



Ethical Perspectives On Health Care Reform

DEBUNKING 'DEATH PANELS'

Unfounded Assumptions Undercut Planning for a 'Good Death'

BY Sr. NUALA P. KENNY, OC, MD, F.R.C.P.C.

One of the most memorable misunderstandings during the U.S. health reform debates arose with a post on Facebook. On Aug. 7, 2009, former Alaska Gov. Sarah Palin wrote:

The America I know and love is not one in which my parents or my baby with Down's Syndrome will have to stand in front of Obama's "death panel" so his bureaucrats can decide, based on a subjective judgment of the "level of productivity in society," whether they are worthy of health care.

The "death panel" rhetoric went viral, and opponents of health reform went ballistic. Palin's post pulled all the strings of moral indignation: patriotism, respect for and protection of the vulnerable, disregard for personal autonomy in health care choices, social judgments of worth based on productivity and the value of life itself.

Neither the term nor the concept of a "death panel" appears in the Patient Protection and Affordable Care Act. Still, by December 2010, the Kaiser Family Foundation determined that 4 in 10 Americans believed the legislation allowed government panels to make end-of-life decisions for people on Medicare.¹

Despite repeated attempts by many to explain that the legislation provided for physicians to be reimbursed for regular discussions with their patients that could help individuals make clear their wishes for end-of-life care, including wishes regarding aggressive life-prolonging measures, the

death panel claim refused to die. It was noted:

The inconsistency of this was breathtaking. The people who made this claim were opposed to guaranteeing universal access to basic health care. They denied the existence of any moral or legal right to health care and railed against the effect on the federal budget of costly entitlements like Medicare. Yet they seemed to be arguing that there already was a right to unlimited care at the end of life, that the reform plan would take it away, and that this was an outrage. At the same time, they did not even acknowledge the existence of the issue of who should pay for this entitlement and why, let alone address it.²

Because of all the confusion and dissension, reimbursement for advance care planning was dropped from the federal bill.

Where did "death panels" come from? Conflation of and confusion about a number of elements in the Affordable Care Act appear to be the basis for some of the misunderstanding. In the original version there was a provision for reimbursing doctors for time spent in advance care planning and end-of-life discussions. This led to unfounded assumptions of death counseling and that the

legislation aimed to reduce health care costs by rationing health care for the elderly, chronically ill and disabled and specifically denying expensive but life-extending procedures at end of life.³ In reality, the inherent ethical issues are at the heart of many of the fundamental moral issues underlying just and compassionate health care at end of life in the 21st century. So, fears are easily raised.

Daniel Callahan, who has thought long and hard on the issue, has reminded us that end-of-life care became an important issue in the late 1960s and early 1970s in large part because of complaints about care of the dying: lack of patient autonomy, indifferent or insensitive physicians and inadequate pain control. There have been substantial improvements in all these areas, but more is needed to provide fairly what has been understood in the Roman Catholic tradition of a good death and what we intuitively understand today as desirable at end of life: adequate pain and symptom management, avoidance of prolongation of dying, achieving a sense of control at the end, relieving burdens on families and strengthening relationships.⁴ These elements are central to hospice and palliative care. However, the reality at the end for so many is in stark contrast and still dominated by frenetic, aggressive, expensive pursuit of life-prolongation in acute-care environments.

Callahan concludes that

... good care for the dying now needs to be seen as a problem that needs a parallel public and professional discussion at what I will loosely call the philosophical level. Two basic questions need to be put on the table. One of them is what we take to be the place of death in human life, and the other, that of the place of death in medicine and health care.⁵

The “death panels” fiasco raises two more concerns: the role of aggressive, expensive medical interventions when death is imminent and the provision of just and fair care for the dying.

Here, we will reflect on three of the fundamental ethical issues inherent in end-of-life care: the importance of end-of-life /advance care planning for empowering patients and their loved ones; un-

derstanding the reasons for and implications of expensive and aggressive care in the face of imminent dying; and the policy and resource allocation challenges of providing accessible, effective and affordable hospice and palliative care.

END-OF-LIFE AND ADVANCE CARE PLANNING

Despite the facts that we will all die and that “virtually all Americans will have a substantial period of serious illness and disability at some point before death,”⁶ discussions about end of life are dif-

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ficult.⁷ The natural human fear of dying and death is shaped today by our death-denying society and by our belief in technology that promises treatment for death itself.

