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Ethics of ICU Care for the Elderly

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<http://dx.doi.org/10.5772/64053>

Abstract

Elders being treated in the intensive care units (ICU) require attention to their special needs, problems, and desires. We can use the five principles of Ethics to identify and respect their wishes, while minimizing our harm to their bodies, spirits, and families. Our technology must be adjusted to clear, attainable goals and consideration of the life they are likely to have after the ICU.

Keywords: hybrid femtosecond lasers, ultrahigh intensities, Photochemically driven laser media, Femtosecond system, Laser-matter interaction

1. Introduction

Elders who find themselves suddenly admitted to a critical care unit may deserve special consideration as we make our ethical decisions. As adults become more dependent on their children, role reversals and projections from an earlier time may muddle the picture of who is the decision maker, who is being cared for and who burdened, and the economics of societal responsibility.

How do we apply traditional ethical principles to this unique group? Is the last of a long time on this planet just a series of losses and wasted resources, or one blessed chance to complete a lifetime of beginnings? How can we help patients and families navigate through the late chapters of this irreversibly terminal process – life?

1.1. “It takes a lot of gold”

A few years after completing my fellowship in nephrology, I realized I wanted to be a pediatric nephrologist. Striding into Children’s Hospital, Oakland, CA, I announced my intention.

The response was consistent and clear: “These children are not just little adults. They are their own beings. If you want to pursue that path, you can start over at internship”. And that was the end of that.

Decades of adult Critical Care and Nephrology later, I’m well on my way to becoming an Elder – or maybe just old. As I contemplate what might be unique in ethical management of the elderly subjected to Critical Care, I’m surprised at the contradictions in my view of who “they” are. Are the elderly just adults grown grumpy and a bit battered, or a special subset of the disabled? Should they be covered by the Americans with Disability Act (ADA)? Like children, are they unable to represent themselves, instead being under the care and control of those who used to be their children? Or are they uniquely valuable vessels of experience and wisdom who deserve our most tender protection? Are they a drag on our economy, or the only real history we have?

Do the few months to years they have left make investing in them a terrible waste? Or does a lifetime of connection, labor, procreation and contribution to society make every remaining minute worth saving? How should I and society balance saving a few weeks or years of sometimes difficult, potentially limited life against the decades we might have saved by pouring those resources into a young person? Are all years of life of equal value? And whose value system will decide?

Walking home up the hill from my hospital in San Francisco, one of my patients could usually be found resting on his front stoop. “Enjoying your Golden Years?” I’d call out. He’d grunt and reply, “Yeah, they’re Golden alright. Takes a lot of gold to get through ‘em”. I realize now he wasn’t just talking about insurance copays and costs of medicine, the struggle to get to a doctor’s office, the pharmacy, the lab and home without falling and breaking a hip. It was a toll metered out in aches, pains, serial losses, suffering, fear, constant decisions about how far to push; fighting, hoping; and eventually letting go, searching for the right way and time to say goodbye. It wasn’t just about this one superannuated adult. It was the systole and eventual diastole of a heart deep in the chest of a family and a community.

1.2. To be or not to be: that is not the question

Critical care practice is the pursuit of how much can be done. Ethics asks the question, what *should* be done, and which *goals* are worthwhile.

St Luke’s Hospital established San Francisco’s first Subacute Unit, a place for patients in probably permanent coma or ventilator dependence. As families arrived with their loved one, I’d ask, “Is this how your family member would want to spend the remaining months or years of his or her life?” The answer was almost always, “Absolutely not”.

Why, then were we doing this?

Typically the response was, “Because one day the doctors came to us and asked, did we want them to keep doing everything, or let Dad die? We couldn’t bear being responsible for deciding to give up” (Figure 1) [1].

