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***What Price Compassion?
Rethink 'terrible choice,' remove hurdles to hospice care***

By Richard Payne, MD

Art Buchwald, the 80-year-old, Pulitzer-Prize winning columnist, recently was honored by the National Hospice and Palliative Care Association for his outstanding support of the hospice movement. Buchwald, who has chosen to quit kidney dialysis, expects to die in the Washington, D.C., hospice where he has resided since early this year. The famed journalist has spoken powerfully and publicly on the importance of hospice care for himself and for countless other Americans.

Unlike many people in this country, Buchwald chose hospice care well in advance of his expected death. This has allowed him, along with his family, to realize the full benefits of the compassionate, end-of-life caring that hospice provides. He made the decision that the quality of his remaining life would be better without dialysis -- and in hospice.

Annually, 2 million Americans are eligible for hospice services given their medical circumstances, yet only half as many choose this type of care. And although the Medicare hospice benefit typically can last up to six months, the median length of stay in hospice programs is only about three weeks. More than a third of the patients who choose hospice care do so in their last week of life.

By not choosing hospice, or by choosing it later than necessary, many people near the end of their lives are giving up a remarkable system of care and support. Most hospice services are administered in the familiar and loving setting of the home, where doctors, nurses, social workers and chaplains work as a team to attend to the needs of each patient as well as family caregivers.

Hospice is particularly effective in controlling pain and other symptoms associated with advanced illness. Practitioners are trained to respect the wishes of patients and families and to focus on care that achieves the highest possible quality of life. This is best accomplished when the patient and family have time to establish a relationship with the hospice providers, though, and it is much more difficult to do well when entry into hospice is just a few days prior to death.

Given these benefits -- and the testimonies of many patients who, like Buchwald, choose hospice -- why do thousands of dying Americans refuse or delay entry to hospice programs each month?

Among other reasons, we live in a culture that glorifies youth and vigor, often denying the reality of aging and death. Many people who are near death find it difficult to acknowledge their mortality, let alone take action.

Further, to elect the Medicare benefit, patients are required to make the so-called "terrible choice." This requires them to acknowledge that they are dying and agree to forgo hospital-based treatments such as surgery and radiation therapy, unless justified to maintain comfort. Most patients and families are not willing to make such decisions until death is almost upon them, hence the short hospice stays.

Several policy changes discussed in recent years could help many patients overcome their reluctance and the financial difficulties that now prevent them from receiving adequate care with the help of hospice.

For a start, Medicare eligibility could be based not solely on the prognosis that death is likely within six months, but rather on the patient's needs for aggressive pain and symptom management, coordinated care and conversation between doctor, nurse, social worker and chaplain for specific services. Patients would be more likely to accept care, and to have longer, better hospice experiences, if they did not have to formally declare that they expect to die in a few months and that they will not seek any further medical treatment.

Creating more efficient, visible pathways to hospice care from hospitals and nursing homes would help as well. This would require more coordination within health-care systems and more training for doctors to recognize and affirm the needs of terminally ill patients. Faith leaders can play a role by encouraging conversations about hospice and end-of-life care in their churches, parishes, mosques and other places of worship. The result should be a better informed public in which people know when and how to choose hospice if this is right for them.

Since moving into his hospice, Buchwald has quipped that "dying is easy." But he and family members also publicly acknowledged the difficulty and complexity of coming to terms with his death. His wisdom in choosing early entry into hospice will make his remaining life more satisfying and increase his chances of truly dying well. All Americans who are nearing death should be so fortunate.

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