Palliative, Hospice, and End-of-Life Care and OBRA Regulations

If you can’t describe what you are doing as a process, you don’t know what you are doing.
—W. Edwards Deming

The ongoing coronavirus pandemic has again brought the issue of managing death and dying in the nursing home to the forefront. This month’s column will review regulatory expectations regarding palliative and end-of-life care and explore some key issues in the implementation of end-of-life and hospice services.

OBRA Regulations and Palliative and Hospice Care
It is instructive and important for all nursing facilities and medical practitioners to know what the regulations and surveyor guidance say about end-of-life and hospice care. There is confusion about the topic and room to improve current practices related to advance care planning and end-of-life care.

The Omnibus Budget and Reconciliation Act (OBRA) regulations and surveyor guidance (F680) expect the facility and the resident’s attending physician/practitioner, to the extent possible, to identify a prognosis and the basis for that prognosis, and initiate discussions/considerations regarding advance care planning and resident choices to clarify goals and preferences regarding treatment including pain management and symptom control, treatment of acute illness, and choices regarding hospitalization. Hospice services are not mandated, but facilities are expected to help residents gain access to hospice services, if desired.

If hospice services are used, the regulations require close coordination between the facility and the hospice to ensure adequate communication and safe and effective patient management. The surveyor guidance points out areas where hospice may (but does not automatically) retain primary responsibility: for example, providing medical direction and management of the resident; assigning a hospice aide as needed to support the resident’s ongoing care; counseling (including spiritual, dietary, and bereavement); and durable medical equipment. There are expectations for timely communication and close coordination between the hospice and the nursing home regarding the care plan and mutual resolution of any related issues.

On paper, this all sounds good. However, tightly coordinated, safe, and effective hospice care only happens sometimes. As noted in previous columns, all care (including the approach to end of life) must respect the fact that all organ systems and conditions interact and cannot be managed in silos. Pain must be treated in the proper context, including recognizing the potential adverse as well as positive impact of analgesic regimens on the patient as a whole.

Palliative Care
As with so many other sensible and simple ideas, palliative care and hospice have become increasingly complex and often confusing. Various terms are used to consider limited care, including “palliative,” “end-of-life,” and “comfort” care. As stated in the attending physician’s curriculum (Module 2-4) of AMDA – The Society for Post-Acute and Long-Term Care Medicine, “Regardless of terminology, the ultimate objective is a patient-centered plan of care that reflects patient values and wishes combined with effective determination of condition and prognosis.”

It has been recognized that many people can benefit from reduced medical interventions and palliative measures even though they are not at the end of life. Palliation can have various meanings, ranging from partially aggressive care to suppression of symptoms only. Not all palliative care is end of life, and it should not be seen as such. Hospice care is a subset of palliative care, not vice versa.

The Hospice Concept

Hospice is a palliative care program that focuses on management toward the end of life. Its underlying premise is that people who are at or very near the end of their life expectancy should be kept comfortable and not receive aggressive medical tests or interventions intended to cure serious acute illness or prevent progression of chronic conditions. While hospices provide a comprehensive package of support and services well beyond medical treatment, pain and symptom management are a standard component.

As originally defined, hospice was intended as a program for individuals who have a life expectancy of less than six months. Over time, however, hospice programs have expanded their reach to encompass more individuals whose death is not imminent.

Simple Diagnostic Efforts
An artificial distinction is often made between palliative care as symptomatic relief and “curative” care as “prolonging life.” It all depends on the patient and the situation. Goal-oriented care does not necessarily correct the underlying conditions; often it is appropriate to stabilize them and minimize the damage they cause.

There is a common misconception that hospice or palliative care implies only symptomatic treatment, and that any kind of diagnostic effort is inappropriate or undesirable. However, there is often a need for competent diagnostic efforts in patients who are receiving palliative care as well as in prospective hospice candidates and many of those who are actually enrolled in hospice care.

For prospective hospice patients, diagnostic effort is needed to ensure that they actually are terminally ill and not simply suffering from undiagnosed or mismanaged medical illnesses or very common medication-related adverse consequences. It is imperative to guard against hospice referrals for inappropriate reasons such as misdiagnosed delirium. For another example, patients who have swallowing problems should not be told they must go on hospice if they decline recommendations to restrict their oral intake or modify their diet and fluid intake (J Am Med Dir Assoc 2019;20:952–955).

For hospice patients whose death is not imminent, clinical reasoning and a simple diagnostic effort often have an important place as a “comfort measure.” Treating a medical condition or symptom correctly can improve comfort and relieve distress in hospice patients, even if it does not necessarily prolong their life. Most diagnoses are made on the basis of history rather than any testing, by obtaining and using relevant details to draw conclusions (LeBlond, Brown, and DeGowin, DeGowin’s Diagnostic Examination, 9th ed. McGraw-Hill, 2008).

For example, it is vital to identify and treat the underlying causes of behaviors and psychiatric symptoms — including in hospice patients — as opposed to just giving patients incorrect medications that cause side effects that increase their distress, which are in turn chased with other medications (Caring 2020;21[3]:P14–15). Medication-related adverse consequences are extremely common and often are highly debilitating and distressing, including in hospice patients (Caring 2020;21[5]:P18).