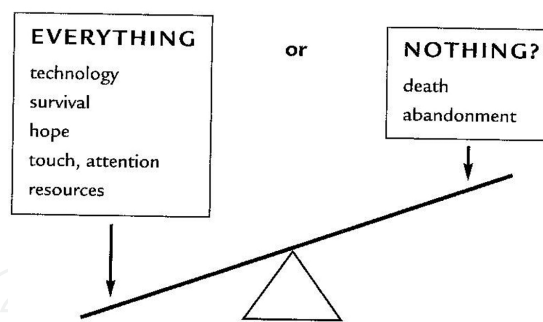


Figure 1. Everything or nothing (Medical Care of the Soul).

Twenty percent of Americans will die in the ICU, accounting for much of the 25% of all Medicare expenditures consumed in the last year of life [2]. Of those in ICU, half will be over 65 years of age. Twenty-five percent of ICU patients over 70 will not leave ICU, compared to roughly 8% of those less than 70. Of the elderly who do survive ICU, many will have experienced significant decline in cognitive or physical function [3–5]. Reported mortality rates vary from 38% at 3 months to 50–80% at a year after ICU [6–9]. Pre-hospital functional status adds additional risk: functionally limited patients experienced higher in-hospital mortality (32 vs. 16%) than those who were more robust [10]. Barely half of patients over 80 years of age who required mechanical ventilation and pressors survived the hospital stay [11].

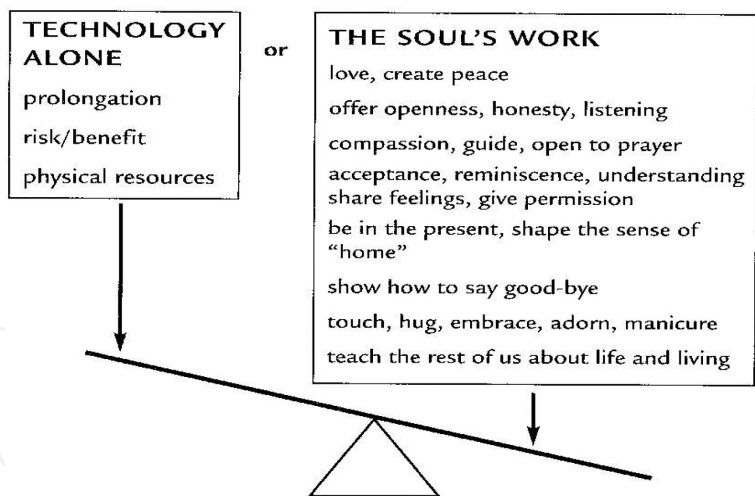


Figure 2. Alternative goals.

I offer these statistics neither to disparage our hubris nor to brag about our successes. Rather, we need to consider what are the goals of our treatment, what burden will be borne and by whom. I learned to ask families and patients a different question: “Faced with a serious or life-threatening illness, would you want us to focus solely on technologic interventions to prolong life, no matter how harrowing? What other meaningful help could we give you in this difficult time?” Some of their answers are in Figure 2 [1].

1.3. Is age per se a disability under the Americans with Disability Act?

Now, understand, I’m in California. Out here, everybody is disabled and deserves at least two “service animals” to make it through the day; alcoholism, drug abuse, halitosis and the jitters are disabilities; if you don’t have a marijuana prescription, you mustn’t realize how wrecked you are, and that lack of awareness is its own disability. Folks out here yearn for disabilities, sue for them, and sustain an army of well-healed lawyers to demand them.

The ADA instructs us that the “disabled” are really just “other-abled” and that their limitations must not be considered in our decisions unless – unless – those “other-enablements” make the burden of therapy so intolerable and the benefits of therapy of so little value to the individual that it’s cruel to impose the proposed therapy upon them.

Well, we cleared that up, didn’t we now?

In my experience, most elderly will fight to the death to be as able as possible. We treat them as disabled at our own risk and should do all possible to support that competency.

Let them have their puppies, their weird hats and habits and their memories. Tailor our therapies to what we presume they can handle. The only disability may be our lack of empathy. And in exactly which textbook, roadside chapel, or CME course are we to find that empathy? The best we can do is an intellectual construct called “Ethics”.

