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POLICY FORUM

Legislative Attempts to Improve End-of-Life Care in New York State

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The development of cardiopulmonary resuscitation, mechanical ventilators, minimally invasive techniques to place feeding tubes, and other technological advances has resulted in radical changes in the myriad ways people with chronic progressive illnesses live their lives and receive medical care. The possibilities for technological intervention increase as patients enter the final stages of their lives. Our society has grappled with the questions of how best to care for patients with terminal illnesses, and the specialty of hospice and palliative medicine has developed in part from a consensus that we could do a better job caring for patients at all stages of their illnesses, but especially at the end of their lives.

Going back to the SUPPORT studies in the 1990s, we know that patients' goals for their care were frequently not clear to treating physicians. Surviving family members reported that symptoms were not optimally treated at the end of life and that bereavement could be complicated by memories of loved ones dying with uncontrolled pain or dyspnea. Treatments patients received often failed to correlate with statements of their preferences and advance directives [1]. The location of the majority of deaths (hospital or home) did not correlate with surveys about where patients stated they would like to be when they died [2, 3]. Families struggle to provide patients with the practical care they need and may impoverish themselves doing so for relatives with chronic progressive, eventually fatal, illnesses. High rates of resource utilization in the last month of life are illustrated year after year in the Dartmouth Atlas studies [4].

Many efforts to improve end-of-life (EOL) care have come from within the health care professions, but even these efforts have generally been felt to be inadequate to ensure that all patients get end-of-life care that is efficient and satisfying to them and their families. Recently states [5-8] have begun to implement legislation and regulations aimed at improving end-of-life care. This article examines some of those initiatives in New York State and discusses their impact and the mismatch between these efforts and the actual barriers to optimizing end-of-life care in practice. Recent initiatives in New York state include the Palliative Care Information Act [5], The Palliative Care Access Act [6], and The Hospice Modernization Act [7], among others [8-10]. While each of these has potential to improve end-of-life care, each also, sadly, misses the mark in a key way.

Attempts to Better Inform and Identify Patients

The Palliative Care Information Act (PCIA), passed in 2010, effective in February 2011, and amended in 2012, requires that physicians and nurse practitioners

offer to provide information to patients about (1) the full range of treatment options available to them if they have a terminal illness, defined as a medical condition with an anticipated survival time of 6 months or less, (2) their prognosis and (3) the risks and benefits of the various treatment options as well as (4) the patient's legal rights to comprehensive pain and symptom management at the end of life [5].

The legislation was sponsored by a nonprofit advocacy group called Compassion and Choices that is "committed to helping everyone have the best death possible" [11]. The group offers free counseling, planning resources, referrals, and guidance and works throughout the U.S. "to protect and expand options at the end of life" [11] (including physician-assisted suicide) by advocating for legislation and assisting in court cases that support its agenda. Compassion and Choices sponsored similar legislation in California called The Terminal Patients' Right to Know End-of-Life Options Act, which passed in 2008 [8]. The California legislation is more prescriptive in detailing the specific treatments about which physicians are obligated to inform patients, including voluntary cessation of eating and drinking and palliative sedation, but does not require them to offer the information unless a patient asks about it.

A key distinction between palliative care and hospice is that palliative care is triggered by symptom burden and not by prognosis. It can be appropriate at any point in the course of a chronic progressive illness when symptoms are inadequately controlled and additional psychosocial support is needed. The name "Palliative Care Information Act" is a misnomer—it is really an *end-of-life* care information act—its provisions are triggered by a 6-month prognosis. The law legislates the physician's basic obligation to engage in an informed consent discussion with patients when changes in treatment are contemplated, emphasizing that this obligation applies to patients with a prognosis of 6 months to live or less.