Nothing should stop us from maximizing comfort and improving quality of life by treating symptoms and conditions properly and minimizing serious medication-related adverse consequences. We should all stop splitting hairs about such things and get back to the basic.

Hospice Interventions, Including Medications
There is no valid reason to exclude palliative or hospice interventions from critical scrutiny about the appropriateness of care. As with all medications in nonhospice patients, a treatment should be indicated and helpful without causing major adverse consequences.

An interesting and widespread practice is the routine use of the so-called hospice comfort pack. A typical comfort pack includes any or all of the following: an opioid (e.g., morphine sulfate, fentanyl, oxycodone), a benzodiazepine (e.g., lorazepam, alprazolam, or clonazepam), an antipsychotic (e.g., quetiapine, haloperidol), an anticholinergic (e.g., hyoscyamine, atropine), an antiemetic (e.g., metoclopramide, ondansetron), and other assorted medications (e.g., hydroxyzine).

Although rapid and aggressive medication interventions should be available for those who are suffering from severe complications of untreatable conditions or who take a turn for the worse toward the end of life, implementing a comfort-pack cocktail as soon as hospice services begin is not justified. Standing orders for as-needed medications such as morphine, lorazepam, and haloperidol are often problematic for patients who are not terminal because the staff have limited ability to understand their appropriate use and cannot differentiate treatable from terminal causes of symptoms.

The idea that opioids and other hospice medications are somehow inherently “humane” is just as erroneous as the misconception that antipsychotic medications are somehow inherently “evil.” They may be helpful for severe pain and for dyspnea (breathlessness) or other distress in imminently dying individuals, but they all have substantial and often severe side effects, especially in various combinations. Many of them cause severe behavioral and psychiatric syndromes (Med Lett, Dec. 15, 2008; https://secure.medicalletter.org/w1301c), which are often chased by giving more medications with major adverse consequences until the patient is sedated.

For example, opioids are often not indicated and are ineffective for chronic noncancer pain (Ann Intern Med 2015;162:276–286), and pain in patients

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with cancer is not necessarily due to cancer. So it is not more humane to put people on opioids when they go on to hospice for conditions that do not warrant opioids. There is no reason why someone who was receiving adequate analgesia with acetaminophen on Tuesday when not on hospice would automatically be put on morphine every two hours as needed for pain when hospice takes over their care on Thursday. Furthermore, when pain does not respond readily to opioids, it is not more humane to keep adding more opioids or to increase the dosages, leading to severe and unnecessary side effects. Although dyspnea at the end of life may be ameliorated by morphine, breathlessness at other times is often due to readily treatable causes — it should not be managed automatically with morphine.

In addition, we must be aware of the possibility that we are hastening death by causing severe medication-related adverse consequences that lead to anorexia and delirium, which are in turn chased by additional medications and dosages, leading to a rapid downward spiral and death. Palliative sedation at the end of life is a legitimate intervention, and such complications may be of less concern in cases of intense suffering due to incurable illness and at the very end of life. However, the unwarranted or excessive initiation of the hospice cocktail can easily lead to a very troubling situation: death hastened by drugs, not by illness, in people whose death was not otherwise imminent. We must ensure that decline and death do not become a self-fulfilling prophecy (J Am Med Dir Assoc 2020;21:1359).

The Difference Between Concepts and Programs

It is our duty to see that all individuals, including those with limited life expectancy and who are at the end of life, get appropriate, effective, and cost-effective care that does not cause harm while intending to do good. We can do that effectively by consistently following a specific decision-making process in all situations (J Am Med Dir Assoc 2000;1:77–85).

We must not confuse hospice and palliative care as concepts with hospice, the commercial or noncommercial enterprise. For various reasons, being on hospice no longer necessarily implies that a person is terminally ill or that death is imminent. Hospice care can cost anywhere from approximately $5,000 to $10,000 monthly, depending on the setting, and may be unnecessarily complicated and costly, regardless of whether Medicare covers it. There is great danger of hospice care transforming into an expensive, unwieldy, and overused service with no effective controls because people confuse the concept with the actual implementation.

In practice, we have a duty to oversee hospice implementation in our nursing homes and collaborate with hospice staff and practitioners in all aspects of care — including pain management — for the good of the patient. We should focus on understanding the processes fully and not get hung up on the words (palliative, hospice, etc.). All hospice services, including but not limited to medication regimens, must be fully coordinated with the overall care plan and the existing medication regimen. All aspects of care plans must be individualized, based on the condition and needs of each patient. We should apply the same principles in caring for and overseeing care of hospice patients as for nonterminal patients. We must avoid cookie-cutter approaches, even while recognizing that there are situations where complications of treatment are secondary to other considerations.

Ultimately, with modest adjustments in interventions and the care plan, it is possible to provide decent basic palliative and end-of-life care for many individuals without involving a hospice. As in all aspects of care, more interventions and services are not necessarily better.