

End-of-Life Care for Older Adults

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Changes in medicine and medical technology in the past half century have dramatically altered the way people die. A hundred years ago, infectious diseases were the major cause of death and the average age of death was 48 years [1]. But by the end of the twentieth century, chronic disease had become by far the predominant cause of death in America [1]. People today live to a much more advanced age, often with ongoing illness.

One role of the physician is to make such long life possible and to help assure that the life being prolonged can remain active, productive, and meaningful. However, despite all the technology at our disposal, death is still the inevitable consequence of most chronic diseases. There usually comes a time in the course of such illnesses when neither cure nor prolongation of life can be a primary, or even reasonable, goal of care. This fact does not mean, however, that the physician has no further role. Physicians, typically primary care physicians, have a vital and valuable part to play in the care of patients who are nearing the end of their lives. Maximizing quality of life and providing effective symptom relief then become the most important goals of care.

The elderly comprise most of those in need of palliative and end-of-life care [2]. Nearly 2.5 million people died in the United States in 2002, and three quarters of those deaths occurred in those aged 65 years and over [3]. Five of the six leading causes of death in this age group were chronic illnesses, the conditions most likely to benefit from palliative care [4]. The elderly also represent the most rapidly growing segment of the population, with those aged 65 years and over expected to more than double from 2000 to 2030, when they will constitute 20% of the population. And the number of people aged 85 years and older is expected to more than double by 2030, and more than double again by 2050 [5]. Thus the need for palliative care for older adults will continue to rise at a rapid rate.

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Life-limiting chronic illnesses include advanced cancer, neurodegenerative diseases, and organ or system failure. Cancer increases in frequency and rate of death with advancing years. The incidence of neurodegenerative diseases and advanced pulmonary, cardiovascular, and renal diseases also increases dramatically with age. These noncancer diagnoses often have less predictable trajectories [6], making accurate prognostication and definite identification of the time called “end of life” more difficult [6–8]. “Diagnosing dying” is a complex challenge, requiring clinical insights beyond those related to traditional diagnosis and treatment, and advanced communication skills to allow the physician to share those insights with patients and families [8,9].

An additional challenge is the decrease in cognitive function experienced by some older patients, whether this means full-blown dementia or reduced capacity for decision making for other reasons. Patient incapacity and the need for family members to take on all or part of the decision-making responsibility put even greater demands on the physician [10,11]. The article by Brody elsewhere in this issue provides a more detailed discussion of decision-making capacity.

But challenges can lead to great rewards in the lives of terminally ill patients and their families. By making end-of-life care a vital component of office-based geriatrics, the physician can supply early assistance with future care planning, help patients and families identify goals of care, provide intensive/active symptom management, and address important life closure issues [12]. Few physicians have had extensive training in how to manage these complex situations, and they may react to them with avoidance or indecision. But the skills for addressing the common concerns of geriatric patients at the end of life are easily developed [6,13]. This article addresses:

- Goals of care
- Communication with patients and families
- Coordination of services
- Symptom management, including physical, psychosocial, and spiritual symptoms
- The active dying process
- Grief and bereavement

Goals of care

The many possible goals of medical care range from prevention of disease and prolongation of life to symptom control and helping patients to achieve a “good death.” It is important to realize that different, and even conflicting, goals of care for a patient can coexist. Such goals also do not remain static; their identification and reassessment is an ongoing process over the course of a patient’s illness, especially as patients near the end of life because priorities and goals often change as symptoms grow more severe or when the

patient comes to understand that proposed treatments have minimal chance of prolonging life [14].