Modern medicine unrelentingly pursues cure and fix. It saves lives but increases the prevalence of chronic illness, defers dying and increases health care costs. While most of our focus in end-of-life planning has been on end of life in cancer, the trajectory to death varies considerably.⁸ Three general trajectories have been identified: cancer with a variable first stage and then short period of evident decline; chronic illness and organ failure, mostly heart and lung, with long-term limitations and intermittent, life-threatening episodes; and frailty and dementia with prolonged deterioration and multiple co-morbidities.⁹ Advance care planning for well persons with sudden-onset cancer is different from planning for persons with the chronic illness/ organ failure trajectory and quite different again for the frail elderly and progressive dementia trajectory. Each of these trajectories present challenges to identifying who is terminally ill and when dying begins.

Moreover, many physicians experience death as the ultimate failure and do not initiate early advance care planning and end-of-life discussions.¹⁰ This reluctance is compounded by the fragmen-

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tation of care between primary care physicians and specialists, especially for the seriously and chronically ill, and the pressures of primary care. Initial discussions and end-of-life discussions frequently occur in acute situations when all are in panic mode. The default position when advance care planning has not been well done is to treat, often invoking the rule of rescue, a “rule” precisely for the rescue of healthy people caught in catastrophic circumstances — such as a mine collapse — where they could be rescued and returned to normal lives. It was not intended to describe a duty to rescue from inevitable death. Not surprisingly then, a high percentage of patients, including those who hoped to die at home, will die in the hospital where the ethos is aggressive interventions, making a good death difficult. Patient and family values, beliefs and grief also present obstacles to conversations about the limits of medicine, the goals of palliative care and dying itself.

From the bioethics perspective, advance care planning has been viewed as a way to promote the principle of respect for autonomy and to extend it to a time when patients may not have cognitive capacity to decide for themselves.

Advance care planning begins with the patient’s values and beliefs. It is,

... an ongoing process, giving patients an opportunity to consider, discuss and plan end-of-life care, with the intention of alleviating potential worries and concerns, and enabling patients to prepare for a potential deterioration in health.¹¹

The early focus was on advance directives, a so-called living will (instructional directive) or on naming a proxy. Advance care planning includes advance directives but when done correctly is a broader and profoundly personal, value-laden endeavor. It has been described as:

a process of recurring clinician-patient-family communication that includes: (1) individualized delivery of medical information; (2) utilization of a shared decision-making paradigm; (3) focus on multiple and evolving treatment decisions across the entire trajectory of a life-limiting illness; and (4) clarification of the patient’s future treatment preferences.¹²

The common theme in all descriptions of advance care planning is that of an ongoing process, one that includes elements of encouraging, supporting and collaborating with patients as they reflect on their illness in terms of potential preferences in advanced stages, especially at the end of life. An important component of this process relates to understanding patient/family values, goals, identity, relationships, coping, end-of-life concerns, and decision-making preferences.¹³ While the traditional aim of advance care planning has been assisting patients to make a directive regarding future treatment decisions in the case of their incapacity, Sudore and Fried have suggested that “the main objectives of advance care planning, rather than treatment decisions, should be to prepare patients and surrogates to work with their clinicians to make the best possible in-the-moment-decisions.”¹⁴ Advance care planning “... is not about ‘getting it right’” in the sense of deciding exactly as the patient directed regarding technological interventions but addressing the spiritual dimensions of care as they unfold, including the burden of following the loved one’s wishes.¹⁵

Some have questioned the effectiveness and usefulness of advance directives. Recent studies looking at the richer advance care planning process have showed their value. In a recent study of older Americans, “Patients who had prepared advance directives received care that was strongly associated with their preferences.”¹⁶ An Australian study of advance care planning at end of life in elderly patients concluded it

... assists in identifying and respecting patients’ wishes about end-of-life care, improves such care from the perspective of the patient and the family, and diminishes the likelihood of stress, anxiety, and depression in surviving relatives.¹⁷

Simply put, advance care planning fosters all the elements of a good death and is far from being death counseling or death panels. Advance directives help put the focus back where it should be — where families, friends, pastors, physicians and the law all should have their focus — squarely on the patient. In the 21st century, advance directives have become useful instruments for carrying out traditional morality.¹⁸

Moreover, advance care planning and end-of-life discussions have implications for both the quality and cost of care in the face of inevitable dying. Patients with advanced cancer who reported having end-of-life conversations with physicians had significantly lower health care costs in their final week of life. Higher costs were associated with worse quality of death.

