse effects of medication, sepsis, disease-related factors, reduced cerebral perfusion, etc.

The neurologic changes associated with the dying process may manifest in 2 different patterns that have been described as the “2 roads to death” (see figure below). The “usual road” that most patients follow presents as decreasing level of consciousness that leads to coma and death. The “difficult road” that a few patients follow presents as an agitated

delirium due to central nervous system (CNS) excitation, with or without myoclonic jerks that leads to coma and death. Based on clinical observation, it is likely that the risk of focal or grand mal seizures is increased along the “difficult road,” particularly when cerebral metastases are present.



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Decreasing level of consciousness

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 unrousable. Absence of eyelash reflexes on physical examination indicates a profound level of coma equivalent to full anesthesia.

Communication with the unconscious patient

Families will frequently find that their decreasing ability to communicate 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. Time spent preparing families is likely to be very worthwhile.

While we do not know what unconscious patients can actually hear, experience 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, things, music, and sounds that he or she would like. Include the patient in everyday conversations. Encourage family 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 to them. The physician or other caregivers 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 OK.

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.

Terminal delirium

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. It may result from any of the standard causes of delirium listed in DSM-IV (American Psychiatric Association, 1994) that can accompany the dying process.

Agitated terminal delirium can be very distressing to family and professional caregivers who do not understand it. 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 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 delirium presents and the patient is not perceived to be actively dying, it may be appropriate to evaluate and try to reverse treatable contributing factors. However, if the patient is close to the last hours of his or her life, this is only effective in a minority of cases (standard approaches to managing delirium are discussed in Module 6: Depression, Anxiety, Delirium).

If death is imminent, it will not be possible to reverse the underlying causes. Focus on the management of the symptoms associated with the terminal delirium and settle the patient and the family.

When moaning, groaning, and grimacing accompany agitation and restlessness, they are frequently misinterpreted as pain. However, it is a myth that pain suddenly develops during the last hours of life when it has not previously been out of control. 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 (see Module 4: Pain Management). Rarely, the trial of increased opioids does not relieve the agitation or makes the delirium worse by increasing agitation or precipitating myoclonic jerks or seizures. If so, then pursue alternate therapies directed at suppressing the symptoms associated with the delirium.

Benzodiazepines are used widely as they are anxiolytics, amnestics, skeletal muscle relaxants, and antiepileptics. Oral lorazepam, 1 to 2 mg as an elixir, or the tablet predissolved in 0.5 to 1.0 mL of water and administered against the buccal mucosa q 1 h prn will settle most patients with 2 to 10 mg/24 h. It can then be given in divided doses, q 3 to 4 h, to keep the patient settled. For a few extremely agitated patients, high doses of lorazepam, 20 to 50+ mg/24 h, may be required. A midazolam infusion of 1 to 5 mg SC or IV q 1 h, preceded by repeated loading boluses of 0.5 mg q 15 min to effect, may be a rapidly effective alternative.

Benzodiazepines may excite some patients and not have the desired settling effect. These patients require neuroleptic medications to control their delirium. Haloperidol (0.5–2.0 mg q hs to q 6 h to start and titrated) given intravenously, subcutaneously, or rectally may be effective. A more sedating alternative is chlorpromazine (10–25 mg po q hs to q 6 h to start and titrated) given intravenously or rectally.

Seizures may be managed with high doses of benzodiazepines. Other antiepileptics such as phenytoin pr or IV, fosphenytoin SC, or phenobarbital, 60 to 120 mg pr, IV, or IM q 10 to 20 min prn, may become necessary until control is established.

Changes in respiration

Changes in a dying patient's breathing pattern may be indicative of significant neurological compromise. 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, sometimes 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, may be very comforting. Low doses of opioids or benzodiazepines are appropriate to manage any perception of breathlessness (see Module 10: Common Physical Symptoms).

Loss of ability to swallow

In the last hours of life, weakness and decreased neurologic function frequently impair the patient's ability to swallow. The gag reflex and reflexive clearing of the oropharynx decline and secretions from the tracheobronchial tree accumulate. These conditions may become more prominent as the patient loses consciousness. Buildup of saliva and oropharyngeal secretions may lead to gurgling, crackling, or rattling sounds with each breath. Some have called this the "death rattle," a term frequently disconcerting to families and caregivers. For unprepared families and professional caregivers, it may sound like the patient is choking.

