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The “Good Planning Panel”

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In “Avoiding a Death Panel Redux,” Nicole Piemonte and Laura Hermer make the argument that the advance care planning consultation provision during the health care reform debate collapsed both because the language in the provision was deliberately misread and because some features of the language could in fact be misleading. We agree on both counts. We add that the cost-effectiveness provisions of the bill make us face difficult decisions we as a nation would rather avoid, but can and must face squarely and together.

It is time for an honest national conversation about at least two issues concerning medical care near the end of life. First, talking about or planning a good death with your doctor or nurse will not make death happen sooner. The data show that better planning for a well-managed terminal illness leads to longer life as well as better symptom control and less distress. Second, we need to quickly and directly confront the cost of end of life care in the United State, recognize the political consequences, and work with the broad middle to advance the common good. End of life care is becoming more intensive and more expensive, but sometimes without achieving commensurate medical benefit. Spending time in the intensive care unit in the last thirty days of life is increasingly common for Medicare-age people who die; 29 percent use the ICU in the last month of life, and only 42 percent of patients with a terminal illness use hospice at any time during their death.[1] And as we wind down that intensive care, 14 percent have a change of health care venue for their in the last three days of life—from hospital to home or hospital to inpatient hospice, for example—probably the worst time to disrupt families.

Let’s rename the “death panel” “the good planning panel.” Hospice care has been strongly associated with increased survival in several studies,[2] and not a single study has shown worse survival. Palliative care also appears to have the “good planning panel” effect of maintaining or even prolonging survival.[3] The data strongly support that people live longer if they have their symptoms controlled, plan for all eventualities (including death), and start working on issues like life review and legacy to preserve dignity. People who complete an advance directive before bone marrow transplantation show double the chance of survival of those who have not.[4] So, we can scientifically lay to rest one of the death panel arguments—that asking patients and doctors to discuss these difficult issues will force people to die sooner. It might make some of us confront our mortality and think about how we might die, but that is almost universally accepted as a good measure of high-quality care and advocated as personal responsibility. This might reduce the percentage of Medicare-age dementia patients who (probably contrary to what they wanted) are in the ICU in the month before they die.

“Good planning panel” interventions have other benefits as well. People who receive palliative care concurrently with curative care have less depression, better quality of life, and better communication, in addition to equal or better survival—and less distressed caregivers.[5] People who talk with their doctors and nurses about death have no more anxiety and depression and better quality of care.[6] People whose spiritual needs are addressed by the medical team have better satisfaction,[7] fewer in-hospital deaths,[8] more hospice use, and better quality of life scores.[9] It's time that we stamp "the good planning panel" imprimatur on all the information pertaining to hospice and palliative care.

The second issue we must address in a national conversation about end of life care is the cost of that care. About one-fourth of all Medicare dollars are spent in the last year of life, and 40 percent of that is spent in the last month of life—at least 8 percent of all Medicare dollars.[10] Although the end of life is a difficult place to think about monetary restraint and value, it is critical to address these issues. We have a lot of new and expensive advances in treatment across the life span, and we need to find room within the current system to pay for them. Better end of life care will actually save money. If most people want to die at home—and most do—we should be able to make that happen by directly addressing the reasonable expected medical outcomes of treatment in the last several months of life. Decision aids to address the issues of transitions are available and endorsed by some professional societies.[11]

The cost savings due to better end of life care are substantial. The average person who uses hospice saves Medicare $2,600 to $6,400 depending on how long hospice is used compared to usual care.[12] Aetna estimated that it saved 22 percent in the last forty days of life when it expanded its definition of hospice and allowed concurrent and palliative care—with far fewer hospitalizations.[13] Kaiser estimated it saved $4,800 to $7,000 per person with an interdisciplinary palliative care team added to usual care.[14] Having palliative care involved increases the number going home with hospice and reduces re-admissions, with attendant cost savings.[15] The number of dying patients who use hospice stands at 45 percent;[16] doubling that would save enough to allow the purchase of many new treatments.

None of these changes will rid us of the necessity, at some point, to use cost-effectiveness (or some definition of value) to make decisions about health care. In that case, the Sarah Palins of the country have it at least partly right. Somebody has to make decisions about what we can and cannot afford as a society.

Take lung cancer as an example of how better communication and more standardized care is needed. Currently, only 31 percent of patients with incurable lung cancer understand that they cannot be cured with chemotherapy.[17] Half of all patients with terminal lung cancer have not heard a mention of hospice from their doctors, even just two months before death,[18] because oncologists prefer not to bring up hospice until no more treatment options are left.[19] Oncologists will not give estimates of survival or, if they do, give overestimates,[20] despite six-month survival being relatively easy to predict.[21] As a result, fourth- and fifth-line chemotherapy is given despite little chance of benefit, thereby delaying hospice and raising costs.[22]

There are solutions. There are clinical pathways that use the best available treatments but emphasize generic drugs, restrict treatments to those based on solid evidence, incorporate more use of advance directives, and refer patients to hospice earlier. Patients' survival is the same or better, hospice use is increased, and cost is reduced by one-third.[23]

We are in a period of major cultural distress in which we simply do not trust others to make those decisions. We are also in an era of entitlement, in which we feel that the system should provide everything for us. But of course, decisions to limit costs are being made every day; they are simply made on or by individual patients, or by private intermediaries for each of the Medicare regions, and for all insurance plans. This mistrust and lack of a sense of common good has no easy fixes. A start would be to acknowledge that resources are finite, that some decisions to limit the consumption of resources are inevitable, and that "value" should therefore play an important role in how we spend this country's limited resources.

There are only a few ways to change health care professionals' behavior: change beliefs, change culture, or change incentives. Paying physicians to sit down with their patients and have these most difficult discussions would seem to be important for all three. Change is hard, and supporting patients and families with their providers to do good planning is sorely needed.

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