Ethics traditionally stands on five pillars: Autonomy, beneficence, non-maleficence, guidance, and distributive justice (aka husbanding society’s resources) (**Figure 3**). I would add a sixth: shaping a story, a legacy, that will ennoble the last of this singular life.

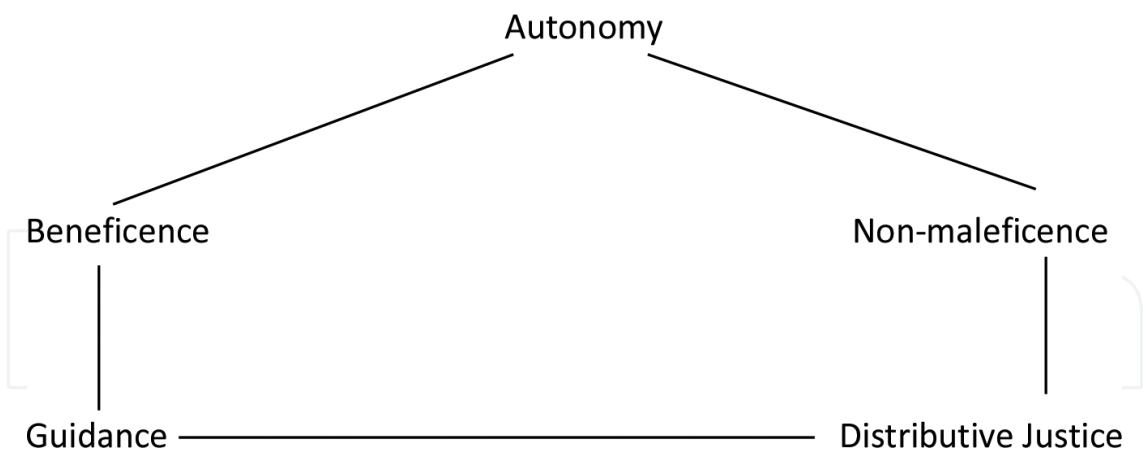


Figure 3. The ethical pentagram.

2. Autonomy

Autonomy is best defined as “the right to refuse unwanted touching”. Many cultures or societies consider individual rights subservient to the imprimatur of family, tribe, community,

or state. American and in general Western views put individual autonomy at the top of the ethical pyramid, with the individual the decision maker. Confounding issues particularly in the elderly include:

- Questions of the patient's competency.
- Intrinsic unclarity of the Advance Directive (AD)
- Children's and other family members' competing claims to surrogacy and understanding of the patient's wishes
- Misunderstanding of the surrogate as "demander" of services, the surrogate's versus the patient's wishes, and secondary gain that may invalidate the designated surrogate
- Conflicting desires in a patient overwhelmed with the onslaught of technology
- Unrealistic predictions on the part of staff, patients, and family. (This will be discussed under "Guidance".)

2.1. Questions of the patient's competence

Families and staff may dramatically over- or under-estimate the extent to which an elder can make a reasoned decision. A decent guideline in the face of "impaired mental capacity" is, "Can this individual understand the consequences of his or her refusal?" We may fall back on a careful mental assessment or psychiatric evaluation to answer this question. Depression, anger, obstinance, dementia, bewilderment, linguistics, and a fear of offending family or healthcare providers (their lifeline) all may cloud the soup.

Thankfully, exploration of friends' and family members' remembrance of the patient's prior wishes may support or give pause about the patient's statements. In this regard, elderly are particularly susceptible to spacial/time disorientation, "sundowning", sleep deprivation, drug effects (especially benzodiazepines, sedation, narcotics), hypothermia, hypoxia, or CO₂ retention. Infections, endocrine disorders or acute illness, family coaching or staff persuasion can run riot on one's decision-making capability. Contrariwise, either our reluctance to be "paternalistic" or a subliminal desire to shape their choices to our or our hospital's advantage may induce us to abandon them to uninformed decision making.