Health care providers should revisit goals of care regularly, particularly during points of crisis or transition. Four major areas of change in a patient's life should trigger a reassessment of the goals of care [15,16]:

- A change in the patient's health status (eg, worsened prognosis or unexpected recovery)
- A change in the patient's treatment setting (eg, hospital to nursing home, or vice versa)
- A change in treatment options that results from disease progression or unresponsiveness to current therapy
- The expressed preference of a patient to change the goals of care

The family or proxy decision maker usually should be present when discussing goals of care with the terminally ill patient. If the patient later becomes unable to make decisions regarding medical care, those entrusted with decision-making responsibility will have additional insight and knowledge of the patient's goals for end-of-life care. Physicians also need to be aware that focusing decision making on the patient alone is not always the norm. In various cultures or subcultures, decision making involves the whole family, with a specific assignment of roles within the family (such as in many Asian or Hispanic cultures). Physicians should be sensitive to patients' and families' cultural contexts [11,17].

Advance directives are valuable in identifying proxy decision makers and do-not-resuscitate (DNR) status, and, ideally, advance care planning will cover a range of situations and care options that the patient or proxy decision maker might face as a chronic disease progresses. But there is no way to anticipate every possibility and permutation in the course of illness, so advance directives will provide only limited information about a patient's goals and wishes at the end of life. The conversations that elicit a patient's choices for advance directives are often more important than the legal document itself [18]. As with setting the goals of care, it is wise for the proxy to be present during these conversations so that he or she may be better equipped to speak on the patient's behalf in situations that have been anticipated and those that have not. Advance care planning should be reviewed whenever a patient experiences a crisis or point of transition, as outlined earlier. It is common for a patient's preferences to change during the course of a life-threatening chronic illness.

Communication with patients and families

Families play an important role in the well-being of those who are dying, but often suffer emotionally, spiritually, and financially as they care for the patient [19]. They may feel hopelessness, anger, guilt, and powerlessness when they cannot relieve the suffering of their terminally ill family member.

Family conflicts may resurface in the face of a terminal illness, and any emotional tension that exists between the caregivers and patient could impede care. It is helpful for physicians to observe how patients and their families communicate and to be sensitive to conflict and cultural influences. Physicians can provide support for patients and their families by allowing them to express their emotions and concerns and by referring them to appropriate counselors or support groups when needed [14,16].

Negotiating goals of care with terminally ill patients and their families can be a challenging task. A stepwise protocol [11,17,20] helps guide physicians through the process:

- Create the right setting
- Determine what the patient and family know
- Ask how much they know and want to discuss with you
- Explore what they are expecting or hoping for
- Suggest realistic goals
- Respond empathically
- Make a plan and follow through

Coordination of care

Good end-of-life care cannot be provided by a physician alone. When possible, an interdisciplinary team should conduct an assessment and craft a plan that meets the full range of spiritual, emotional, and physical needs of a patient at the end of life [7,11]. Primary care physicians are often skilled at coordinating care between specialists and other health care providers, but coordinating an interdisciplinary team in the care of a dying patient can be a more daunting task. Fortunately, there are resources to assist physicians.

Hospice services are the most commonly used resource for terminally ill patients. Hospice refers to a philosophy of care and not any specific infrastructure. Hospice care is provided by an interdisciplinary team, and focuses primarily on symptom control and psychologic and spiritual support for dying patients and their families. In the United State, these services are generally provided by public or private agencies in home-care programs, long-term care facilities, or special residential facilities. Hospice care is defined by the Medicare hospice benefit, which requires a physician's certification that a patient is expected to live 6 months or less. Because it can be difficult to predict the life expectancy of elderly patients who have chronic diseases, many of them are never referred to hospice care, whereas others receive hospice services for only a short time before their deaths. For older adults who have a noncancer diagnosis with a less predictable trajectory to death, it may be best if the physician asked, "Would I be surprised if this patient died in the next 6 months?" Many have found this question to be useful in identifying patients who should be considered for end-of-life care. There is widespread agreement that earlier identification of patients who would benefit from

hospice care, and earlier admission to hospice programs, would greatly enhance the quality of end-of-life care in the United States [7,21].