“Policies that promote increased communication such as direct reimbursement for [end of life] conversations, enhanced physician education about [end of life] communication ... may be cost-effective ways to improve care and to reduce some of the rising health care expenditures.”¹⁹

Advance care planning is first and foremost about respecting patients and their wishes at the end of life. When done well, it helps to make possible the conditions for a good death. Those conditions require resources, and so the issues of cost and value must be considered together.

COSTS AT END OF LIFE

A disproportionate share of health care costs is spent at the end of life. In the United States, 10 percent to 12 percent of the overall health budget and 27 percent to 30 percent of Medicare costs are attributable to 5 percent of beneficiaries who die each year. One-third of that expenditure is during the last month of life. Canadian researchers found that 21.3 percent of health care costs are in the final six months of life.²⁰ Recognizing that there are some methodological difficulties in assessing costs at end of life, the trends regarding expenditures are clear and consistent.²¹

Some assume that this money assists patients in their dying, but most of these costs relate to life-prolonging care including ventilator and resuscitation in the final 30 days of life.²² Importantly, increased intensity of care here does not equate with better end-of-life care.²³ Treatment intensity

at end of life shows small gains in post-admission survival, but these marginal returns diminish for hospitals with above-average treatment intensity and wane with time.²⁴

Respecting patient autonomy through fostering conversations about values and preferences regarding care at the end of life is crucially important. However, responding to those preferences in the provision of care can present some difficult ethical issues for proxies, clinicians and payment systems especially when shaped by inappropriate expectations regarding what is clinically possible.²⁵ When persons make a judgment to shift to the goals of hospice and palliative care, the ethical issue becomes the fair and just provision of that option.

What of the many situations where persons or their proxies are requesting expensive, minimally life-prolonging interventions when death is near? There is a difference between respecting patient autonomy in refusing offered interventions and in responding to treatment requests and demands from patients. As health economist Mary Ann Baily has said: “Refusing to let people do things to you is one thing, but demanding that people do things for you is quite another.”²⁶

Because virtually all patients are covered by health insurance — public and private — responding to any and all possibilities for any one patient seeking expensive, aggressive life-prolonging interventions during imminent dying means others go without care which, in some cases, may be truly lifesaving. These possibilities raise important issues about balancing the individual good and the common good.

Aggressiveness of care is increasing in each of the trajectories of dying and has effects on survival, patient and family satisfaction, quality of

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life and cost. Treatment of cancer patients has become increasingly aggressive.²⁷ Since cancer incidence rises with age, this is a serious issue in aging societies such as in North America. Among

patients who died of cancer, chemotherapy was used frequently in the last three months of life. The cancer's responsiveness to the chemotherapy does not seem to influence the use of chemotherapy.²⁸

The last decade has seen the development of a number of extraordinarily expensive cancer drugs touted as "lifesaving." In reality, bevacizumab for non-small cell lung cancer will yield a

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gain in overall survival of two weeks at a cost per QALY [quality-adjusted life years] of \$1,206,000. Erlotinib for pancreatic cancer will yield a gain in overall survival of two weeks at a cost per QALY of \$660,000. Bevacizumab for breast cancer will yield a gain in overall survival of six weeks at a QALY of \$496,000.²⁹

These, at best, are minimally short-term life-prolonging treatments. Some people resist economic assessments that monetize the issue, such as quality-adjusted life years. These cost-effectiveness analyses privilege certain values and ignore others of importance — such as maintenance of hope. Cost-effectiveness analyses do, however, give us a way to think about comparisons and can help us link costs to value.

