UNDERSTANDING COMORBIDITIES AND TREATMENT OPTIONS IN HOSPICE CARE

By Crossroads Hospice & Palliative Care
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No two hospice patients are the same. This statement underscores the complex nature of caring for someone who suffers with a progressive, terminal illness. In the hospice setting, determining a plan of care (POC) for a patient should be intensely individualized. No two patients will present, or will be viewed, in exactly the same manner. An extensive understanding of the disease process — coupled with a strategic team approach to communications — is required to ensure a hospice patient with comorbidities is appropriately managed.

How prevalent are comorbidities in hospice? How fluent is the medical community in the language of comorbid disease? What are the implications for the patient and family? What are best practices for providing care given the confusion comorbidities bring to the discussion? This paper covers these and other subject areas, drawing attention to important considerations regarding this multi-faceted subject.

Understanding Comorbid Conditions in Hospice

In 2012, an estimated 1.5 to 1.6 million patients received services from hospice and the number of patients and families served by hospice has steadily increased — growing from 1.2 million in 2008. When hospice care in the U.S. was established in the 1970s, cancer patients made up the largest percentage of hospice admissions. Today, cancer diagnoses account for less than half of all hospice admissions (36.9 percent).1 Currently, less than 25 percent of U.S. deaths are now caused by cancer, with the majority of deaths due to other terminal diseases.2

The top four non-cancer primary diagnosis for patients admitted to hospice in 2012 remained debility unspecified (14.2 percent), dementia (12.8 percent), heart disease (11.2 percent), and lung disease (8.2 percent).1 Other non-cancer diagnosis include stroke, kidney disease, liver disease, Amyotrophic Lateral Sclerosis (ALS), and HIV / AIDS.

With patients continuing to present with a wider range of illnesses, it is not surprising the process for determining adequate care and exceptional symptom management has become more complex. Healthcare providers make decisions about treating comorbid conditions in hospice patients each day, quickly and deliberately — with the decision often appearing effortless to the patient and the family. But what goes into each individual decision is as intricate as it is important. There is much more to the determination process than meets the eye. With the comorbidities topic a complicated one, the natural starting point is a basic understanding of definitions.

A primary diagnosis is the terminal condition that makes a patient eligible for hospice. A primary diagnosis is directly tied to a specific disease such as ALS or cardiac disease, for example.

A comorbid condition is one that exists simultaneously but is independent of the primary diagnosis. Often times, the comorbid condition can be considered terminal in its own right. Consider the stroke patient who also suffers from liver disease. These conditions directly contribute to a patient’s terminality.

A secondary (or related) condition is one that is a complication of, and/or occurring as a result of, the primary condition. An example is hypertension with cardiac disease, or diabetes with renal disease.

How prevalent are comorbid conditions among patients receiving hospice care? Hospice patients have an average of 3.3 diagnosis1 when they are admitted to a hospice program. At the time of the U.S. Department of Health and Human Services’ National Health Statistics Report, the most common hospice diagnosis was malignant neoplasm (46.4 percent). Following closely behind were heart disease (32.2 percent), congestive heart failure (15.4 percent), essential hypertension (23.5 percent), dementia (21.3 percent), chronic obstructive pulmonary disease and allied conditions (14.8 percent), diabetes mellitus (12.2 percent), and cerebrovascular disease (10.9 percent).3

Determining Treatment

"Is this a hospice-covered therapy?" The question is asked by healthcare providers in hospice settings daily. According to the Centers for Medicare & Medicaid Services (CMS)4, "drugs and biologicals related to the
palliation and management of the terminal illness and related conditions, as identified in the hospice plan of care, must be provided by the hospice while the patient is under hospice care.