Most people express a preference for dying at home, and family members can often support that wish [18]. But various factors may make it impossible to deliver quality end-of-life care in the patient's home. Hospice care can also be provided in nursing facilities, and a growing number of nursing homes have instituted palliative care protocols for the care of residents at the end of life [8,22]. Patients who have less intensive-care needs may be suited for placement in an assisted living facility, where hospice services can also be provided. In addition, many hospices have residential units designed to care for patients who require intensive symptom management or have physical care needs that cannot be met in other settings. For patients for whom hospice is not a suitable choice, other community resources can be mobilized, including home health agencies or area agencies on aging [23]. The use of community resources is covered in more detail in the article by Holmes elsewhere in this issue.

Symptom management

Symptom management refers not only to physical symptoms that need to be addressed, but also to psychosocial concerns and spiritual distress. It is important to recognize that these three areas are interdependent, and that effective care of the whole person requires attention to all three in an integrated fashion. Primary care physicians can reduce or alleviate the burden of suffering in all of these areas. In most cases, the physician will want to coordinate care with other professionals who are integral to the patient's care, usually nurses, social workers, and home health aides. Many older patients will also appreciate the opportunity to meet with spiritual care professionals. Some patients may benefit from consultation with experts in palliative medicine or geriatrics or professionals who have more advanced psychosocial expertise, such as neuropsychologists or geriatric psychiatrists.

Specific details about symptom management are beyond the scope of this article, but the Further Readings section identifies resources for further information in all three areas.

Physical symptoms

The most common physical symptoms in terminally ill elderly patients include pain, dyspnea, nausea and vomiting, constipation, and fatigue. Certain symptoms are common no matter what the cause of death: nearly three quarters of all dying patients experience pain, and half have difficulty breathing and loss of appetite [24]. In most cases, the primary care physician can substantially relieve the burden of suffering from these symptoms. Consultation may be required in a few cases.

Evidence suggests that physical symptom management may be even more important in elderly dying patients than in others [10,18]. Many symptoms near the time of death, no matter what the cause of death, are more common with advancing age. Those aged 85 years and older are more than twice as likely as those younger than age 55 to experience confusion (52% versus 21%) or loss of bladder control (51% versus 24%) [24]. Elderly patients are also more likely to experience dizziness or loss of bowel control.

Pain

Pain is a common symptom in older adults in general, with estimates as high as 50% of older adults experiencing major pain [25]. But although pain is widespread in elderly people, pain relief often is not achieved. It has been shown repeatedly that elderly people are at greater risk for inadequate analgesia than younger persons. Women and non-Caucasians are also at increased risk for poor pain relief. When older patients suffer from advanced illness, particular attention is required to ensure pain relief. Rates of pain in metastatic cancer range from 60% to 90%, and pain is also common in the advanced stages of many other chronic diseases, with rates from 50% to 80% reported. Pain may be caused by the disease process itself, comorbidities, or the medical treatments provided.

Pain assessment should include a thorough history, relevant physical examination, and assessment of functional status. Atypical presentations of pain are common in elder patients, and may include confusion, fatigue, withdrawal, and depression. Inquiring specifically about pain is even more important in elderly patients than in the general population. The multiple comorbidities of elderly patients often complicate the assessment of pain, and pain from multiple sources is common.

A standardized approach should be used to assess pain and to evaluate the severity of the pain. Such an approach can also enhance communication about the effectiveness of interventions used to relieve pain. Standard tools include the numeric rating scale, the visual analog scale, and the faces scale. Special tools have been developed for pain assessment in cognitively impaired patients [18]. Cognitively impaired older patients who are unable to report their pain pose a particular challenge in pain assessment. Self-report may need to be replaced by careful observation of behaviors and facial expressions. Pain should always be considered in the differential diagnosis of agitation or withdrawal in older adults who are cognitively impaired.