Elders may be overwhelmed by the flood of too many or inappropriate choices ("Do you want us to do this or that?", "We can go three different ways here. Which do you choose?", "Do you wish Resuscitation (CPR)?" in a patient who would not benefit from it). Financial issues ("I don't want my family to lose everything I've built") and the wish to continue taking care of loved ones beyond the time of one's ability to do so are ever-present weights. We must minimize these effects – confine the family to input that reassures the patient, and ourselves to questions that don't add to the patient's distress and confusion.

2.2. Intrinsic unclarity of the Advance Directive (AD)

Many AD's spell out what appears to be a DNR as follows:

"I do not wish life sustaining measures if (a) the burden outweighs the likely benefit, (b) I have irreversible coma, or (c) it will only delay my death".

When patients sign this, very few of them or their surrogates realize that: (a) They have no idea what burdens (risk, suffering) are headed their way, nor have they begun to consider what amount of damage would be acceptable for what outcome (benefit, quality of life); (b) irreversible coma usually takes weeks to months to predict; and (c) every breath we take delays our death. At precisely what point do we conclude those breaths are no longer in our best interest?

2.3. Children's and other family members' competing claims to surrogacy and understanding of the patient's wishes

Very few designated surrogates have really explored the elder's quality of life issues, their desires for the last of life, their fears and wishes for what they want to leave behind. Much less would they explore their own motivations. The other family members are even more adrift without a paddle about their role, responsibilities, and rights. Families implode over these issues: "How could you want Mom to die?" "How could you want her to suffer?" Without clear guidance from medical, counseling, and chaplaincy personnel, the resultant wound in a family can suppurate for generations.

Adult children may also believe that their surrogacy begins even when the patient is competent and able to express their wishes, or that it gives them the power to represent their own wishes rather than those of their elder. Not so.

I begin end of life (EOL) discussions, "I'm not asking you to decide if your mother/father lives or dies. Their illness will decide. I'm asking you to tell me what they would be saying if they could: how much they would want me to put them through to attain what quality of life, and what scene they would want at the end. Then I can tell you what I can achieve. If the best I can do is a death they would have hoped for, I'll tell you how we can get there". After they get over the shock that it's not their, but their parent's choice, almost uniformly they appreciate having the burden lifted. I would put this not under paternalism or "maleficence" below but guidance and my sixth pillar.

2.4. Misunderstanding of the surrogate as "demander" of services, the surrogate's versus the patient's wishes, and secondary gain that may invalidate the designated surrogate

How many times we hear, "We have to do everything because that's what Dad said he wanted" [12, 13]. Yet rare is the masochist who would include in their wishes procedures that would be unduly painful or pointless. Patients don't want suffering without a prospect of return to "worthwhile" life. That "worth" must be explored with each individual. For one it may be "Only if I will be independent and not confined to a facility" (hospital, SNF, subacute). For another, "Only if I won't be a burden to my family" (financial? time? distraction from their responsibilities to the grandchildren? watching me deteriorate?). Or another, "As long as I can play bridge and put on my makeup". As long as I don't smell bad".

And we must consider whether the designated surrogate remains valid. Is the IHSS money they receive each month affecting their assessment that Mom would want to be kept alive

though in a condition she never would have wanted? Is the cost of time away from work persuading them it's time for comfort care? Are they acting as loving adults? How much of their animus is a resentful or desperately dependent little child trying to get even or make up for past transgressions? This is not judgmental fantasy. I've lived it, seen myself an experienced physician transformed lickety-split into a babbling child, and seen so many families go through it. Perhaps when it's our parents we're all of these, all the time.

2.5. Conflicting desires in a patient overwhelmed with the technologic onslaught

My parents both refused to establish Advance Directives or read my book. "We're going to beat this cancer" was Dad's refrain. As his gurney was wheeled into the ICU he begged over and over, "No machines. Don't make me suffer". He survived several days, half the time ripping off his O₂, half the time thrashing to have it put back on, long enough to squeeze our hands, throw air kisses and tell a last few long-winded, gasping jokes, and say how much he loved us. Then he was gone.