Once the patient is unable to swallow, cease oral intake. Warn families and professional caregivers of the risk of aspiration. Scopolamine, 0.2–0.4 mg SC q 4 h or 1 to 3 transdermal patches q 72 h or 0.1 to 1.0 mg/h by continuous IV or SC infusion, or glycopyrrolate, 0.2 mg SC q 4 to 6 h or 0.4 to 1.2 mg/d by continuous IV or SC, will 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.

If excessive fluid accumulates in the back of the throat and upper airways, it may need to be cleared by repositioning the patient or postural drainage. Turning the patient onto one

side or a semiprone position may reduce gurgling. Lowering the head of the bed and raising the foot of the bed while the patient is in a semiprone 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.

Loss of sphincter control

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 people 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 fear that pain will suddenly increase as the patient dies, there is no evidence to suggest 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 forehead 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 overdiagnose pain when fleeting forehead tension comes and goes with movement or mental activity (eg, dreams or hallucinations). Do not confuse pain 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, discontinue routine dosing or continuous infusions of morphine when urine output and renal clearance stop. Titrate morphine breakthrough (rescue) doses to manage expressions suggestive of con-

tinuous pain. Consider the use of alternative opioids with inactive metabolites such as fentanyl or hydromorphone.

Loss of ability to close eyes

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. Eyes that remain open can be distressing to onlookers unless the condition is understood.

If conjunctiva remains exposed, maintain moisture by using ophthalmic lubricants, artificial tears, or physiologic saline as previously discussed.

Medications

As patients approach the last hour of their lives, reassess the need for each medication and minimize the number that the patient is taking. Leave only those medications to manage symptoms such as pain, breathlessness, excess secretions, and terminal delirium and reduce the risk of seizures. Choose the least invasive route of administration: the buccal mucosa or oral routes first, the subcutaneous or intravenous routes only if necessary, and the intramuscular route almost never.

Module 12, Part 2: Expected death

Objectives

The objective of part 2 of this module is to:

- prepare and support the patient, family, and caregivers

As expected death approaches

No matter how well families and professional caregivers are prepared, they will often find a prolonged death to be draining, particularly if the patient is intermittently restless or agitated. As death approaches, review the status of the patient and answer questions. Families may need to hear gentle repetition and clarification of the goals of care, the futility of life-prolonging therapies, and the irreversibility of unfolding events.

Advance discussion should ensure that everyone is aware of personal, cultural, and religious traditions, rites, and rituals that may dictate how prayers are to be conducted, how a person's body is to be handled after death, and when/how the body can be moved. To expedite arrangements for the funeral, memorial services, burial, or cremation, suggest that the patient and/or family contact the funeral home in advance.

Throughout the last hours of life, particularly as death approaches, families will benefit from repeated contact with their physicians and/or other members of the interdisciplinary team. To minimize confusion and unnecessary telephone calls, clarify the role of the physician and members of the interdisciplinary care team and their contact information in advance.

Families will settle best if questions are answered calmly and their concerns addressed promptly. To be effective, ensure that a knowledgeable physician, or other health care professional, is available by telephone 24 hours per day, 7 days per week. Delays in communication only heighten anxiety and may leave families frustrated that the care provided was not the best that was possible.

Signs that death has occurred

As expected death approaches, answer questions and review the signs and potential events that may occur as the patient dies. The heart stops beating; breathing stops; pupils become fixed; body color becomes pale and waxy as blood settles; body temperature drops; muscles and sphincters relax, urine and stool may be released; eyes may remain open; the jaw can fall open; and observers may hear the trickling of fluids internally.

What to do when death occurs

If the patient dies at home, remind families and caregivers that there is no need to call 911. If a home hospice program is involved, have the family call the hospice. If a home hospice is not involved, determine in advance who should be notified.

Make certain that family and professional caregivers understand that there are no rules that govern what happens as soon as the patient dies. Unless death is unexpected, or malice is suspected, involvement of the coroner's office is usually not required, although local regulations may vary. If the patient has not requested organ donation or made an anatomic gift to a medical school, the physician or other health care professional need not attend quickly to witness what has occurred. Presence may be helpful if family members are distressed and need immediate support with their acute grief reactions.