Pharmacologic treatment is required for pain in most terminally ill older adults. Acetaminophen is well tolerated and generally recognized as the drug of choice for mild pain in elderly patients. The adverse effects of non-steroidal anti-inflammatory drugs, including cyclooxygenase-2 inhibitors are greatly increased in elderly people, and most experts prefer to avoid their use where possible [26,27]. Adjuvant analgesics, including antidepressants and

anticonvulsants, can be considered, but a high degree of caution regarding adverse effects and potential for interactions with other drugs must be exercised in the elderly population. Corticosteroids should also be considered for relief of refractory pain in the terminally ill, where the risk for serious adverse effects may be outweighed by the potential benefit. Corticosteroids are particularly likely to be beneficial in pain caused by bone metastases and neuropathic causes [26,28].

Opioids are the mainstay of therapy for relief of moderate to severe pain. They should be titrated upward until pain relief is achieved or unmanageable adverse effects are manifested. Titration should be done with special care in elderly patients because of their altered pharmacokinetics and increased sensitivity to adverse effects. In addition, one should consider the possibility that longer-than-usual dosing intervals may be needed. Most patients will do best on regularly scheduled or around-the-clock dosing, with rescue or as needed (PRN) medication available for episodes of breakthrough pain.

Oral administration is the simplest and preferred route for most elderly patients. Initial treatment and titration to pain relief should use immediate release preparations of opioids. However, once good pain relief has been achieved, sustained release preparations will provide equivalent analgesia with dosing at substantially reduced intervals (every 8–12 hours). Rescue medication should be maintained in the immediate release form.

Some patients will not be able to use the oral route for various reasons (eg, difficulty swallowing, gastrointestinal obstruction). Fentanyl is the only opioid currently available commercially for transdermal delivery. Transdermal patches are effective for many people, but elderly patients may have more erratic responses because of alterations in skin integrity, subcutaneous fat, and serum albumin [26]. Alternatively, compounding pharmacists may prepare cream or gel versions of opioids for transdermal administration. Morphine gel has also been used as an effective topical analgesic treatment for painful skin lesions, including pressure ulcers [29]. Opioids may also be administered rectally, either using ready-made suppositories or by rectal administration of immediate or sustained release oral preparations.

Parenteral administration of opioids may be needed in some patients. Subcutaneous administration (either continuous or intermittent) may be highly effective, and intravenous infusions are used in many patients who have pre-existing ports from earlier therapies. Intramuscular (IM) injections should be discouraged. In addition to causing pain, absorption from IM injections is erratic, and the analgesia achieved is generally no better than with less invasive routes [26,28]. A small percentage of patients will require epidural or intrathecal delivery of analgesics, usually because of refractory systemic adverse effects from other routes [28].

The specific opioid may be chosen by availability of the preferred route or that of sustained release preparations. Oxycodone and hydromorphone have shorter half-lives and lower potential for accumulation of toxic metabolites than morphine, so they may be preferred in elderly patients. In

general, meperidine should not be used because of its poor oral absorption and neurotoxic active metabolite, particularly problematic in older patients who have reduced renal function [26].

Nonpharmacologic methods may be useful adjunctive measures for pain relief in elderly patients. Massage, exercise, positioning, and application of heat or cold can contribute to relief in some cases. Mind–body techniques, such as relaxation or imagery, may also be helpful, but the physician should take care not to send the mistaken message that their usefulness means the pain is “all in the patient’s head.” Elderly patients vary in their receptivity to these techniques [26].

Dyspnea

Dyspnea, or breathlessness, is a highly distressing symptom common in many end-stage disease processes. Although reversible causes should be sought and aggressively managed, dyspnea unfortunately remains a significant symptom for many individuals even after maximal disease treatment. Opioids, particularly morphine, provide highly effective relief of dyspnea for most patients. Benzodiazepines, and to a lesser extent, phenothiazines, have been used to treat dyspnea. There is no clear evidence as to which category of medication will be most effective in any given patient, and clinical judgment combined with therapeutic trials is the best approach. The use of oxygen is common in treatment of dyspnea, but it is not always effective. Hypoxemia does not necessarily correlate with the subjective symptom of dyspnea, and its correction may not produce symptom relief. The drawbacks of oxygen therapy include cost, the intrusive and noisy apparatus, restrictions on activity, and difficulties in keeping tubing or masks in place in many elderly patients. The relative benefits and drawbacks should be weighed for each individual, and a therapeutic trial to assess benefit considered. Use of oxygen only on a PRN basis should also be considered. Nonpharmacologic interventions for dyspnea, such as positioning, dehumidification of ambient air, the use of fans, and soothing environmental changes, are often highly effective adjuncts to pharmacologic treatment. Calm reassurance by the physician or other health care professional is also of great therapeutic benefit when combined with other interventions.