The law was deemed necessary because, for example, most physicians do not have a formal informed consent process with signed documents when changing end-stage congestive heart failure patients from one oral medication to another, and as a result it is difficult to know whether such a counseling takes place. The presumptions of the law's sponsors were that physicians don't discuss the range of options with their patients with advanced disease, that this is a more urgent problem than failure to discuss it with patients at earlier stages in illness, and that patients get poor end-of-life care because they are inadequately informed about options like hospice and hospital-based palliative care and their right to refuse unwanted treatments. If only patients were aware of these options, the thinking goes, they would choose them, and they would get more suitable care at the end-of-life. It seems almost intuitive that if patients were better informed more of them would enroll in hospice and enroll

earlier, refuse unwanted invasive and nonbeneficial treatments, and be more satisfied with their end-of-life care.

But there are several problems with these presumptions. First, the PCIA doesn't ensure that patients (or their surrogate decision makers) will be provided accurate information in an unbiased manner. There is no question that the information provided is inadequate in many cases. There is no question that information may be presented in a highly biased manner that influences the choices made by patients and families. There is no formal monitoring of the discussions patients and families have with their physicians. We don't know when physicians who have a bias against the use of percutaneous endoscopic gastrostomy (PEG) tubes present evidence about their nonbeneficial use in patients with advanced dementia to patients with other causes of dysphagia where evidence suggests a benefit. Nor do we know when a physician with a bias in favor of the use of PEG tubes extrapolates the evidence about their benefit for patients with head and neck cancer who are receiving combination chemoradiation therapy to patients in different clinical situations where the evidence does not suggest a benefit or there simply is no evidence base.

There is reason for concern about inaccurate or biased information being given in this context: ignorance about hospice care, at the systems-based practice level and as a medical specialty, abounds among physicians and nurses. Nothing in the PCIA prescribes the information to be provided or monitors for accuracy.

Some of the lack of physician knowledge about hospice is the result of the huge changes in hospice care over the relatively short time since its introduction in the U.S. in the late 1960s and its incorporation into the Medicare program in the early 1980s. There have been many changes in the Medicare hospice benefit since 1984 [12], and the physician unaware of this may discuss hospice care in a way that misinforms the patient and family about what it has to offer them. An uninformed physician trying to comply with the PCIA might advise a patient with a refractory malignant small bowel obstruction that her options are surgery or inpatient hospice. When asked what hospice will do for the bowel obstruction, the uninformed physician might answer "nothing," while the well-informed physician might answer, "treat your pain and nausea, help you decide whether you want artificial nutrition and hydration and provide it if you want it, and help you and your family cope with the frustrating reality that we don't have a way to fix this problem caused by your cancer." The decision made is likely to depend a great deal on which answer was given.

It is clear to me, as a physician who has practiced palliative medicine for 20 years in a variety of hospital, ambulatory, and home-based settings, that accurate information is necessary for optimal end-of-life care—necessary but not sufficient. That is the weakness of the PCIA. Better information does not address systemic constraints on patients' choices. The nature of the Medicare hospice benefit creates a program that is not able to be tailored to every patient's end-of-life care choices. Often, after a detailed discussion of the benefits and limitations of hospice care, my patients make

a well-reasoned decision *not* to enroll in hospice. Of course, they want the benefits of hospice care: skilled symptom management, home-based care, integrated interdisciplinary management, and psychosocial and spiritual support. But my hospice-eligible patients regularly choose to forgo the hospice care option for two reasons: it does not include concurrent care or extended home-care hours.

Lack of concurrent care is a frequent practical obstacle to optimal end-of-life care that can be brought to light in an informed conversation. Some patients forgo a hospice referral because they are not willing to discontinue a disease-specific therapy that is helping to control symptoms or slow the course of their disease progression, thereby improving their quality of life. Such a therapy seems like it ought to be covered by hospice benefits, but often such therapies are considered “curative” (though no one expects them to effect a cure) and are not covered by Medicare (or, in many cases, private insurance). This misuse of “curative” is intentional, an artifact of the low reimbursement rates for routine hospice home care (\$189.37 per day in New York City in 2013) [13]—if a disease-specific palliative therapy costs too much, it cannot be provided by most hospices at present. Pediatric hospice has permitted concurrent care [14], and demonstration projects that allow concurrent “curative” and palliative care for adults are expected in the coming year [15].

