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Doctors need to confront end of life care

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in PATIENT CARE

by Philippa Kennealy, MD, MPH 31

"Avoiding those twin traps of overtreatment and therapeutic nihilism"

Recognize this phrase? It's from our Hippocratic Oath, the one I took, standing beside my newly assigned cadaver, in my second year of medical school.

"What Broke My Father's Heart", recently in the *New York Times Magazine*, is an exquisitely painful story of medicine and our Oath gone awry in the United States. I urge you to read it.

End-of-life care is a subject many physicians would prefer to avoid talking about or confronting. I suspect this is related to our American optimism and apparent conviction that death only happens to others.

For the medical profession, is it that we feel held to such a high standard that the death of a patient represents failure? Or is it, as some in the public accusingly point out, more crass than that? Does a patient's passing imply a lost future source of revenue?

The author writes:

> Thanks to advanced medical technologies, elderly people now survive repeated health crises that once killed them, and so the "oldest old" have become the nation's most rapidly growing age group. Nearly a third of Americans over 85 have dementia (a condition whose prevalence rises in direct relationship to

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> longevity). Half need help with at least one practical, life-sustaining activity, like getting dressed or making breakfast.

I moved to the US after training in South Africa. While repeating my residency training here, I was shocked to be assigned, as an intern on an ICU rotation, to follow and care for intubated frail elderly patients in their 80s and 90s.

I don’t recall it ever being spoken, but I think there must have been a tacit understanding between physicians and the public in South Africa that the limited resources of the ICU would be reserved for the younger patients — men injured in car accidents, middle aged women with strokes, teenagers stabbed in bar fights. This was not racial — as a medical and surgical house officer in Johannesburg, I had never seen anyone over the age of 70 in the ICU.

Right or wrong, this “agreement” was driven by the fact that ICU beds were scarce, and heroic care for the elderly was neither expected nor provided.

As the US public, our fondness for medical technology advance has created the kinds of ethical dilemmas that kept me and my colleagues on our hospital’s Ethics Committee very busy when I was in practice.

This is one of the most telling parts of this sad story:

> Without the device, Dr. Rogan told me later, my father could have died from cardiac arrest during surgery or perhaps within a few months. It was the second time Rogan had seen my father. The first time, about a year before, he recommended the device for the same slow heartbeat. That time, my then-competent and prestroke father expressed extreme reluctance, on the advice of Fales, who considered it overtreatment.
>
> My father’s medical conservatism, I have since learned, is not unusual. According to an analysis by the Dartmouth Atlas medical-research group, patients are far more likely than their doctors to reject aggressive treatments when fully informed of pros, cons and alternatives — information, one study suggests, that nearly half of patients say they don’t get. And although many doctors assume that people want to extend their lives, many do not. In a

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> 1997 study in The Journal of the American Geriatrics Society, 30 percent of seriously ill people surveyed in a hospital said they would “rather die” than live permanently in a nursing home. In a 2008 study in *The Journal of the American College of Cardiology*, 28 percent of patients with advanced heart failure said they would trade one day of excellent health for another two years in their current state.
>
> When Rogan suggested the pacemaker for the second time, my father was too stroke-damaged to discuss, and perhaps even to weigh, his tradeoffs. The decision fell to my mother — anxious to relieve my father’s pain, exhausted with caregiving, deferential to doctors and no expert on high-tech medicine. She said yes. One of the most important medical decisions of my father’s life was over in minutes. Dr Fales was notified by fax.
>
> Fales loved my parents, knew their suffering close at hand, continued to oppose a pacemaker and wasn’t alarmed by death. If he had had the chance to sit down with my parents, he could have explained that the pacemaker’s battery would last 10 years and asked whether my father wanted to live to be 89 in his nearly mute and dependent state. He could have discussed the option of using a temporary external pacemaker that, I later learned, could have seen my dad safely through surgery. But my mother never consulted Fales. And the system would have effectively penalized him if she had. Medicare would have paid him a standard office-visit rate of $54 for what would undoubtedly have been a long meeting — and nothing for phone calls to work out a plan with Rogan and the surgeon.

These words highlight many of the problems seen in our fragmented system of care:

- lack of **continuity of information** amongst different providers
- lack of a **team approach** to medical decision-making
- lack of **true listening** to the patient or family on the part of clinicians
- lack of **fully informed consent**
- lack of **appropriate “reward”** for the physicians whose counsel and support have the potential to save our healthcare system

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millions if not billions of dollars spent on unnecessary (or, in this case, unwanted) treatments

- **perverse incentives** to reimburse those physicians who provide *more* care, with *more* money

Much of this is known and debated in the public forum. This overuse of resources is spoken about in generalities that have obviously failed to hit home. Well-meaning doctors who're in the habit of offering all the technologically available care options while practicing CYA medicine, are continuing to practice as they always have.