After expected death occurs

When expected death occurs, the focus of care shifts from the patient to the family and those who provided care. Everyone present will have a different experience and a different sense of loss. 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.

Encourage all who are present, including caregivers, to take the time they need to realize what has happened and say their good-byes. There is no need to rush, even in the hospital or other care facility. Allow everyone to touch, hold, and even kiss the person's body as they feel most comfortable. Be sensitive to the limits allowed by personal, cultural, or religious practices. Maintain universal body fluid precautions. The time spent with the body will help people through their acute grief. It will help them to develop a new sense of awareness of what has happened. It will benefit everyone as the event becomes more distant and family members start to adapt to the absence of their loved one.

To facilitate the acute grieving process, professional caregivers may wish to create a visually peaceful and accessible environment when family members are ready. 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. If eyes remain open, eyelids can be manually held closed for a few minutes and will usually remain closed once they dry. If they remain open, a small amount of surgical tape or a short Steri-strip will hold them closed for longer without pulling on eyelashes when they are removed. If the jaw falls open as muscles relax, a rolled-up towel placed under the chin of an elevated head will usually hold the jaw closed until muscles stiffen some 4 to 6 hours later.

Caregivers who have not been present for the death can assess how family members are handling their loss by listening to a recounting of how things went leading up to the death and afterward. Spiritual advisors or other interdisciplinary team members may be instru-

mental in orchestrating events to facilitate the transition that those present are experiencing. Grief reactions beyond cultural norms suggest a risk of significant ongoing or delayed grief reactions.

When the immediate family is ready, invite others who have been close to the patient, including caregivers, to come to the bedside to witness what has happened before the person's body is moved. When letting people know what has happened, follow the guidelines for communicating bad news. Try to avoid breaking unexpected news by telephone, as communicating in person provides much greater opportunity for assessment and support (see Module 2: Communicating Bad News). As additional visitors arrive, spend a few minutes to remind them of the changes in body color, temperature, and the scene they will see. This can reduce the surprise and make the transition a little easier for everyone.

Moving the body

Once family members have had the time they need to witness what has happened, 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.

Once ready, family members or professional caregivers at the request of the family may call a chosen funeral service provider and arrange to move the person's body. Most funeral services are available to transfer the body 24 hours per day, 7 days per week, and will attend at home within a short time of the call. If the patient is in a health care institution, the funeral home will deal directly with the institution.

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. To avoid delaying the process, ensure that the physician who will complete the certificate has ample warning that one will be required. Usually, the physician does not need to be called at the moment of the death just to do this.

Families who have not discussed funeral arrangements in advance may have many questions about burial, cremation, embalming, and/or different types of services. If the funeral director is not available, a little time spent by the physician answering their questions will ease the anxiety of the surviving family members.

For many, the arrival of the funeral directors to remove the body is the next major confrontation with reality, particularly if the death has occurred at home. Some family members will wish to witness the removal. Others will find it very difficult and will prefer to retire to another place and allow professional caregivers to handle things discreetly.

For some, the thought that the person's body will be enclosed in a body bag is intolerable. Ensure that professional caregivers and funeral directors have the sensitivity to recognize when this is an issue and negotiate a suitable alternative (eg, not closing the bag until it has been removed from the vicinity of the home). Institutional caregivers should be aware that there may be similar reactions by family members when professionals prepare the body for transfer to the morgue.

Other tasks

At home, 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. They may notify health care service agencies so that services can be stopped and equipment removed from the home when it is convenient for the family. They may suggest how to secure valuables. They may dispose of medications, particularly opioids, in the toilet, and they may dispose of biological wastes. Caregivers should be clear about local regulations governing ownership of medications after a death and waste disposal.

When family members are ready, professional caregivers can let the family know how to reach them, then leave them to have some privacy together.

Bereavement care

Immediately after the death, those who survive will need time to recover from their stress and fatigue, and restore their environments back to normal.

A bereavement card and attendance at the patient's funeral may be appropriate. For many physicians and members of the professional team, encouraging follow-up visits from family members to assess the severity of their grief reactions to their recent loss and coping strategies and to provide support is a part of their professional duty of care.

