

An Other Angle

by Fel Stancio

For those who gave me their love and trust, with my gratitude and love,
Felician Stancioiu

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Prologue

The following represents my attempt to bring to you, unsuspecting reader, unsolicited expertise and wisdom on the vast subject of healthcare and some related issues. What motivates me to do so? Firstly, after my Internal Medicine internship in a Brooklyn, NY hospital I have had a lot of time to reflect on issues that I let go with the flow then. Secondly, there are some changes that can be implemented relatively easy in the system and make a big difference. Thirdly and the most important is that in doing so I'm having fun in a special way, a "je-ne-sais-quoi" as the little Frenchmen in me will say, that prompted me to add stuff that I considered important to share with you.

This book is structured in two distinct parts, the first being made of the author's thoughts and experiences on healthcare as we know it and some thoughts on what it could be. Second part was added as a help to the curious or compulsive reader (I fit in this category, and I try to treat others the way I want to be treated as my mother advised me some time ago); it comprises citations considered relevant to the subject followed each by quotations which I thought may give the reader a good idea on the content of the publication. This may save reader's time by avoiding duplication of the research work that was already done by the author (...and maybe more time will be spent reading my own stuff). I felt the need to write the first part fluently and more artistic (probably because while I was typing Betty the cat was constantly trying to put me in a loving, playful mood). At the same time I felt compelled to mention the work that was done previously on the topics discussed in a more formal way (probably this seriousness is a sign of respect for my predecessors' accomplishments) and a second part was created (some may think it's the better part, but I don't want to know!). Considering that the emotion imbibed by describing my personal experiences does not mix well with the precise analytical aspect of the studies mentioned, I had to keep them separated. Although aware that this may yield an awkward format for the book, I couldn't think of something better for now.

And what's up with the title? Well... it was not an easy choice. First title chosen emphasized a certain topic and was "Dead or Alive". After a while it sounded both weird and lacking excitement (deadly combination indeed!) and with the addition of new material it was not reflecting everything covered, so soon came "An Intern's Arrogance", maybe in an attempt to rehabilitate the intern's image which received a serious blow not long ago. An intriguing title and thus a useful marketing tool, but the negative connotations were slowly catching up so finally, after coming across a quote from Albert Einstein's fountain of wisdom (and which I chose as a motto for this writing), I got to the title that you see above and I hope you like.

All stories told below involving my experience are real and unaltered by any artistic license; an eventual need for a fiction part was fulfilled by suggestions on improving healthcare delivery and was written with the sincere hope that one day they will come through one way or another. I hope there will be no need for other explanations once you're done reading the book.

“We can’t solve problems by using the same kind of thinking we used when we created them”

Albert Einstein

PART ONE

Who Do We Think We Are?

Everybody is different and unique at least from a genetic standpoint, which is a major determinant of our lives. Yet we all have something in common, something that brings us together, an invisible link. As the poet John Donne elegantly put it together centuries ago, (and was brought to my attention as a motto used in Hemingway's "For Whom the Bell Tolls") we're like an island, which gets smaller with the loss of every individual. This may seem an awkward metaphor for encompassing the human nature, but so far it's the most succinct that I have come across.

Trying a less artistic approach and going to the root of the issue, one can get a little frustrated with to say the least lack of consensus. Philosophy, as humankind's highest form of intellectual effort gave us the duel between idealism and materialism with no clear victor. No philosophical system created to date, be it idealistic or materialistic could give a consistent and complete description of world and life.

Science, more pragmatic and closer to everyday life is attempting to explain life through biology but by its own rigorous standards falls short when it comes to explaining the origin of complex life forms on Earth.

To date the only successful experiments that attempt to create life in conditions similar to those existent on earth hundred of millions years ago, were producing amino acids from carbon dioxide, nitrogen and water under ultraviolet light, high temperatures and electrical discharge simulating lightning (Oparin). The amino acids, as the building blocks of proteins are essential for any independent living being. Yet if we admit that these building blocks were created by chance in the primitive conditions dating back billions of years ago, to organize them into a single viable cell requires something much more than chance. It's like looking at a pile of bricks and

waiting for the steel, glass, plastic and wood to appear and then to organize by themselves or with the help of the elements into a beautiful townhouse. Or to expect that a group of monkeys (literally) will build a nice, functional building.

Another thing worth mentioning is that to date there is no successful attempt for making a single cell from scratch or a strand of original DNA from its building bases that can yield a viable organism. Although we have a rough estimate of the number of genes necessary to make a living cell (200-300), we don't know exactly what all those genes do and we don't have yet the ability to assemble such a structure.