The tragic stories like that of daughter, Katy Butler, provide the shocking emotional impact. These stories, while focusing to some extent on money, financing and screwed-up incentives, are really all about immense human pain, suffering and loss of dignity.

Isn't that what we, as doctors, are commanded to relieve?

What then does this all mean for you, a practicing physician, an entrepreneurial doctor, a medical practice business owner?

The creativity of true entrepreneurship is born from passion. Most physicians I communicate with describe their ongoing desire to making a meaningful contribution and a difference, despite their disillusionment with clinical practice.

If this is indeed true, then I challenge those of you touched by this story to awaken your creativity, your curiosity, and your commitment, to respond to this crisis in end-of-life care. You won't have all the answers — no one does — but surely we as an intelligent, compassionate, inventive group can come up with something better than this.

Philippa Kennealy is a family physician and certified physician development coach who blogs at The Entrepreneurial MD.

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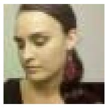
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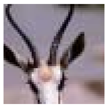
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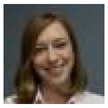
Amy

Tagged as: Hospital, Patient, Primary care

{ 11 comments }

Astrid August 10, 2010 at 1:57 pm 1

Of course, end-of-life care should be provided, but it should refelect the3 wishes of hte patient. Too often, end-of-life care is said in the same sentence as something about how elderly people are a drain on our resources. Some elderly people indeed may not want all this heroic intervention, but some may, and it is ageist and ableit to deny the elderly life-saving support that they wish based on either their age or some pre-existing condition, like dementia. IN the Netherlands, in my opinion, "end-of-life care" has become too much "making sure we get rid of those expensive demented seniors".

Barbara Shey August 10, 2010 at 3:04 pm 2

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It would be great if EOL training were mandated for license renewal. Too many practitioners are purveyors of bad information about the goals, services, philosophy and criteria for hospice care. Ask any critical care nurse to tell a story of futile care bordering on assault in the ICU because no one would have the “hard conversation” with the family. The subject should only be broached by someone knowledgeable, educated and comfortable with the subject. Perhaps an algorithm that mandates a palliative consult would be a good start

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ninguem August 10, 2010 at 4:12 pm 3

“……Medicare has made minor improvements since then, and in the House version of the health care reform bill debated last year, much better payments for such conversations were included. But after the provision was distorted as reimbursement for “death panels,” it was dropped. In my father’s case, there was only a brief informed-consent process, covering the boilerplate risks of minor surgery, handled by the general surgeon.

I believe that my father’s doctors did their best within a compartmentalized and time-pressured medical system. But in the absence of any other guiding hand, there is no doubt that economics helped shape the wider context in which doctors made decisions. Had we been at the Mayo Clinic — where doctors are salaried, medical records are electronically organized and care is coordinated by a single doctor — things might have turned out differently. But Middletown is part of the fee-for-service medical economy. Doctors peddle their wares on a piecework basis; communication among them is haphazard; thinking is often short term; nobody makes money when medical interventions are declined; and nobody is in charge except the marketplace……”

Sorry, that’s just garbage. You don’t need the Mayo Clinic, nor do you need a diagnostic code for “End of Life” counseling.

He could have seen his primary care doctor, under current Medicare rules and been counseled over all the usual end of life matters, with the diagnosis of coronary artery disease, cardiac arrhythmia, late effect of stroke, dementia not otherwise specified, just based on the story as presented in the NY Times. Spend half an hour, document you spent half an hour, bill 99214, Medicare payment is about a hundred dollars in my area. Call it 99215, payment is about $130. Time spent about 40 minutes. I'd say whether or not to accept a pacemaker or other life-sustaining treatment is high-risk decision making.

In fact, the perfect way to create an assembly-line mentality and guarantee the thoughtful discussion will NOT take place, is to create an integrated system as described.

I have a just such a discussion with an elderly patient, and family, bill as described, on average once a week. Audits happen rarely, and I get through them just fine, because the diagnosis, complexity, and time spent perfectly justify the billing.

You don't have to "mandate EOL for license renewal". Good Lord. Why do people insist on making these things so complicated?

ninguem August 10, 2010 at 4:19 pm 4

The family could, I suppose, insist on a herniorrhaphy under local or regional anesthesia if the surgeon and anesthesiologist were comfortable with that. They could have chosen to decline the pacemaker.