The chronic illness/organ failure trajectory also shows increasing expensive, aggressive interventions at end of life. Congestive heart failure is a major cause of death in the U.S.; more than 25 percent of Medicare beneficiaries die within one year of the incident diagnosis, and 36 percent die within one year of a heart-failure-related hospitalization.³⁰ Stage IV congestive heart failure with a life-expectancy of one to two years is a terminal illness. Before becoming terminal, all congestive heart failure patients have had medications, angioplasties, defibrillators and interventions provided from common resources. As each intervention fails, the next more complex and expensive step — even heart transplantation — is just assumed to be necessary. Patients dying of conges-

tive heart failure are less likely to be supported by hospice and more likely to die in hospital than patients with cancer.³¹ A Canadian study demonstrated that:

In 2006, the mean cost per patient with [heart failure] in the last 6 months of life was \$27,983, more than 5 times the per-capita health care expenditure in Alberta (\$4,995) in the same year ...Hospitalizations accounted for over 70 percent of costs in the last six months of life.³²

Aggressive interventions for the frail and elderly are also being seen, especially in increasingly complex cardiac and non-cardiac surgery for patients in their 80s and 90s. Some procedures, such as aortic aneurysm repair, have a cost of \$363,000 QALY gained.³³ The fastest growing segment of the dialysis population is patients over the age of 75 and

[l]ess stringent selection of patients has led to treatment of an increasing proportion of elderly patients, patients with diabetes, and patients who are frail and have complex co-existing conditions ... Among elderly nursing home residents, the initiation of dialysis is associated with a substantial decline in functional status and high mortality.³⁴

These extraordinary costs in the face of inevitable dying raise questions about how highly we value life at end of life for some individuals and our notions of justice and the common good.

Clearly, life is precious, especially for those of us who believe that life is a gift with intrinsic value. But what does this mean for expenditures of common resources in inevitable dying? Br. Daniel Sulmasy, OFM, MD, has said, "... the value of life is both finite and priceless and ... this is related to the notion of transcendental value."³⁵

In this sense the value of life is above all human pricing, not of infinite value. To accept life as precious does not mean acceptance that any and all costs should be expended to prolong biologic life for some.

Menzel summarizes Becker's work on five commonsense factors to explain why most per-

sons put a very high value on extending life at end of life³⁶ and adds two more:

Low opportunity cost of remaining resources; high value of life despite compromised quality, others' benefit from the patient's survival, maintenance of hope in the face of death, and shifting reference points that increase life's subjective value. Two additional factors commonly cited in health economics ...: the effect of insurance on person's demand for life-extending care and provider-created demand.³⁷

All of these factors are important. Three deserve particular attention in relation to linking value and cost: hope, insurance and provider incentives. The maintenance of hope in the face of death is understood as important for terminally ill and dying persons. "Don't ever take away hope!" is almost a commandment for caregivers. However,

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"... hope is almost always promoted for its impact on a single dimension — life prolongation."³⁸ In reality, hope is complex and vulnerable to exploitation.³⁹ Menzel notes that hope can have multiple objects: biological survival, a good death, a good "life after life"; that hope carries distinct dangers and monetary costs; and that the most resilient forms of hope are about "making sense."⁴⁰ Maintaining hope has more to do with attending to all these objects than of betting against the medical odds and probabilities. Miracles don't need medicine!

We can easily understand the value of prolongation of days or weeks of the life of a loved one. Who pays for that prolongation is a separate issue. Insurance has had a significant effect on demands for life-extending care, regardless of cost. Insured persons are not paying directly

and are inclined to demand everything from the common pool of resources, especially when they have "nothing to lose." Moral hazard has been used to describe this situation in which people insulated from risk behave differently from how they would if they assumed all risks and costs. When moral hazard meets a market mentality in the context of fear of death and imminent dying, a perfect storm of demand ensues with no linking of personal value, communal cost and the common good. This market mentality is in stark contrast to the Roman Catholic social teaching of interdependence and commitment to the common good.

Provider-created demand is a crucial element in aggressive interventions not only because of the cure-fix-intervene ethos of medicine but also because of perverse incentives.