Professional members of the interdisciplinary team can also offer to assist family members, when ready, to deal with outstanding practical matters, secure documents to redeem insurance, find legal counsel to execute the will, meet financial obligations, close the estate, etc.

Dying in institutions

This discussion about preparation for expected death and what to do when the patient dies is relevant to patients dying in any setting (eg, at home, in hospital, in nursing homes, other extended care facilities, jails, etc). However, a few remarks are warranted regarding the particular challenges of ensuring a comfortable death in an institution whose culture is not focused on end-of-life care.

As many patients approach the end of their lives, they prefer to remain with the caregivers they know, rather than be transferred to another facility. Institutions should make the

environment as home-like as possible. To help ensure privacy, move the patient to a private room where family can be present continuously and intimate with the patient if they would choose to do so. Encourage the family to surround the patient with a few personal things or photos. Prepare the professional staff and encourage continuity of care plans across nursing shifts and changes in house staff. Avoid changing settings abruptly simply because the patient is dying. For instance, transferring from a nursing home to hospital or vice versa can be very disruptive and distressing to everyone.

Priorities and care plans at the end of life differ considerably from those for life prolongation and cure. It is frequently challenging for physicians and other health care professionals to incorporate both into a busy hospital or skilled nursing facility. If the provision of end-of-life care proves to be difficult in these settings, consider a specialized unit where patients and families can be assured of the environment and the skilled care they need.

Module 12, Part 3: Loss, grief, bereavement

Objectives

The objective of part 3 of this module is to:

- identify and manage initial grief reactions

Loss, grief with life-threatening illness

As patients and families confront life-threatening illness, they are vulnerable to many different anticipated, if not actual, losses. These include: loss of functional capabilities, control, independence, body image, dignity, relationships, sense of future, etc. As illness progresses, the risk of losing control over fundamentally important aspects of their lives increases, at times dramatically.

Grief reactions, the emotional reactions to loss, frequently run very high as everyone confronts the possibility of the end of the patient's life and the change death will bring. Multiple coping strategies may occur simultaneously. Some will be helpful. Others may become destructive.

To be effective in end-of-life care, physicians need to be able to recognize grief and assist with appropriate interventions.

Normal grief

Normal grief reactions include a whole range of physical, emotional, and cognitive behaviors. The bereaved may note feelings of hollowness in the stomach, tightness in the chest, heart palpitations, weakness, lack of energy, gastrointestinal disturbances, weight gain or loss, or skin reactions. Many say they feel emotional numbness, relief, sadness, fear, anger, guilt, loneliness, abandonment, despair, or ambivalence. They may be concerned about cognitive symptoms such as disbelief, confusion, inability to concentrate, and preoccupation with or dreams of the deceased. All of these are normal grief reactions to any type of loss.

Some people will make a conscious effort to deal with the loss. Others will deny what is happening and avoid dealing with the loss. Some coping strategies (eg, increased smoking/alcohol/medication intake, overworking, and suicidal ideation) may accelerate and even become destructive, especially in the face of seemingly insurmountable loss.

Recently bereaved may seek assistance from their physicians for these symptoms. Recognition of the cause is important if useless or misleading investigations or medication trials are to be avoided.

Complicated grief

When grief reactions occur over long periods of time, are very intense, or interfere with the survivor's physical or emotional well-being, they become symptoms of complicated grief. There are 4 categories of complicated grief reactions. Chronic grief is characterized by normal grief reactions that do not subside and continue over very long periods of time. Delayed grief is characterized by normal grief reactions that are suppressed or postponed. The survivor consciously or unconsciously avoids the pain of the loss. In exaggerated grief, the survivor may resort to self-destructive behaviors such as suicide. Finally, in masked grief, the survivor is not aware that the behaviors that interfere with normal functioning are a result of the loss.

The physician needs to be attuned to behaviors that might indicate complicated grief, especially if these continue beyond 6 to 12 months. The survivor may not be able to speak of the deceased without experiencing intense sadness. Themes of loss may continue to occur in every topic during a clinical interview. Minor events may unexpectedly trigger intense grief and sadness. The survivor may be unwilling to move possessions belonging to the deceased. Sometimes the survivor will develop symptoms similar to those of the deceased. When complicated grief is suspected, referral for specialized help is warranted.