Nausea and vomiting

Nausea and vomiting may be caused by the underlying medical conditions or by their treatments (eg, opioids). Different causes of nausea can be addressed in particular ways. For example, gastric stasis may be treated with prokinetic medications, such as metoclopramide. Antihistamines, like meclizine, may relieve movement-related nausea. Much of the nausea that occurs at the end of life is mediated by stimulation of the chemoreceptor trigger zone, and treatment may include dopamine antagonists, such as phenothiazines or butyrophenones, or 5HT antagonists,

such as ondansetron. Unfortunately, many elderly patients are particularly vulnerable to the adverse sedative, anticholinergic, and extrapyramidal effects of these medications, which limits their usefulness. A common exacerbating factor is caregiver insistence that patients who do not have an appetite should nevertheless eat. Physician counseling about this problem is reviewed below.

Dehydration and weight loss

Although these conditions are not typically symptomatic, they are often of great concern to family members, who may worry that their loved one will “die of thirst” or “starve to death.” Concerned family are undoubtedly also influenced by the fact that feeding is seen as a sign of love, and they might worry that withholding food and hydration will hasten death. However, nonoral administration of fluids or calories in a dying patient does not prolong life. On the contrary, it may make the life that remains less comfortable by increasing congestion and swelling, or by possibly enhancing tumor growth in cancer patients. Patients and family should be reassured that it is natural to lose interest in eating in advanced illness, and that taking in less fluid and fewer calories can actually help make the patient more comfortable. It does not cause suffering and can ease the physical part of the dying process. Reassurance from the physician is usually well received and can be an important source of relief and comfort [30,31].

Patients who are dehydrated in the advanced stages of illness may experience dry mouth, but this is not related to thirst, and any discomfort can be relieved with the use of ice chips or a wet cloth.

Fatigue

Fatigue is another common symptom, but regrettably not one that is easily relieved. Although correctible factors, including depression, should be sought and addressed where appropriate, persistent fatigue is common in advanced illness. Letting patients know that fatigue is not unusual can be valuable for them and their families, who may interpret this symptom as a sign the patient is “giving up.” Counseling regarding energy conservation strategies, including identification and pacing of high-priority activities, may be helpful. Medical interventions have limited effectiveness, but carefully selected patients may benefit from a trial of therapy with psychostimulants. There is modest research evidence of benefit with methylphenidate, and anecdotal reports of positive effects from modafinil.

Constipation

Constipation is common in elderly people, and is further increased by advanced illness and debilitation. It is also a frequent adverse effect of many drugs, including opioids and those with anti-cholinergic side effects. Even in

the absence of such drugs, decreased gastrointestinal motility can occur near the end of life, and the clinician should always be aware of the possibility that ileus, mechanical obstruction, or metabolic abnormalities can lead to a decrease in the number of bowel movements.

A common error in the treatment of constipation is failure to titrate to an effective dose of a single agent. Regular administration of stimulant laxatives (eg, senna, bisacodyl) or osmotic agents (eg, milk of magnesia, sorbitol, lactulose, polyethylene glycol) is often necessary for management of constipation in the terminally ill. Opioids are a major cause of constipation, and as Cicely Saunders [32], the founder of the modern hospice movement, has stated, “The hand that writes the opioid prescription should also write the laxative.” Preliminary studies have shown encouraging results relieving constipation with oral administration of opioid antagonists (in particular, methylnaltrexone, which does not cross the blood–brain barrier).