[These] [i]nclude fee-for-service medicine, paying physicians for the piecemeal use of technology, the training and acculturation of doctors aggressively to use technology, fear of malpractice suits, often excessive patient demands and expectations, direct-to-consumer advertising, constant industry advertising to physicians backed by pharmaceutical detail men going straight to doctors, and a media that dotes on medical breakthroughs and "promising" research.⁴¹

So, many factors influence the continued pursuit of expensive, minimal life extension in the face of imminent dying. Some factors are within us in our fear of death and our grief at the loss of loved ones; others are rooted in our death-denying culture, death-defying technology and the hubris of modern medicine. Justice and compassion at end of life require us to conclude that,

Additional life at end of life does indeed have value disproportionate to its length. It is important to see that it does, and why it does, so that we do not follow a crude, uniform cost-effectiveness formula that glosses over real variations in value. It is equally important, however, that we allow neither the emotional power and sympathy that surrounds and suffuses the end of life nor the insurance effect to lead us into a functionally blind acceptance of high value

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beyond all demands and desires for life-extending care at the end of life.⁴²

Aggressiveness at the end of life may be a value for some. But it may also be a result of the lack of advance care planning and end-of-life discussions and planning, overly optimistic prognosis, institutional and professional ethos and the availability of real options for care at the end of life such as hospice and palliative care services.

HOSPICE AND PALLIATIVE CARE

In order to engage in advance care planning, patients must have real options to the ongoing pursuit of aggressive care in accessible, affordable and effective hospice and palliative care. The death panel fiasco has focused us on the issue of the care we owe to those who are at the end of life. Leonard Fleck has put the issue of justice at end of life clearly, asking:

What does it mean to be a just and caring society in meeting the health care needs of the terminally ill when we have only limited resources to meet virtually unlimited health care needs? ... Relative to all the other health care needs in our society, especially the need for lifesaving or life-prolonging health care, how high a priority ought the health care needs of persons who are terminally ill have?⁴³

How much society ought to invest in end-of-life care with palliative goals is an issue requiring its own in-depth reflection. Clearly, optimizing resource allocation in end-of-life care is crucial for all systems. "Achieving 'grand' efficiency, therefore, requires the provision of clinically and cost-effective palliative care services that best meet the patient's needs and that are provided

with no waste of resources and by a well-trained and motivated palliative care team."⁴⁴

Estimating the real costs of end-of-life care with palliative goals is complicated by some of the philosophical, organizational and funding differences between hospice and palliative care. Hospice care, dominant in the U.S., attracts individuals who are generally white, educated and with higher incomes, and there are legitimate concerns regarding the commercialization of hospice.⁴⁵ Studies have shown that hospice in the last month of life for nursing home residents lowered government expenditures.⁴⁶

Palliative care, a specialty of medicine and other health disciplines, deals with acute symptom management and provides institutional care for difficult cases of dying. Palliative programs have multidisciplinary teams providing care in home and community settings, so costs are diffuse. A Canadian study has identified the importance of assessing the total cost for palliative care because real costs are shared among health care systems, families and not-for profit organizations.⁴⁷ Clearly, the issue of public payment for end-of-life options is a crucial justice consideration. In addition, system responses to just hospice and palliative care options also need to take into account a host of special issues that include racial, ethnic, cultural considerations,⁴⁸ spiritual and religious concerns,⁴⁹ and significant inequity in services for rural patients and families.⁵⁰

Costs are a justice concern. How societies respond to demands for expensive, aggressive mini-

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mally life-prolonging treatments in inevitable dying must be part of a general civic discourse about what we owe each other in care; that discourse becomes ever more fragile.

And so, we come full circle. Far from “death panels,” the promotion and support of advance care planning are ways to assist patients and their loved ones to reflect deeply on what matters to them in life and in death. These reflections are important and complex, which is why Donley and Danis make a strong case for including the costs of end-of-life care as part of advance care planning:

End-of-life choices are often very complex, involving various unpredictable value judgments, including the following: (1) a patient’s opinion on quality of life vs. length of life; (2) their conception of a “good” dying experience; (3) religious beliefs; and (4) personal circumstances (for instance, family pressures and/or financial status). Neglecting any part of the equation, including finances, make it less likely that the clinician and patient will make the best choice, all things considered.⁵¹

Conversations about our belief in and dependence on medical science and technology; the value of life-prolongation in the face of imminent dying; the costs of this pursuit; and the obligation of a society to provide just and compassionate care at end of life are all interrelated. Palin got the issues and the underlying values confused, but she helped put the importance of empowering the terminally ill and dying for these conversations on the agenda.

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