Misunderstanding of Palliative Care Leads to Preventable Suffering

“Identity Problem” As Public, Patients, and Doctors Confuse Palliative Care with End of Life Care

A new review says palliative care’s association with end of life has created an “identity problem” that means the majority of patients facing a serious illness do not benefit from treatment of the physical and psychological symptoms that occur throughout their disease. The editorial is co-authored by palliative care experts at Harvard Medical School, Massachusetts General Hospital, the American Cancer Society, and Johns Hopkins University, and appears in the New England Journal of Medicine The authors say palliative care should be initiated at the same time as standard medical care for patients with serious illnesses, and not brought up only after treatment has failed.

The authors say for palliative care to be used appropriately, clinicians, patients, and the general public must learn the fundamental differences between palliative care and hospice care, a distinction that is not well-known. Seven in ten Americans describe themselves as “not at all knowledgeable” about palliative care, and most health care professionals believe it is synonymous with end-of-life care. While both are intended to relieve suffering, hospice care provides care for people in the last phases of an incurable disease so that they may live as fully and comfortably as possible. Palliative care focuses on helping patients get relief from symptoms caused by serious illness and is appropriate at any age or stage in a serious illness. (For more information, see: "Palliative Care" on cancer.org.)

Adding to that is the fact that debates over “death panels,” physician-assisted suicide, and other factors have made policymakers reluctant to devote resources to initiatives perceived to be associated with death and dying. The authors point to lower levels of government funding for palliative care research compared to funding for other specialties.

“The practice and policy behind palliative care must be considered independently from end-of-life care,” write the authors. “Palliative care should no longer be reserved exclusively for those who have exhausted options for life-prolonging therapies.”

The editorial presents clinical, economic, and political cases to show the value of earlier palliative care, and use them to propose initial priorities for clinicians and policymakers to integrate early palliative care into practice. The authors say implementing earlier palliative care would not only improve quality of life, but would also reduce spending and help patients with advanced cancer clarify their treatment preferences. And evidence shows patients who are given palliative care early on even have better outcomes.

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