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A Hospice Dilemma
Commentary

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Abstract

Hospice has undergone a metamorphosis sense it's coming to the United States in the late 1970's.

This is an opinion on the ethics of the dynamic changes that are occurring.

Keywords: Nursing, Hospice

Since its emergence in the United States in the 1970's, Hospice end-of-life care has evolved from a volunteer driven program of care for dying cancer patients to a multi-million dollar business. There is more for-profit than not-for-profit hospices, with more and more seeking licensure. For many, hospice has become a lucrative business opportunity rather than a service oriented operation. We all know that for viability, a business should be profitable, but to what extent? What does the "business of hospice" mean for end-of-life care?

There is a rise in the length of stay due to the unpredictability of death for the added non-cancer terminal diagnoses: such as COPD, Alzheimer's, failure to thrive, and dementia. Unfortunately, the unpredictability has become an excuse for some agencies to admit too early and discharge at the 180-day mark. Admission to hospice is based on the assumption that death will occur within 6-months if the diagnosis follows a natural course. Do some patients who meet admission criteria for hospice care live beyond the 6-months? Of course they do; but most do not. What the untimely admissions mean to the patient and family is that when hospice care is truly appropriate and needed, it may not be available for them. Additionally, the extended length of stay has increased the total reimbursement allowed by Medicare for each patient, know as the CAP (daily rate x 180 days), which has put hospices on notice with Medicare and influenced other payers. Does this mean that patients with non-cancer diagnoses should be denied hospice care?

States are reevaluating licensure criteria to improve the standards at the same time the Centers for Medicare and Medicaid Services (CMS) has revised the Conditions of Participation (COP). These efforts are to ensure that all providers are delivering quality hospice care. CMS is

reviewing hospice reimbursement because of the rapid growth in hospice claims. Troubled state Medicaid programs are also looking at hospice reimbursement as a possible safety net. If these entities cut hospice reimbursement, who will pay for hospice care?

Too many hospices say they provide all the mandated services – medical care, nursing care, services of a home care aide, social service care, spiritual care, assistance with medications and supplies related to the terminal diagnosis, and bereavement services – but in actuality they do not. When addressing the public on what the mission of hospice "really is" and what hospices "should provide", too many caregivers and patients say their hospice provider did not measure up. Does the disparity in care from one hospice to another put a black mark on all hospices?

These troubling issues and questions concern hospice providers who work daily to provide the best possible care within the guidelines dictated by federal and state authorities. The frustration arises when confronted with hospices that are more involved with the bottom line than the front line. To answer the first question, we cannot let the "business of hospice" be the end to hospice. Quality end-of-life care is too important and much needed in our society. Should patients with non-cancer diagnoses be admitted? Of course they should. Careful assessment and monitoring of the progression of the disease is needed to ensure a timely discharge, if needed, so that hospice days remain for the time when needed most. Hospices and licensing agencies must police hospice care to ensure that programs meet the standards so that reimbursement for all eligible patients will be there when needed. And finally, the disparity in hospice care is a great concern for providers and payers. It is heartbreaking to hear a patient or caregiver say, "The hospice we had said I could not have that kind of pain medicine."

Does the ethical principle of "do no harm" apply to hospices that mislead the public for profit and place hospice as a provider benefit on the watch list for reimbursement? You may argue that no physical or mental harm exists, but doesn't the lack of care harm cause harm? What if hospice did not exist to provided needed end-of-life care for individuals? As our baby boomer population comes of age, more and more people will need quality end-of-life care. Without a hospice benefit and the supportive professional care to dying patients and their families, harm is a result.

There is no greater gift for a professional caregiver than to offer comfort and care to the dying and their families. No other service can provide the care needed better than hospice. Hospice organizations are doing all possible to educate the public on what hospice service really is and what hospices should provide. When referring patients, professional providers and caregivers need to ask these questions at a minimum:

- What services does your hospice provide?
- Do you have a nurse on call and available 24/7?
- How long does it usually take a nurse to get to a patient's home in cases of symptom management or death?
- Do you have 24/7 pharmacy services?
- What supplies and medications do you provide?
- What caregiver support do you offer?
- Do you have physician support available 24/7?
- Do you have home care aids available daily, if needed?

- Do you offer spiritual and psychosocial care?
- How often does the chaplain or social worker visit?
- Do you have volunteers who visit?
- Do you have bereavement care and support after the death?

If you are not satisfied with the answer to these questions, call another hospice. If the chosen hospice provider fails to provide the services promised, question the hospice. If in doubt about what hospice should provide, look online, go to the library, call your state's Department of Health, or call your state's hospice organization. There are many resources that examine and discuss the mission and goals of hospice care and what providers should offer. As health care professionals, we must not let this valuable service be jeopardized.