Additionally, until recently, dually eligible (for both Medicaid and Medicare) patients with extended hours of home care paid through Medicaid managed long-term care programs (MLTP) had to disenroll and give up their extended hours to enroll in hospice. This was often a barrier to hospice utilization, especially for patients with diagnoses other than cancer who were likely to need extended hours of home health aide assistance for long periods of time before becoming hospice-eligible. The regulations changed in August 2013 [16], allowing patients to enroll in hospice without giving up their extended home-care hours, and we expect this practical change will have a bigger impact on hospice referrals by the end of the calendar year than we have seen from the PCIA in the nearly 3 years since it was implemented.

Other recent New York initiatives came out of the Medicaid Redesign Team, a task force created in 2011 to restructure fundamentally the New York Medicaid program to achieve measurable improvement in health outcomes, sustainable cost control, and a more efficient administrative structure [17]. Several proposals related to hospice and palliative care were ultimately included in the MRT program and have been or will soon be implemented. The Palliative Care Access Act is one of these programs, and it requires health care facilities (as opposed to practitioners) to have policies and procedures in place that improve access to palliative care services for all patients with advanced life-limiting illnesses or conditions.

The Palliative Care Access Act requires that care facilities develop mechanisms for identifying patients who might benefit from palliative care services and those who are making decisions on behalf of patients who are unable to do so themselves. This effort is commendable but does not account for the significant shortage of trained

staff, limited capacity of existing programs, inadequate funding for palliative care services, or the common assumption that palliative care necessarily means “end of life.” Since patients may benefit from palliative care throughout a long portion of a chronic progressive illness, they may well want concurrent care during this time. Making sure that identifying patients as those who might benefit from palliative care does not bring with it an incorrect assumption that they want *only* palliative care is a challenge, given the way “hospice and palliative care” or “palliative and end-of-life care” are often lumped together as a single category.

Attempts to Lengthen Hospice Stays

Another initiative of the Medicaid Redesign Team was incorporated into the Hospice Modernization Act of 2011 (written communication with Kathy McMahon, October 2013). This was an effort to expand hospice use by changing the definition of terminal illness from a life expectancy of 6 months to one of 12 months. For this to apply to Medicare and Medicaid beneficiaries in New York state would require action at the federal level, but it can be used to expand hospice eligibility for patients with commercial insurance. But eligibility does not seem to be the problem.

It is well known that typical stays in hospice are far shorter than the 6 months’ life expectancy required for hospice eligibility—50.1 percent of patients die or are discharged within 14 days of admission [18, 19]. Furthermore, prognostication is more difficult the further the patient is from death. Our ability to prognosticate 6 months’ survival for cancer patients is reasonably accurate, but far less accurate for those with end-stage organ failure or dementia. Our ability to prognosticate 12 months’ survival is likely to be even less so. Some physicians might make earlier referrals if the eligibility criteria were 12 months rather than 6, and some patients might avail themselves of earlier referrals, but only if hospice is seen as a program that helps people cope better and live well with their progressive illnesses. In my experience, patients (and their families) want to see themselves as living well until they die, but want the “dying” phase of their illness to be relatively short.

Conclusion

There is no question, for those patients and families who want to focus on preparing for death, hospice programs continue to do “death and dying” well. But hospice isn’t just about death and dying; hospice is a program to help patients live as best they can despite the presence of a life-limiting illness. As professionals and as a health care system, we can and should aspire to improve the quality of care provided to patients who are dying of chronic progressive illnesses. If we don’t make the efforts from within the health care system, “solutions” will be imposed on us by those who are not involved in provision of care. These may easily address problems that exist but that are not the rate-limiting steps in the process of improving care. We must also be attentive to the diversity of our patients and recognize that, while there may be strong majority views about what constitutes excellent care at the end of life and strong views from much of our society about what they would like their dying to be like, there are also wide variations in such beliefs. A health care system that strives to

provide excellent care for all patients at all phases of their lives must be able to accommodate these variations.

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