Skin care

Problems with the skin are most effectively addressed through prevention. The patient should be bathed routinely, with thorough drying to reduce the risk for maceration. Topical antibiotics or antifungals can be used as needed. Pressure increases the risk for ischemia and subsequent skin breakdown. Standard nursing techniques will greatly reduce this risk, although it is important to recognize that the skin is just one more organ system prone to failure in the very late stages of life. When elevation is not required for social interaction or symptom relief, keeping the head of the bed lowered can minimize sacral pressure. Bony prominences should be protected with hydrocolloid dressings. Despite short-term discomfort with turning, most patients are more comfortable overall with regular turning, which also helps to minimize skin breakdown. A “logroll” technique should be used, and a draw sheet will reduce shearing forces. The care of skin wounds that do develop should focus more on comfort than healing. Minimizing dressing changes, use of nonadherent dressings, and attention to odor management are ways to promote comfort [33].

Psychosocial concerns

Psychosocial sources of distress include anxiety, depression, and family needs. All are common issues during the course of an advanced illness, and need not be “medicalized” for all patients. Nonetheless, a substantial number of patients will have sufficient distress to merit interventions beyond simple support.

Anxiety

Anxiety is a common response to the uncertainties involved in confronting one’s impending death, but it may also be fueled by poorly

relieved physical symptoms, such as pain or dyspnea. In addition, it may be a primary psychiatric problem, even one of longstanding duration. Non-pharmacologic interventions include counseling, social services, and directly addressing any specific fears about what happens in the dying process. When pharmacologic management is also needed, chronic anxiety often responds well to a selective serotonin reuptake inhibitor. Benzodiazepines may be needed for some patients, but their potential to increase the risk for falls and delirium should be carefully considered.

Depression

Most patients facing a terminal diagnosis experience a range of sad, angry, helpless, and even hopeless feelings. For many, however, these feelings are temporary, intermittent, or moderate in intensity. Clinical depression is not always easy to identify in terminally ill patients, as many of the standard markers (eg, poor appetite, sleep disturbance, fatigue) may be caused by the underlying illness [34]. Research has suggested that simply asking the question “Are you depressed?” can be an effective method of screening [35]. Dysphoria and anhedonia are also more specific signs of depression. As with anxiety, treatment of depression may include non-pharmacologic and pharmacologic interventions. Psychologic counseling, along with spiritual support, may be valuable, and antidepressants, combined with renewed attention to meticulous management of other physical symptoms, may also contribute to relief for many patients. In severe cases, and with patients very close to death, there may be benefit in a trial of psychostimulants, which will provide faster response to therapy. Standard antidepressants can be started concurrently where appropriate. Mirtazapine may be a particularly useful antidepressant in advanced illness, because of its common side effects of enhanced appetite and improved sleep [26]. A more detailed description of the recognition, assessment, and management of depression can be found in the article by Lawhorne elsewhere in this issue.

Spiritual issues

Regardless of previous spiritual beliefs or practices, most people have spiritual or existential concerns when facing the imminent end of life. Many elderly people address these concerns in the context of an established religion, but increasing numbers will do so in other contexts. Religion and belief in God are not necessarily part of spirituality, which can be defined broadly as an involvement in that which is beyond our normal senses, and which gives life meaning [9,36].

Research suggests that patients want physicians to inquire more about this aspect of their lives, but the extent to which individual physicians are comfortable discussing matters of spirituality varies. At a minimum,

physicians should ask about possible spiritual concerns and should be able to validate common questions that arise, such as “Why is this happening to me?” “What has my life meant—to me and to others?” and “What happens to us after we die?” The physician need not provide answers to these questions, but can help immensely by acknowledging their importance and the frequency with which they are asked at this stage of life. Physicians should not feel that they are expected to pursue discussions beyond their level of comfort; neither should they take such questions as a license to impose their own beliefs or to proselytize. Spiritual care providers may be available from the patient’s own tradition or from hospice programs, hospitals, and nursing facilities. Most chaplains are skilled at working with patients from diverse backgrounds and on each patient’s own terms [34,36].