Technology has its own steamroller momentum. One author observes, "Although patients may not want to die in pain or without family, most prefer not to die at all" [2]. What starts as O₂ soon becomes dialysis, a ventilator and then surgery. What begins as a chemistry panel evolves to a series of tests, an unexpected diagnosis the treatment of which has disastrous consequences. My Father often quoted, "When you're up to your ass in alligators, it's hard to remember your original purpose was to drain the swamp". How often we're sinking in a wallow of serial misadventures that have nothing to do with the presenting complaint. Few of us at any age have the clarity, prescience, and courage to say no at just the right time.

The momentum of technology easily runs over the calm voice that asks, "but, why not?" Even when we use Advance Directives and EOL discussions to try to control the steamroller, far too often the message gets lost on the way to the providers [14].

We owe it to our patients and families to empower them and give them realistic choices – not "Do you want us to do everything (and of course it will come out well), or give up (needlessly).

In our choice of sedation, narcotics, psychoactive drugs, tests, and procedures, I believe we must go beyond "informed consent". We need to give our patients and families the tools to make choices not from fear (namely the current Presidential Campaigns) but from reasonable hope and realistic information.

2.6. Denial of the probable outlook on the part of staff, patients, and family

These will be discussed under "Guidance".

3. Beneficence and non-maleficence

It is said the road to Hell is paved with good intentions. It's possible the road to Heaven might be paved with bad intentions, but I doubt it.

So many of our huge ethical conflicts hang on disagreements about what constitutes an intention to do good (beneficence) and what an intention to do evil (maleficence). Hippocrates' proscription that a physician must never intend to cause a patient's death comes from a time when death was natural, we could do little to prevent it, and to cause it intentionally was offering the devil help for which he had little need.

Today we're much more capable of prolonging a patient's life in a fashion horrifying to them and their family. More and more, death comes only when we permit it by withdrawing our machines, our pressors, our one more round of chemotherapy, and our one more even more brutal surgery.

Calling it "second effect", we pretend there's a clear, bright line between our responsibility to provide support and symptom relief, versus Physician-Assisted Suicide. This line is tethered on either shore by the idea that a medication given to relieve suffering may incidentally (surprise, surprise!) hasten death. The charge nurse at my subacute called me late one night. A terminal, comatose, ventilator-dependent patient had been off the vent for 7 days. The staff and family were suffering terribly. He asked, "Can I plug the trach so he can die peacefully?" Was the patient in pain? No. Were there signs of distress? No. Since we have no permission to consider family or staff distress and pain, my answer was: "No".

There is worry that if we're empowered to cause death at will, we'll be on the "slippery slope" of Nazis getting rid of those we consider unworthy – those with disabilities, minorities, too few years left or too expensive to care for. The economically unworthy. The unproductive. The unpleasant. Those unlike ourselves [15, 16]. I would say this is less a slippery slope than a meadow with lots of overgrowth hiding potholes. Oregon and other experiments show that the option of assisted suicide forces caregivers to provide much better palliation, so suicide is not their patient's only option. And it works. A vast majority of Oregon patients die at home. Only one in 500 directly access the option of physician-assisted suicide [17, 18].

Woody Allen said, "I'm not afraid of death, I just don't want to be there when it happens". Our euphemism for treatment focused on quality rather than quantity of life is "Comfort Care". I'm fascinated that hidden in that is a damning admission: much of what we do to patients is "Discomfort Care". I've proposed in ethics committees at several hospitals that all patients are "Comfort Care" unless on admission we order "Discomfort Care".

We act beneficently when we tailor our offerings to the patient's goals, whatever they may be [19]. When we propose to cause discomfort unlikely to achieve an outcome the patient would appreciate, we're acting maleficently. We provide the most beneficent guidance when we reassure a patient and family that their choice to reject a proposed treatment will be met not with rejection or resentment, but support and a commitment to vigorous symptom management.