It was proposed that the initial "soup" of organic molecules presumed ubiquitous in the primitive conditions found on Earth in the beginnings eventually and gradually associated themselves into more advanced forms of life. The problem with this theory is that today we know that nucleic acids (DNA and RNA) are the essential molecules of organisms capable of independent living and to think that they were synthesized from scratch it's like assuming that the above example with the self-assembling townhouse were true.

If we were to use only science as our way to describe what happened on Earth from its formation, basically we have to take the steps from the principles of physics (simple molecules, like carbon, hydrogen, oxygen and nitrogen, etc.) to chemistry (apparition of more complex molecules, like water, carbohydrates, aminoacids, various polymers) and finally to biology as the most advanced form of matter. And while the step from physics to chemistry is not as difficult to imagine, explain and reproduce scientifically, it is impossible to give ANY logical reason for the matter to spontaneously organize itself at a level which requires completely different principles and interactions. It is a giant leap that science cannot explain using any kind of logic.

Biology teaches us that a landmark of any independent living matter is the membrane, capable of separating that organism from its environment and assuring the success of homeostasis (maintaining a near-optimal environment inside that organism so that basic functions can be performed). Infective molecules such as prions (basically proteins) lack this feature, but they're also incapable of

existing without a living host and I wouldn't even call these particles "life forms". After all, there are a lot of factors capable of disrupting the existence of living organisms besides the prions and they're only chemicals. Viruses have this external coating and have little more than nucleic acids as internal components, but they generally need a host to infect; their utter simplicity confers them only very limited viability outside of being a parasite.

Knowing that a membrane and nucleic acids are essential for a living organism to exist and contemplating the formation of early life forms, we are headed towards a "chicken-or-egg" dilemma: were the nucleic acids first or the membrane? Common sense tells us that molecules as complex as nucleic acids are made only inside the cell; freely in the environment they wouldn't last, if they could be synthesized at all. So by elimination we have a very easy way out from this "dilemma", but the struggle just begins.

Previously it was mentioned that for the simplest cell to exist it takes about 200 genes, which means more than 100,000 nucleotides in that genome, and in a certain sequence. If we were to use a computer and calculate what is the chance that this will occur by chance of simply adding one of the five nucleotides to the chain, then we'll get an overwhelming number (more than 1 in trillions of trillions of trillions). (Is this how the term "gazillion" was invented?) and practically make synthesis of such a molecule no different than a miracle. Not to mention that in order to yield a viable result, one really must have a template to build such a complex thing.

So first we have to observe the organic molecules that make the membrane come together spontaneously for no obvious gain, and then in a relatively short time to have the synthesis of the nucleic acids to make the whole thing last. Pretty scary!

Another big dilemma facing "spontaneous" life formation is the so-called "Cambrian explosion", which means that after life forms on Earth consisted as single cells for about 3 billion years, something happened and multi-cellular forms of life became preponderant beginning around 600 million years ago. Wouldn't you feel like patting the dinosaurs on the back and asking rhetorically: "What took you so long?"

Getting serious now, the only alternative remains that these organisms were brought to Earth from outside and found here suitable condition for development and reproduction. This is not a new theory; one can find it written a few decades ago in most biology textbooks. But if we're looking more thoroughly, one can find this explanation of life in basically all ancient writings: The Bible, Ramayana and Mahabharata, Egyptian, Greek and Roman mythology, Central American and African inscriptions and orally-perpetuated traditions.

Really, really old and quite widespread (and really I was not even thinking of being original here).

How can then one approach this thorny issue without getting pricked? Let's try to carefully approach this like handling a rose: let's try to avoid mistakes. One of the things coming to mind here is the urge our minds feel: the constant *need* to explain everything by means that we can understand and control, which from start limits our capacity to experience everything that we otherwise could. This is not a veiled praise for drug use or a call to eliminate our intellectual skills, but a call to try and remain open to things that cannot readily demonstrated in a lab or through an experiment. We evolved from controlling bows and arrows to being able to move objects with no physical link million miles away (orbital probes and other space-age technology). And while the conquering of space is a victorious challenge for mankind, there is another one, more difficult but much more rewarding which basically means controlling ourselves in degrees we never thought possible.

In my opinion the best take on life is offered by faith and detailed in the Bible; not only this is the most consistent writing that humankind has ever known; but also the way it was written suggests a source of inspiration that is above any individual and is transcending centuries with the same ease it is offering intimate details of the people and facts described. I'll stop here in my religious diatribe, the only reason being not to scare away people who do not believe in God's awe and might as much as I do.