The active dying process

Care during the last hours of life should be a core competency of every physician, and anticipatory guidance should be provided to all patients and their family members. Guidance about what to expect helps reduce fear and anxiety about the process while also increasing the patient’s confidence. Hospice programs can be invaluable sources of support in providing this guidance, and physicians may also find it useful to devote a family meeting to the topic. Managing the active dying process requires careful planning with the patient, the family, and the care team, with attention to communication plans and the expected symptom management needs. This preparation should also include plans for care of the body after death. Common patient and family guidance needs are outlined in **Box 1**.

Death generally comes as a consequence of widespread systemic change rather than the failure of a single system or organ [9]. Homeostasis in the body is lost and catabolic processes develop, leading to progressive and irreversible decline. Understanding this fact helps in addressing the active dying process more effectively [21]. The individual’s ability to distribute, metabolize, and use drugs may be rapidly impaired, and rapid changes also occur in physiologic parameters. Anticipatory treatment provides the most effective symptom management during the active dying process [33]. All nonessential medications and treatments should be stopped, and for those that are continued, the route of delivery should be re-evaluated. When patients are not able to take oral medications, many medications can still be given by buccal, rectal, or subcutaneous routes; the best route will vary with the individual patient and family. The family should be reassured about hydration issues.

Pain management remains an important goal, but pain may actually decrease at this stage because of decreasing neurologic activity and the buildup of endogenous chemicals with analgesic properties. The major metabolites of opioids are cleared by the kidney, and thus are likely to

Box 1. Patient and family guidance needs to prepare for the dying process*Patient and family tasks*

- Identify sources of available health care support; consider use of hospice care.
- Anticipate symptom management needs and prepare family.
- Facilitate life closure needs.
- Plan for rituals and rites: funeral or memorial service.
- Plan for desired place of death; facilitate home death or plan for other sites.

Family education

- What are common behaviors near death (eg, communication in metaphor and visits from deceased friends and relatives).
- What are the signs that death is near.
- How to recognize that death has occurred.
- What to do after death occurs.

accumulate during this phase. The potential for adverse neuroexcitatory effects, which increase the frequency and severity of terminal agitation and delirium, has led to the recommendation that routine administration be discontinued, and any signs of pain be managed with breakthrough (PRN) doses only [33].

Loss of the ability to swallow and manage secretions is common in the active dying phase. Secretions may accumulate in the oropharynx and the tracheobronchial tree, leading to gurgling or rattling sounds that may be distressing to the family (the so-called death rattle). Anticipatory management is the most effective approach, combined with reassurance to the family that these sounds do not reflect actual patient distress. Started early, anticholinergic medication will minimize the accumulation of such secretions, but will not dry up already established secretions. Postural drainage may be helpful, but suctioning should be discouraged because of its stimulating and painful effects [26,33].

Terminal delirium may present with confusion or restlessness, and may develop into a highly agitated state that is distressing to patient and family. Remediable causes of agitation that may be suspected, such as unrelieved pain or a distended bladder, should be quickly assessed and addressed. Treatment should then focus on muscle relaxation and sedation, which will minimize distress for the patient, family members, and others in attendance. Benzodiazepines are highly effective in relieving this syndrome, with their sedating, muscle-relaxing, and anticonvulsant properties. They can be given and rapidly titrated through the buccal or subcutaneous route.

Occasionally, these agents have a paradoxical effect, and neuroleptics may be required instead. Nonpharmacologic treatment is also valuable: dimmed lighting, soothing music, and gentle touch can be helpful. Family members may also benefit from these strategies. Those attending the deathbed can be encouraged to speak soothingly to the patient. Family members can help ease the final passage by giving the dying person permission to let go, and by giving assurance that those left behind will be all right [26,33].

Other common changes near death, such as mottled skin color and irregular breathing patterns, should be discussed with families. Most hospice programs have handouts that describe these signs of impending death, along with signs that death has occurred.