I believe that the elderly, who have more experience of loss, suffering, and hard choices than the most of us can imagine, especially need that reassurance.

4. Guidance

Several events in the 1960s and 1970s conspired to change our views of authority. These include the revelations about secret carpet bombings of Cambodia, then Watergate, followed by a series of scandals reminding us that those who had power over us might be acting not in our best interests, but in their own; a burgeoning awareness and resentment of the “paternalistic” all-powerful doctor; the beginnings of informed consent and Advance Directives; rapidly evolving technologies for lethal warfare, even as we learned to sustain life beyond the death of one or more organ systems.

I don’t believe these developments were unrelated.

Recently, a local high school teacher asked me to discuss with her class Rebecca Skloot’s book, *“The Immortal Life of Henrietta Lacks”* [20]. I was stunned to discover that well into the 1980s, malignant HeLa cells were being injected into prisoners to see if they would “take”. The Tuskegee syphilis project was still going, and even today there are no real guidelines for informing patients when their tissues or fluids are going to be used for research or commercial gain. By no one’s fault, “Informed consent” remains a nebulous dream, and the rights of those who are powerless are questionable at best.

Still, I believe the recoil away from paternalism has gone far too far. Instead of trusting whatever the doctor says to do, our patients are now given a grocery list of unweighted options while lawyers are drooling just outside the waiting room door. Once we were a profession. We’re well along to becoming shopkeepers too busy watching over our shoulders for the health inspector to remember our calling. We now sell to our “clients” or “stakeholders” – who used to be “patients”.

Many elderly don’t want a lot of falderal and jabber. I’ve had Hispanic patients listen to my protracted recommendations and explanations, then reach out, palms up, and answer, “Yo me pongo en sus manos”. I put myself in your hands. I’m stunned by the stoicism and submission to fate manifested by many seniors. But we fail them if we accept this cloak of power without adapting our guidance to their values and needs.

I have a few recommendations:

- Learn the truth of what we’re providing. Consistently, Critical Care doctors and nurses, Nephrologists and I presume other specialties overestimate the likelihood of successful outcomes at three times what is true. To an ICU nurse or doctor, “success” may be discharge to the floor. To a hospital nurse, discharge to a skilled nursing facility (SNF) or (God willing) home. To a doctor in training, success may be turfing the patient somewhere, wherever the Discharge Planner orders them to send the patient. All our dialysis patients are living. There’s no body count of those who have died. As mentioned earlier, we have little idea if they made it out of hospital, nor how long or how well they’ll live. The data are there [4, 5]. We fail our patients and our responsibilities when we deny the realities they’ll face after discharge. If we don’t know the odds, how will we guide our patients and families?