Tasks of the grieving

After a major loss, there are typically 4 tasks the bereaved must complete before they will effectively deal with their loss. These tasks apply to the many losses that precede the death, as well as to the death itself. While the tasks are interdependent, they are not necessarily completed in sequence.

For many, realization and acceptance that the loss or death has actually occurred can be a major hurdle. If such individuals spent little or no time at the bedside after the death realizing what happened, they may continue for months to deny that anything has occurred. Denial can be unwavering. Some bereaved may even continue to look for the person, waiting for his or her telephone call and/or return. Until such people realize that the person has died, they cannot begin to resolve what has happened and move on.

Knowing that the death has occurred is not enough. To be able to move on, the bereaved need to experience the pain caused by their loss. As this can be very distressing, many who are bereaved try to avoid the pain, and physicians frequently try to blunt it with medication. While this may be necessary for temporary management of destructive reactions, if overdone, medication may prolong both the grief reactions and the pain associated with the loss.

Once they have realized what has happened and the pain that the loss has caused, the bereaved need to recognize the significance of their losses and the changes to their lives. Finally, as grief proceeds, the bereaved need to reinvest their energy into new activities and relationships.

All of these tasks may seem relatively straightforward to the inexperienced onlooker. However, for the person who is emotionally distraught and now feels very lonely and abandoned, each task may seem insurmountable and may take months or even years to resolve.

While support from family and caregivers may be intense for the first few days or weeks after the death, the degree of support inevitably diminishes as others less affected get on with their lives. If the person who has suffered the greatest loss is unable to move on and dwells on his or her loss, impatience for change may create a rift and increase tensions between the bereaved and other members of the family/caregivers.

Assessment of loss, grief

To effectively anticipate and reduce the grief reactions of our patients and families, physicians must repeatedly assess their anticipated and actual losses, emotional responses, and coping strategies. Gentle inquiry may provide support to the bereaved, and help the physician understand how the survivor is coping.

Other professionals, such as hospice nurses, social workers, and chaplains, can greatly facilitate the assessment and monitoring of grief. While religion may be an important component of coping, it is beyond the scope of this module to discuss it in any detail. Use a chaplain or pastoral care professional to help determine and understand the religious background and framework held by each family member.

Grief management

If the loss, grief reactions, and coping strategies appear to be appropriate and effective, the situation can be monitored and supportive counseling provided. Survivors may feel they are “going crazy” or “losing their mind.” Permit them to discuss their feelings. Reinforce that grief is painful and prolonged, but normal. Encourage the survivor to talk about what it is like to live without the deceased. Encourage participation in rituals such as attending the funeral or memorial services, or identifying personal rituals.

Explain that the length of time needed for the grief process will vary with each person and situation. There is no “right” way to grieve. Each person will have his/her own way. In general, most people who are bereaved are able to reenter the world after 1 to 3 weeks. However, active grieving can go on for a year or more. Sadness can continue for much longer but typically does not intrude on or prevent new life.

If loss, grief reactions, and coping strategies appear to be inappropriate or ineffective and/or they have the potential to cause harm (eg, destructive behaviors or suicide), they will need to be assessed quickly. Consult someone who is skilled in loss, grief, and bereavement care so that therapy can be instigated quickly to reduce the risk of harmful/destructive activities.

Summary

Competence, teaching, and calm, empathic reassurance are critical to helping patients and families in the last hours of living. These important hours often leave lasting memories for families, as well as for caregivers and professionals. For the majority of dying patients, physiologic changes occur that are predictable, including loss of appetite and thirst, decreased blood perfusion, neurologic dysfunction, changes in respiration, loss of ability to swallow, and loss of ability to close the eyes. Knowledge of metabolism at the end of life is important for medical management, especially if pain or terminal delirium occurs. Suggestions about how to manage dying in institutional settings include making room for private visits, cultural observance, and communication. When death approaches, be sure the family knows what to do and what to expect, including matters such as when rigor mortis sets in, how to call the funeral home, say goodbye and move the body. Care does not end until the physician has helped the family with their grief reactions and helped those with complicated grief to get care.