However, hospice does not cover therapies used to cure rather than palliate the terminal illness and its secondary (or related) condition. Hospice also does not cover therapies used to treat a patient’s non-related comorbid conditions. The CMS cites the Final Rule from the original Hospice Rule in 1983: Hospices are responsible for all care of the patient related to the terminal prognosis (not diagnosis) and the related conditions. The ruling further reads, “Unless there is clear evidence that a condition is unrelated to the terminal prognosis, all services would be considered related. It is also the responsibility of the hospice physician to document why a patient’s medical need(s) would be unrelated to the terminal prognosis... determination of what is related versus unrelated to the terminal prognosis remains within the clinical expertise and judgment of the hospice medical director in collaboration with the IDG.”

The POC should identify the condition being palliated. If the condition is a result of multiple organ system dysfunction or disease states, then services and medications provided by the hospice to manage these conditions would be related to the terminal diagnosis. In theory, a cancer patient with cardiac disease could receive blood pressure medication if indicated. But these decisions are rarely simple ones, requiring clinical expertise and judgment, including collaboration from other IDG members. Armed with tools and data, the IDG can begin a conversation which will lead to decisions that will continue throughout the patient’s hospice journey. Individualized decisions must be made beginning with two initial 90-day recertification periods. Following the initial 180-day period, recertification must occur every 60 days for as long as the patient receives hospice services. In all cases, physicians are involved in the discussion and are required to sign off on decisions.

The challenges can be many for physicians seeking to make appropriate treatment determinations for the patient and within hospice rules and regulations. For one, it can be difficult to determine the terminal illness when the patient presents with multiple conditions. What’s more, it is not unexpected that the primary diagnosis will change while the patient is receiving hospice services. Key questions physicians need to ask: What is the aim of the intervention? How does the primary disease behave with and without intervention? What about comorbid conditions? How does the primary disease usually progress over time? How about for comorbid conditions? What is the likelihood of acute deterioration if treatment is reduced or withdrawn?

Impact on Patient and Family

Faced with the reality of a terminal illness, the hospice conversation can be a daunting one for patients and families — and physicians alike — to have. With the complexities of what will and will not be treated and how aggressively an illness will be treated, the result can be an overwhelming sense of confusion and frustration. When the focus shifts from curative care to comfort care, there will be many questions and concerns. Patients will be further confronted with the realities of mortality. Inconsistent advice may lead to difficulties with trust and compliance. And there may be feelings of abandonment by the medical community accompanied by feelings of despair.

Open communication and candid conversations have been proven to go a long way in helping patients and families understand not only the purpose of hospice care but also the role of healthcare providers in determining treatment and the comforting role of hospice on the clinical course of the illness. To be effective, these conversations should be started at the time of initial diagnosis and continue throughout the disease journey. This practice helps patients and families better understand how, when, and why treatment will be administered thereby easing what is typically a heavy emotional burden.

Healthcare Professionals Best Practices

In order to lessen the impact on both patient and family, all healthcare professionals that are part of the IDG — including the patient’s personal physician, hospice physician or medical director, nurses, nurse practitioners, and therapists — need to open a line of communication and keep it open. It is important for the hospice organization, family, and physician to function as a true team in ensuring decisions are made based on accurate data and all are aware of the decisions and implications for the patient.
Diagnoses and conditions can change. A comorbid condition could become the primary condition. A secondary condition could improve. Changes need to be monitored and communicated as they happen with a clear understanding of what should happen next explained to all parties involved.

Healthcare professionals on the front lines are called on to gather data, seek clarification, and be up to date on hospice rules and regulations. As such, they need a comprehensive knowledge of hospice-approved diagnosis and covered secondary conditions as well as an understanding of what therapies are and are not covered depending on each situation.

Managing comorbidities in hospice patients is no easy undertaking. Developing an individualized POC requires a comprehensive understanding of the comorbid conditions, the ability to monitor and react appropriately as conditions change, and a strategic plan for communicating with the clinical team as well as the patient and family members.

References
1. 2012, National Hospice and Palliative Care Organization (NHPCO) National Data Set and/or NHPCO Member Database.
4. § 418.106 Drugs and Biologicals, Centers for Medicare & Medicaid Services.
5. Palmetto GBA, October 12, 2012 – Hospice Coalition Q & A.