Hopefully you got my drift by now: while we can't leave logic and common sense out of everyday life, by the same token we can't

pretend we have the life's logic figured out to the degree that there's no gray areas, to say the least. There's a huge amount of facts that still remain to be explained in every field of science, and probably the biggest thirst of knowledge exist in biology (life sciences).

It's difficult to explain faith to somebody unwilling to listen, so please bear with me to the end and I won't even pretend I'll be able to make you understand dear reader.

One of the ironies here is the scientists' mind, which would accept a theory as evolution, which cannot be materially proven (and is being challenged by genetics), but has in its favor inferences which lead to believe something. But there is no room for the unproven (directly, as rigorous scientific standards would have it) presence of God in these brains. But if this scientist would take the time to seriously read the Bible, there are at least the same number of arguments in favor of this.

Come to think of it, the biggest obstacle in accepting faith lies in our fears and pride. The seasoned "intellectual" may reason this way: if there is somebody infinitely stronger than me than how and what portion of my life can I control? How am I really free to choose and how will my achievements stand in comparison to this absolute power?

I remember stated in a documentary that some scientists think that religion was created to alleviate the fears of our ancestors, like in this simple example: one night, while observing the sky the prehistoric loner has seen a lightning and got scared; immediately his brain thought of a higher power that produced this frightening spectacle of which he had no control over.

So it's being said that religion was created as an antidote for one's fears fueled by ignorance; one can see that in many polytheistic religions there are assigned deities for forces of nature that cannot be controlled or understood by mere mortals.

There are some problems with this theory. One might say that the opposite is true: the best antidote for fears is a logical, practical explanation, not the invocation of an overwhelming force that cannot be controlled. If we naturally fear something that we cannot explain, then to calm this fear we cannot invoke forces that we cannot understand or control. If we are afraid of the dark, we don't invent a

powerful and uncontrollable “master of the darkness” to calm us down.

Then somebody could say that “master of darkness” was created and perpetuated in order to keep others in check by playing on their fears. It works up to a certain point. For those who think that the Old Testament is not trustworthy, there was Jesus. He did not surround himself with terror or use people’s fears to get a kingdom or gain riches; yet he is indeed the most important man who ever lived and his accomplishments during his short life were the most consequential ever.

I am not trying to and I cannot diminish the accomplishments of science and technology in creating an environment that is more advantageous for human kind, this is as true and undeniable as our existence. Rather, all I am trying to make a pure atheist scientist see is that there we have limited knowledge of the things we can perceive and if one was to build his/her universe based on only the facts that can be explained, it would be a very small part of the real world.

Thus science should not be used as an anxiolytic (fear-killer) or to give us a false sense of mastery of our universe and shouldn’t get in conflict with faith for hopefully obvious reasons.

About 150 years ago, Darwin postulated that all living organisms have a common ancestor and various species appeared as a result of evolution and mainly through natural selection. Since then the principles of genetics and heredity were discovered and recently biologists are willing to accept that there may have been more than one initial organism (common ancestor) in the tree of evolution and the mechanism of evolution as a basis for the apparition of species involves genetic mutations at least as much as natural selection.

Indeed, genetics changes a lot Darwin’s theory. For many organisms in the upper echelon of the evolutionary tree, humans included, the offspring is the result of combining genetic material half of which is maternal and half paternal. The progeny is not exactly a clone of the parent, not only because of this division but also because the most important genetic changes that are passed from an individual to offspring take place during meiosis and is

completely random; not related to common-sense theory like natural selection. Changes taking place in the parents' somatic cells DNA during his interaction with environment are NOT transmitted to the offspring; there is a complete separation between the somatic cells and the reproductive cells.

The principles of evolution and those of heredity come at odds here: the former are pro-change, the latter are very conservative.

If adaptation to the environment plays a crucial role in natural selection, then one would expect people along at tropics to have much less hair compared to the Eskimos and those living in cold climates, who should be very well endowed in the fur department. Fortunately Mother Nature doesn't have to play by our theories.

Another important point may be a challenge to the "out of Africa" theory, which states that all humans have had a common ancestor who lived long time ago in Africa. (One can only imagine Eve getting hints from other animals including the serpent while trying to persuade Adam that "he's the man" and generally speaking that he's doing a good job, and this happened long before marriage counseling and Viagra were discovered).

