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In This Issue:

In My Opinion, Scott Sattler, MD.....	4
"Thoughts on Being Mortal: Part II....."	
Open Forum, Join Luh, M.D.	5
"MACRA REgulatory Burdens & the Treat of Phys. Burnout"	
Physicians Supporting Physicians	6
Off Call: Jack W. Walsh, M.D.....	7
Off Call: Carlos P. Sullivan, Jr. M.D.....	8
Welcome New Members.....	9
HDN Tattler	10
Coming, Going & Moving Around.....	10
Social Calendar / Friday PM Rounds.....	10
Q1 Resolutions Now Accepting Testimony.....	11
Welcome Medical Students.....	11
Health Department Update, Donald Baird, M.D.....	12
Significant New Laws of Interest to Physicians 2017.....	13
Trends in Late Stage Screenable Cancers: Cervical CA..	14
AMA Statement on Future of Health Care Reform	15
Don't Forget Deadline: Medicare Participation Status...	20
Continuing Medical Education/Grand Rounds Calendar	25
Classified Ads	26

Cover Photo

"DRIFTWOOD AND SHADOW 1"
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Thoughts on Being Mortal: Part 2

Scott Sattler, M.D.



In last month's Journal I mentioned Atul Gawande's book *Being Mortal: Medicine and What Matters in the End*. The author is an accomplished general surgeon and professor at Harvard Medical School. In this book he addressed the current state (2015) of end-of-life (EOL) care in the United States and offered his readers a set of significant suggestions to help guide each other through the murky waters of difficult potential EOL conversations.

Rarely do I read through a book three times in one month. Even more rarely do I reprint large unreferenced blocks of text by another author without painstaking reference. Suffice to say that I have now done both. I find myself compelled to elaborate on Dr. Gawande's work, addressing in more detail his perspective of the interface between medical practice and mortality and highlighting his pithy recommendations for changing the nature of our roles as physicians and patients. With gratitude and apologies to Dr. Gawande, I acknowledge that a vast body of material in this commentary has been extracted, often verbatim, from his *Being Mortal*.

On the inevitability of mortality:

It is remarkable how, despite the omnipresent clues that our bodies simply wear out, as a society we essentially ignore that reality. Fewer people save money for their retirement now than they did before the great depression. Two centuries ago the average life span was about 30 years, and now in the more developed countries it is over 80. We've never lived this long before, and this prolonged aging comes with a host of irreversible physiologic changes.

1. Difficulties eating: As we age, tooth enamel wears away allowing softer parts of teeth to be exposed to wear and decay. The flow of saliva decreases and the mouth dries, enhancing this process. Gums recede and the sensitive roots of teeth are increasingly exposed to wear and decay. Joint and muscle aging make it more difficult to brush and floss thoroughly. Oral sensory nerves deteriorate over time and we don't sense the warnings of inflammatory pain as clearly, so dental infections increase in severity. By the age of 60 most of us in this country will have lost, on an average, about a third of our teeth. Past the age of 85 nearly 40% of us will have no natural teeth at all. Chewing is critical to survival. Unfortunately over our lifetimes about 40% of jaw muscle mass is lost and our jawbones lose about 20% of their bone mass, making mastication yet more inefficient. We shift to softer foods, often with higher sugar content that leads to yet more oral infections.

2. Calcium migration from bone to artery: As we age past 50, we lose about 1% of the calcium in our boney skeleton annually and simultaneously accumulate calcium in our arteries, joints, heart valves, kidneys and occasionally our pancreas and gall bladder. Research has found that bone density loss may more accurately predict atherosclerotic cardiovascular disease than does cholesterol level. As we age, it is almost as if our bones leak calcium into our various body tissues, especially our arteries, narrowing them. This in turn leads to a higher blood pressure needed to push blood through these hardened vessels to our various organs, and this means the heart has to work much harder to generate the circulation

of blood that keeps us alive and well, thus wearing out the heart pump sooner.

3. Muscle and nerve deterioration: Starting around the age of 40 muscle mass and power begin to diminish. By age 80 the average person has lost somewhere around 25 to 50% of their muscle mass. Deterioration in the sensory and motor neurons makes even fine movements much more difficult. Handwriting deteriorates and the use of tiny keypad buttons on cell phones becomes more and more difficult. Large iPads begin to replace small cell phones. We tire more easily. A lot more easily.