Immediately after death

When death occurs, the primary focus of care becomes the family. Friends and family members should be encouraged to spend as much time as they wish with the body, allowing them to begin to absorb this profound change in their lives and to say goodbye. Where appropriate, brief preparation of the body may make this process easier for family: removing all catheters, tubes, and machinery; cleaning up any body fluids released; and placing the body in a natural and relaxed position.

Regulations regarding pronouncement of death vary according to state, and physicians should be aware of relevant local and state regulations. Generally, a physician is not required to pronounce death in a case where it was expected, and the hospice nurse may do so. Similarly, restrictions by funeral directors may vary regarding when the death certificate must be signed by the physician. In most communities, there are no specific regulations about when the body must be removed. Families should be encouraged to take as much time as they desire with the body; considerable evidence suggests that spending a longer time than is customary in American society may benefit the grief process.

Grief and bereavement

After the death, family members require time to absorb the loss and its impact on their lives. The acute phase of grief is often intense and requires considerable support. A phone call from the physician in the first few days after the loss is often deeply appreciated, and a condolence card is another welcome expression of support and recognition of the loss. Physicians who had a close relationship with the patient or family may also wish to attend visitation or funeral services. Although most families do not expect this, they are frequently moved by it, and the physician may also find it beneficial for personal closure.

Experts describe four related tasks of grieving that follow the death of an important person in one's life [33]:

- Step 1. Recognize the loss.
- Step 2. Experience the pain of the loss.
- Step 3. Recognize the significance and meaning of the loss.
- Step 4. Reinvest in life; discover what is left.

These steps do not necessarily proceed in a linear fashion from one to the next. The first task has been described as the recognition of the loss. Deeply involved family caregivers often find this step surprisingly difficult, and physicians may hear comments like "I can't believe he is really gone" or "I just can't seem to take it in." The second task in moving through the process of grief is experiencing the pain of the loss. This may be very difficult, and physicians may want to alleviate this suffering with medications. But although pharmacotherapy may be needed for highly agitated, destructive, or severely depressed reactions, drugs should be prescribed with caution. There is significant risk that extended use of medication will prolong the grief process and complicate its eventual resolution.

A further task for those who grieve is to absorb and recognize the significance of the loss and its multidimensional effects on their lives. Finally, bereaved individuals must find ways to reinvest in living and determine what aspects of life—as it was before the death and as it is now—can give it meaning. This phase often has a deep spiritual dimension [33,36].

Modern American society tends to set expectations about the grief process that are at odds with human nature and need. The "acceptable" timeframe for grief is far too short, and the expectations for "getting over it" are unrealistic. Studies of grieving adults show that grief is often an active process for 1 to 2 years after the loss, and that many individuals describe a process of learning to live with the loss as opposed to a "recovery" from it. Normalizing and validating these common responses can be helpful to the bereaved, especially when it comes with the powerful imprimatur of the physician. At the same time, the physician should remain alert for signs of complicated grief that requires more expert management than most physicians are trained to provide. These signs may include intense reactions that do not subside or fluctuate over time; suppressed or postponed reactions; exaggerated or destructive behaviors; and lack of awareness of feelings or behaviors. People experiencing complicated grief need the assistance of a professional who has special expertise in this area. Physicians should identify such professionals in the community and offer referrals to patients who have complicated grief.

Grief support services may be available through local hospices, even for those who did not use the hospice services in many cases. Community-based groups also offer grief support, and the surviving spouse of an elderly patient may particularly benefit from participation.

Summary

Caring for elderly patients and their families at the end of life gives physicians the opportunity to have a meaningful impact on the lives of others. By expanding our clinical expertise beyond the arena of cure and the preservation of life, we can discover new ways to encounter our patients as full human beings and to share a profound life passage that many of us might otherwise ignore. The skills that are needed to enter this new arena are well within the grasp of the office-based clinician, and physicians who employ them are rewarded with the fulfillment of knowing they have provided an invaluable service at a time of greatest need.

Further readings

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