Key take-home points

1. If managed well, the last hours can lead to significant personal and family growth. If managed poorly, life closure may be incomplete, suffering may occur unnecessarily, family distress may continue long after the patient's death, and those who watch may worry that their own death will be similar.
2. During the last hours of their lives, patients usually need skilled care around the clock. The environment must allow family and friends ready access to their loved one in a setting conducive to privacy and intimacy.
3. Advance preparation and education of professionals, family, and volunteer caregivers is essential. 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.
4. The physiologic changes of dying are complex. To control each symptom effectively, physicians need to have an understanding of its cause, underlying pathophysiology, and the appropriate pharmacology to use.

Part 1

5. At the end of life, fatigue need not be resisted and most treatment to alleviate it can be discontinued.
6. Most patients lose their appetite and reduce food intake long before they reach the last hours of their lives. Anorexia may be protective, and the resulting ketosis can lead to a greater sense of well-being and diminish pain.

7. Most patients also reduce their fluid intake, or stop drinking entirely, long before they die. Dehydration in the last hours of living does not cause distress and may stimulate endorphin release that adds to the patient's sense of well-being.
8. Maintain moisture in mucosal membranes with meticulous oral, lip, nasal, and conjunctival hygiene and lubrication.
9. The majority of patients experience increasing drowsiness, sleep most if not all of the time, and eventually become unarousable. Absence of eyelash reflexes indicates a profound level of coma equivalent to full anesthesia.
10. Presume that the unconscious patient hears everything.
11. Moaning, groaning, and grimacing accompanying agitation and restlessness are frequently misinterpreted as pain. Terminal delirium may be occurring. While a trial of opioids may be beneficial in the unconscious patient who is difficult to assess, benzodiazepines or sedating neuroleptics may be needed to manage terminal delirium. Benzodiazepines may paradoxical exciting effect, these patients require neuroleptic medications to control their delirium.
12. Diminished hepatic function and renal perfusion may change pharmacology of chronically administered medications.
13. Secretions from the tracheobronchial tree frequently accumulate. Scopolamine or glycopyrrolate will effectively reduce the production of saliva and other secretions.

Part 2

14. Institutional dying presents particular challenges. Priorities and care plans at the very end of life differ from those for life prolongation and cure.
15. Planning discussions should cover personal, cultural, and religious traditions, rites, and rituals that may dictate how prayers are to be conducted, how a person's body is to be handled after death, and when/how the body can be moved.
16. When expected death occurs, the focus of care shifts to the family and those who provided care.
17. Attend to acute grief reactions, especially when the body is moved.

Part 3

18. To deal with loss of any kind, individuals must complete each task of the grieving process.
 - a. Accept the reality of loss
 - b. Experience the pain caused by the loss
 - c. Adjust to the new environment after the loss
 - d. Rebuild a new life
19. Physicians need to be able to recognize grief and assist with appropriate interventions. Some grief-coping strategies (eg, increased smoking/alcohol/medication intake, overworking, and suicidal ideation) may accelerate and even become destructive.
20. Based on media dramatization and vivid imaginations, many people have developed an exaggerated sense and fear of what dying and death are like.
21. For the bereaved person who is emotionally distraught and now feels very lonely and abandoned, each task of the grieving process may seem insurmountable and may take months or even years to resolve.
22. If loss, grief reactions, and coping strategies appear to be inappropriate or ineffective and/or they have the potential to cause harm (eg, destructive behaviors or suicide), they will need to be assessed quickly. Consult someone who is skilled in loss, grief, and bereavement care so that therapy can be instigated quickly to reduce the risk of harmful/destructive activities.

Pearls

1. Use only essential medications. Stop routine dosing and continue to offer opioids “as needed.” Accumulating serum concentrations of active drug and metabolites may lead to toxicity and terminal delirium.
2. Know the signs of the dying process.

Potential pitfalls

1. Maintaining parenteral fluids. They may have adverse effects that are not commonly considered.
2. Oropharyngeal suctioning. It is likely to be ineffective at clearing secretions, yet very effective at stimulating a gag, cough, or vomiting.
3. Removal of the body insensitively or too soon. This can be more distressing for families than the moment of death.

Resources

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