4. Brain changes: At the age of 30 the average human brain weighs about 3 pounds and essentially fills the skull. By the time we are 70 brain shrinkage has created about a 1-inch gap between brain and skull, unfortunately giving the brain much more room to bounce off the skull's walls and get hurt when exposed to even minor trauma. Moreover, that part of the brain that atrophies often includes the frontal lobes, the area of the brain that provides judgment and planning. The hippocampus, which organizes our memory, is also frequently involved. Given these changes, as we age we begin to avoid multitasking as we notice our brain's processing speed diminishing. By the age of 85, for about 40% of us, working memory and judgment have diminished to the point of clinical dementia.

5. Miscellaneous other realities of aging: Useful lung capacity diminishes as our lung tissue ages and stiffens. Bowels slow down. Various sphincters lose strength and control. Skin tissue no longer sweats as well, causing dryness and heat intolerance. Subcutaneous tissue atrophies making us

***SOMETHING ON YOUR MIND? WANT TO SHARE YOUR THOUGHTS WITH YOUR COLLEAGUES?
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"Mortal", Continued on Pg. 22

North Coast Physician

“Mortal”, Continued from Pg. 4

increasingly thin skinned and prone to skin infections. Our sense of smell diminishes. The eyes age rapidly. Proteins in the lens discolor and lose elasticity compromising both near and far vision. By the age of 60 the amount of light reaching the retinas of our eyes is about one-third that of a 20 year old. The ears lose functional capacity as arthritis of the connecting bones of the middle ear diminishes transfer of sound waves to an aging sensory organ that has been progressively damaged by accumulated sonic trauma for decades.

All of these gradual but profound changes make the role of a physician much more difficult. Medical professionals mostly concentrate on repair of acute health problems and focus on prolongation of quantity of life, and not so much on the inevitable multisystem deterioration of quality of life as our bodies simply wear out. Historically physicians acquire little training to meet these patient needs. 97% of medical students in our country have never taken a course in geriatrics. This, coupled with a broad range of doctor/patient relationship styles, has led to great difficulty in providing quality end-of-life care in our health system.

The types of Doctor/Patient relationships

Dr. Gawande suggests three primary styles of relationships doctors have with patients:

a. Dr. Paternalistic -- “Doctor Knows Best” and makes all the critical decisions, telling the patient only what they ‘need to know’ and expecting patients to do as instructed. Think “Father Knows Best” and “Marcus Welby, MD” from the 1960’s.

b. Dr. Informative -- who tells the patient all the facts, good and bad, and leaves the choice entirely up to them. This can be described as a ‘retail’ relationship with the MD as the provider of information and the patient as the consumer. The role of the doc

is to supply up-to-date knowledge and skills. The role of the patient is to supply the decisions. These providers tend to know more about science and less about patients.

c. Dr. Interpretive -- This doctor’s role is to help patients determine what they want, what is most important to them, and what makes up their concerns and worries. After hearing the answers to these questions, then they tell you what path they think would most likely help you achieve your health care goals. Decision-making is shared. The physician becomes counselor and contractor on the patient’s behalf.

Interestingly, studies show that patients want quality information and guidance from their physicians while they also want to maintain their autonomy, their element of self-control.

The current shortcomings of EOL management

Frailty happens. Life is finite. Physicians of critically ill patients often come up against the unfixable. Unfortunately as a profession we frequently fall back upon the default, which is: “Do something. Try to fix something, even if it takes aggressive treatment.” All too often under these circumstances the only mistake clinicians seem to fear is doing too little. Unfortunately focus on treatment of multisystem failure with ever more aggressive therapeutic intervention simply doesn’t work to improve quality end-of-life patient care. Placing a patient’s hope on the possible success of a third-level course of chemotherapy is not a reasonable plan. It’s a wish, like wishing your ticket will win the lottery. It’s important for patients and providers alike to have a plan in place if hope doesn’t work out. We overlook the reality that ‘unfixable’ doesn’t mean ‘unmanageable.’ It is important that we help such patients develop a plan that offers their best chance of maintaining a life that feels worthwhile, by their definition. A difference in death rates can be traced to the fundamental human need for a reason to

live. The job of the physician is to support the patient’s ideal of maximizing the quality of their remaining days while securing as much freedom from the ravages of disease as is possible and retaining enough function for active engagement in the world.