The surgeon could conceivably have chosen to say, "patient and family decline pacemaker, inguinal herniorrhaphy remains medically indicated, they understand increased risk, etc………" and proceeded with surgery.

Say the patient died perioperatively. You DO understand, it would be counted among the "medical errors", the "prevention" of which is a cottage industry, and subject of a recent post here.

RBechhold August 10, 2010 at 9:34 pm 5

End of life care is not respected nor is it well paid. medicine is fee for service and that drives the majority of care. I have seen terminally ill patients taken to the cath lab, have PEG tubes placed

and given chemotherapy all in the name of being ” aggressive” because the patient wants everything done. In fact, patients want everything that is medically useful. Surgeons handle it the best. When consulted, they evaluate and if surgery has nothing to offer they say so and sign off. But how often have I been told by physicians ” can’t you just give them some chemotherapy?” I could, and I make good money doing so, but I am not interested in pushing drugs that I know are of no benefit..
We need hospitals to make quality end of life care just as important as good cardiac surgery or labor and delivery. Looking at the use of dialysis, chemotherapy and PEG tubes are just a few of the issues that warrant attention. And certainly, criteria for admission to the ICU.
Physicians have a duty to be good stewards of medical resources by using them wisely and educating patients and families through true informed consent so that they can feel confident in the care they choose and do not choose.

jsmith August 11, 2010 at 1:05 am 6

Sure, mandate EOL training, opioid training, senior abuse training, wife abuse training, cultural sensitivity training, transgender pt sensitivity training, the list can go on and on. Absurd.

ErnieG August 11, 2010 at 6:14 am 7

I’m in agreement with ninguem and jsmith- why the need to regulate more? It seems that what is really needed are strong, competent, and confident generalists who know how to talk to patients. Unfortunately, they seem to be a dying breed.

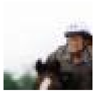
Marya Zilberberg August 11, 2010 at 9:20 am 8

Really great post! My family has just struggled with a similar situation, and it is not really necessarily a single-point answer (http://evimedgroup.blogspot.com/2010/08/requiem-for-my-father.html). Our culture is not just risk-averse, it is death-averse. We have the sense of entitlement to live on no matter what, and technology is the answer. I have to say that evidence-based medicine practiced in this context does not allow for either a patient’s or a physician’s more spiritual, if you will, impulses to prevail.

Should evidence of a 2-month prolongation of life translate into wide-spread treatment? Does effect size matter or is it just the p-value that we are after? Many times I hear from my peers that the difference between two treatments was significant with the p-value < 0.05, but when I probe them for the actual magnitude of effect, they do not remember. A p-value may be important to a journal, but in the office it is the effect size in the context of one's values that should matter.

The answer is for us as a society to start rethinking our attitude towards the end of life and to come to terms with death as the inevitable conclusion of a life. Otherwise both patients and physicians are complicit in creating and perpetuating this false idea that we all can and deserve to live forever.

BobBapaso August 13, 2010 at 8:05 pm **9**



Death is a normal part of life. Death is not a bad thing. God created death.

Caroline Andrews August 16, 2010 at 8:04 pm **10**

I agree that elderly patients who have little chance to resume an independent life should not have heroic measures just to keep them alive.

I am concerned, though, with the idea that those over, say, 70 just be allowed to die. My father is 92, active, and leads a full and independent life. He contributes a lot to the lives of his children and grandchildren and does most of the yard work for the busy family. The idea that we could have lost him years ago because of the denial of life-saving care at a hospital is something I don’t want to contemplate.

Decisions about the end of life should always be an informed decision between patient and doctor and not based on arbitrary age limits. I find the latter chilling.

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C. Lesko August 26, 2010 at 11:17 am 11

I am an R.N. who just went through a 19 month illness with my Mom before her death. It is our family values that it is humanity's duty to provide all available care and God's place to decide when enough is enough. I had an unbelieveable nightmare with physicians who thought that they knew best for us and why wouldn't I see their point of view! My Mom was a "young" 89 before her illness- in fact doctors thought that she was in her 60s or younger when they hadn't seen her record. Yet our wish to be aggressive in treatment was viewed as innappropriate. What especially bothers me is that when I began nursing in 1971, the patient's wish to be aggressive would not even have been questioned. Today that is not the case. I hear doctors and nurses saying to families, "You wouldn't want your loved one to suffer, would you?" as a manipulation tool to stop care for the elderly. Age discrimination is alive and well in medicine, as well as lack of respect for ones' moral beliefs. It was only God's miraculous intervention of sending Mom a doctor who respected our beliefs which allowed Mom to die as we believed. (Our family beliefs are personal moral choices and not a denominational belief. Our faith respects the patient's beliefs.)

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