- This is way beyond mere numbers. Dr. Chris McIntyre of Nottingham, England noticed that patients passing his door on the way to dialysis were laughing, chatting, and upright. Those leaving were silent, sullen, and often in wheelchairs. One 26-year old sent him a note to the effect: “I’m not stupid. I know I need dialysis to live. But if what you’re doing makes me feel so bad, mustn’t it be hurting me?” His and other attentive nephrologists’ exploration of that question is transforming dialysis practice.
- Listen and ask. I can’t tell my patients whether I can achieve what they’d value if I haven’t found out what that is.
- The old “there are no atheists in the trenches” may well be true. Whatever we or our patients believe, the search for meaning, healing and spiritual growth are pervasive [21–23]. We should attend to these yearnings as vigorously as we treat a fever or an infection.
- Don’t offer procedures that won’t work or will do more harm than good. It’s very healing to begin, “I’m not offering you CPR because it won’t work, and will hurt you. Ethically, I can’t do that”. “I’d discourage choosing ventilation, because it will isolate you from your family if it comes to that, and I don’t believe it will lead to your getting out of the hospital. Here’s what I’d propose instead”. “You say what’s most important to you is being in the garden with your family and pets. If we go down the technologic route, I don’t believe we can get you there. Instead, here’s how we could achieve what you want”.
- One of the greatest disillusion of Hospice workers is how many patients are referred to them in the last hours or few days of life. So much good could have been done in the months prior. A patient says, “Oh, I’m not ready for hospice”. Translation: “I’m not really dying”. How about proposing an organization focused on assuring you the best quality life in the time you have left. Would you reject that? Sacrifice time to hold onto denial? The organization of which I speak is called Hospice. Our local Hospice staff assert they’re not in the business of dying. They’re in the business of fostering the best remaining life possible.
- We should be much clearer about the risks of “Discomfort Care” and much clearer about the manifold benefits of “Comfort care”. Patients circling in critical care are somewhat like battered spouses: abused, wounded, desperate, but afraid to say “no” to their abuser. We have the power to turn that “no” into a “yes” for healing.
- Our elders are getting older, our population more diverse. Our physicians and nurses are being driven out of practice earlier by the flurry of computers, computerized documentation and pathways, bean counters and “core measures”. Data show that the numbers of administrators/clerks/middle managers/surveillance personnel in healthcare are increasing logarithmically. The number of doctors and nurses is unchanging or shrinking. Income and educational disparity block access to healthcare jobs for many minority groups. That leaves healthcare providers younger, whiter (or more foreign) and less and less like those we serve. We can’t evaporate our prejudices or deny our inability to truly empathize with many of our patients. All we can do is recognize our deficiencies, acknowledge them, and ask our patients to guide us through.

5. Distributive justice

Though this may be the ethical principle on which our self-respect and our health care systems succeed or collapse, it's where we most fail [24, 25]. We talk about the disproportionate cost of sustaining the elderly with high-tech medicine. We wring our hands over thousand dollar pills and million dollar treatments when we can't afford immunizations for children. We feel guilty about America's rather mediocre outcomes in a world where most societies can afford about \$2 a day for healthcare. Two decades ago, ethicists estimated the cost that America could afford to "buy" an additional year of life was \$100,000. I can't imagine what it would be now.

But whose life? And what quality of life? In the collapse of the World Trade Center, the compensation deemed appropriate for a stock broker's life was pegged at hundreds or thousands of times the worth of a cook's life, or the life of the firemen and police who rushed in to save others, or the soldiers, airmen, and sailors who volunteered to sacrifice their lives to try to protect us from another attack.

Some years ago, Bill Mauer and the Robert Wood's Foundation put together a magnificent four-part series, "On Our Own Terms (OOOT)". You can order this, watch it, absorb it. I remember two young Asians acting as surrogate for their uncle who'd had a devastating stroke with no chance of recovery. Their decision was something to the effect, "Our culture cherishes and protects our elders. We do not want our uncle to suffer needlessly. We should stop". At the last minute, a social worker piped up, "But he has 100 days of Medicare SNF benefits!" They turned on a dime (or \$200,000.) "Oh, then we would want our uncle to be given every chance". One hundred one days later, as they became financially liable, the uncle was withdrawn from life support, never having regained function or consciousness.

So the government and insurance companies try to sway us by tamping down payment and charging us for every complication. Hospitals watch "opportunity days" like hawks or children sobbing over their last precious penny, while their CEOs are amongst the best paid in the world. Workers have to decide between lowering their insurance co-pay or feeding their kids and sending them to a community college. We bluster about "Oh, well, look at how much we waste on wars, corruption, incompetence in the public sector and greedy bankers who get multi-million dollar bonuses for causing the Great Recession".

Then we all get up, buck up, man up and go back to burning all the technologic resources we can.

We are supposed to be husbanding the 15% of our society's resources that go to healthcare. We fail miserably. So, what resources could we protect, and what remaining wealth could we help our patients and families salvage in a time of loss?

6. A sixth pillar: the final scene

The quantity and quality of additional life we can offer our elderly patients is limited. Nevertheless, the memory of that time will be particularly intense, its significance for good or ill, for

healing or harm immense, and its lifespan as close to “immortal” as we know. As with the devolution of a woman named Henrietta Lacks into trillions of HELA cells, our human touch and voice during a serious illness can shape most powerfully the individual’s sense of their value to their loved ones and their society, while confirming the survivors’ best hopes or worst fears for how they can expect to be treated by the world in which they live.