Dr. Gawande writes: “Medical professionals concentrate on repair of health, not sustenance of the soul. Yet – and this is the painful paradox – we have decided that they should be the ones who largely define how we live in our waning days. For more than half a century now, we have treated the trials of sickness, aging, and mortality as medical concerns. It’s been an experiment in social engineering, putting our fates in the hands of people valued more for their technical prowess than for their understanding of human needs.

“That experiment has failed. If safety and protection were all we sought in life, perhaps we could conclude differently. But because we seek a life of worth and purpose, and yet are routinely denied the conditions that might make it possible, there is no other way to see what modern society has done.”

Approaching the difficult discussions

How are we to accomplish these EOL goals? What can we do? First, we have to acknowledge that we, as health care professionals, do not have the answers. Neither do the patients have the answers. But together we do. To find these answers providers have to have serious conversations with their patients. The following are questions Gawande suggests to help guide such a conversation and determine what a patient’s wishes and desires for end of life planning might entail, whenever serious sickness or injury strikes and either body or mind start to break down. These questions may assist one in filling out a POLST form or discussing DNAR status or deliberating another course of chemotherapy or a recommended surgery or procedure.

“Mortal”, Continued on Pg. 23

North Coast Physician

“Mortal”. Continued from Pg. 22

The Critical Discussion:

1. What is your understanding of your current condition and its potential outcomes?
2. What are your fears and what are your hopes regarding your condition?
3. What tradeoffs are you willing to make to deal with your condition?
4. What tradeoffs are you not willing to make?
5. Given all this, what course of action do you feel might best serve you?

It may be necessary for a provider and a patient to discuss the patient’s larger goals, reframing partially considered positions. Gawande suggests that if a patient says “I want more information”, it’s good to ask what the patient specifically wants to know. Don’t just automatically launch into Dr. Informative. Then tell them. Then ask what they understood you just said. Also, if you as provider are talking more than 50% of the time, you’re probably talking too much.

Interestingly, over the past few weeks I have mentioned the possibility of physicians having such a conversation with friends and family and have repeatedly received the response of “Why don’t doctors ever ask these questions! They’re so important!”

The Need for Life Stories

People see their lives as a series of stories. Again, to quote Gawande: “Technological society has forgotten what scholars call the “dying role” and its importance to people as life approaches its end. People want to share memories, pass on wisdoms and keepsakes, settle relationships, establish their legacies, make peace with God, and ensure that those left behind will be okay.

They want to end their stories on their own terms. This role is, observers argue, among life’s most important, for both the dying and those left behind. And if it is, the way we deny people this role, out of

obtuseness and neglect, is cause for everlasting shame. Over and over, we in medicine inflict deep gouges at the end of people’s lives and then stand oblivious to the harm done.”

A patient’s death and dying are two of these stories. They and their families want to be able to recall the story of a good death. The patient wants to be remembered as having had a good death. They need the freedom to shape their story, to give their remaining days meaning. A primary way to make our death not meaningless is to see ourselves as part of something greater: a family, a community, a society. We all seek a cause beyond ourselves. Our cruelest failure in treating terminally ill patients is the failure to recognize that they have priorities beyond

“Laws”, Continued From Page 19

AB 1676 (Campos) – Employers: wage discrimination

Existing law prohibits an employer from paying an employee at wage rates less than the rates paid to employees of the opposite sex in the same establishment for equal work and establishes exceptions to the prohibition based on bona fide factors other than sex. This bill specifies that prior salary cannot, by itself, justify any disparity in compensation under the bona fide exception to this prohibition.

(Labor Code §1197.5)

AB 2048 (Gray) – National Health Service Corps State Loan Repayment Program.

Requires the Office of Statewide Health Planning and Development to include all federally qualified health centers located in California in the National Health Service Corps State Loan Repayment Program’s certified eligible site list. As part of the application process for the program, the bill requires program sites to agree to provide matching funds. *(Health and Safety Code §127940). §*

“MACRA”. Continued from Pg. 5

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