I’m drawn back to the start of this article, my brief dalliance with pediatric nephrology. Pediatricians have told me they mainly take care of the parents. Elder care may be mainly about the children – those who were created by these elders, who carry the treasures and burdens their elders passed on, and will live to make sense of what it was all about.

This “pillar” is a combination of guidance, beneficence, and non-maleficence. It’s my impression that the majority of elders understand the fix they’re in. Their main concerns are that they not suffer, not be a burden, and that the family and friends they leave behind will be ok. Most family members, when we scrape away all the internal conflicts and unspoken promises, are desperately afraid they’ll do something wrong and pray they’ll have protected and honored their parent to the best of their ability. Our actions and words can either empower and support those hopes, or shatter them.

Malidoma Some’, an African shaman, wrote, “Why do the dead walk where I come from? They walk because they are still as important to the living as they were before ... We must see our dead so that we can truly mourn them, all the way through, without restraint, to release the grief from our hearts once and for all” [26]. In the Good Ol’ USA, so many lives slip away in an air controlled hospital room. The body is whisked off to a distant mortuary to be gussied up. The last scene is to a large extent in the hands of healthcare workers. Our training for this? Nada. Our comfort with it: Nil. But like a spiritual credit card, the rewards to be reaped? Priceless.

Alas, when I offer our Family Practice residents the chance to put in a central line or intubate a patient, they’re on it like tics on a hound. When I invite them to participate in helping shape the last of a patient’s life, the vast majority suddenly have to get to that noon meeting instead.

If you’re a hammer, everything looks like a nail. If you’ve never seen a nail, you’re not going to be a very good hammer.

I describe in my book a family tearing up the place one midnight of a months-long hospitalization. They were demanding that Mom be re-intubated for a fourth time, though they knew she had no prospect of surviving. The attending Intensivist had the courage to refuse. Called in for an emergency Ethics consult, I asked did they understand she was dying? Yes. Was this how she’d want the last of her life to go? Their answer: absolutely not.

So then, what would she want? They were clear: She’d want to be in bed with her 2 dogs, that stinky comforter she always loved, playing her horrible honky-tonk music and all of us sitting around laughing and crying about great holidays we’d had together.

We told them we could create that scene. They jumped at it.

The nurses moved everything to a larger room, got the Ativan and fentanyl going. Security snuck her dogs up the back stairway. The night nursing supervisor pretended she was blind

and deaf to what was going on, while hauling heaping trays of goodies up from the kitchen. The tribe arrived and made it all familiar.

When I came in the next morning, the music was indeed rowdy, the comforter indeed well suffused with organic history, and the exhausted crowd were crashed all around her bed, reminiscing with much laughter and tears.

“How’s she doing?”

“Doc, she died three hours ago. We just couldn’t leave her alone quite yet”.

If we don’t ask, we won’t know. As with any procedure, shaping the last of life has risks and benefits, burdens and outcomes. As with any procedure, we can do it well or badly, or miss it altogether.

I believe we should craft the final scene with as much care as we do our H&P, our list of allergies and diagnoses, our SOAP plan and accursed discharge paperwork. The scene and its meaning to the survivors will live decades beyond anything else we do. How do we proceed?

As emphasized by Hospice, it’s not what we DO, but just being present. Truly present.

- Listen, learn, ask, be guided.
- Apply our and the family’s resources to create a memory which will enrich us all.
- Reassure the patient that indeed their legacy will be a positive one for those they care about, and describe how we will help make that so. What needs to be healed, what said? What will you regret not doing or saying when you had the chance?
- Don’t run away to an imaginary meeting.
- Share our gratitude with the patient and family for opening up to include us in their final scene
- Know this is the “Core Measure” by which we will be most remembered and judged.
- Don’t forget.

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