Looking back it is quite possible that Adam was not aware of his cousins living abroad and when his sons and grandsons found this out they also discovered they didn't know how to live together well (or peacefully coexist, to use the politically correct term).

Considering that present day continents were separated for more than half million years ago, there's another big question mark on the existence of a unique common ancestor. There should be a common path of evolution from monkeys to Homo Sapiens Sapiens on all continents. The oldest boats are no more than 10,000 year old, and for the primitive Homo Sapiens of Africa to travel more than 10,000 miles through Siberia to get to Alaska only to get back south towards Central America just after getting used to the taste of snow seems like a hard sell. Also, consider how well-entrenched human populations are, even today after inventing all kind of gizmos that make travel much easier. Do you think that our presumed ancestors, without fire (which dates relatively recent) or horses (and no close relatives to visit for holidays in remote places) would just adventure

in new places for the pure exploratory joy? And still will be a mystery about why and how the isolated human communities in remote islands of the Pacific and Americas were formed, considering the striking resemblance in the gene pool.

Gene mutation occurring during reproduction is random; for very similar results to happen in a multitude of different places is something much less probable than winning the lottery in a few generations.

What alternatives are there?

We know that genes are the basis of heredity and the best material definition of a species.

According to evolution, the best individual traits are passed on to next generations through natural selection providing the way of perpetuation and progress for a species. I think that in humans natural selection plays at best a marginal role. Hint: would you just stand there and watch while a beast or a disease or other natural occurrence is massacring your friend? I hope not.

A real example is offered by the inhabitants of ancient Sparta, who would throw off a cliff the children considered to be too weak or otherwise unfit to live, and give us the whole story of what can happen to a society which only values certain qualities. By eliminating the ones thought to be bad, theoretically they should have only benefited and thrived, win wars and conquer the world. But history teaches us otherwise.

I always wondered why would a monkey consider itself better off with no facial hair and no tail? I think that in a world with no stock market and fashion magazines, serious female would think twice before considering having a baby with such an incomplete monkey geek.

Why lose the body hair at all, after all? Only to replace it with wearable pieces subject to fashion changes?

And why would the monkey feel a need to get social on each other and talk instead of using the very efficient sign language with the occasional shouting or moaning? Or was it again the lone, hairless, tailless male trying to impress the unsuspecting female

monkey and the ulterior need to brag about it?

And again, why and when human ancestors felt the need to cover specifically their genital area with pieces of clothing that certainly don't have a warming or protecting role? This again has nothing to do with adaptation to environment and certainly was not dictated by natural selection.

Speech and symbolic representation seem to be though an essential trait in humans, since it appears all over the globe, across all human populations and in an independent fashion as it was developed in ethnic groups with no contact between them, producing different languages and dialects. (So the biblical explanation of the language barrier makes sense).

I think that the theory, which implies that "work created the man", is incorrect. Firstly, according to the Bible toiling the soil was given to man after his creation and as a punishment for disobedience.

But for those in search of a logical argument, if we see work as a planned effort then it is not specific to humans. When a bird is building a nest it's not just putting a piece on top of another, but building something with a very precise purpose and timeframe. And although it doesn't use blueprints, it certainly is a directed effort (and who knows, maybe birds do brag about who's nest is roomier and safer). There are certainly more examples in the animal world of directed small changes in the environment for habitat or reproduction, although not as spectacular as the human imprints.

Work does not have to be a conscious effort as we may perform physical effort while our thoughts wander elsewhere, and as stated above organized effort is not specific to humans. As for work as a conscious, carefully planned effort as a hallmark of human brain, I think there are great limits to this concept also.

Where would stand an artist's creation or an inventor's effort without inspiration?

The artist cannot plan to be inspired and the scientist may spend years or decades in worthless effort if an original contribution is not made.

A popular quote says that genius is 1% inspiration and 99% perspiration. While it is true, if you take away the 1% you are not left

with anything remarkable.

Probably the biggest single difference between animals and mankind is not the ability to work or the opposable thumb or some physical trait, at which man is mostly outdone by various animals.

The biggest difference, as stated above, is the ability of symbolic representation and abstract thinking. We have first proofs of it with the first drawings and ideograms. I think that the first symbolic representations uncovered by archeology, starting around 40,000 years ago also mark the first manifestations of mankind as we know it. Whether it initially served a practical purpose (marking a territory or event) or pure artistic expression, this remains to be seen.

After the mapping of the human genome and SNP's (single nucleotide polymorphism) and using recombinant genetics models we get hints that Homo Sapiens Sapiens (as biologists like to call us) existed in this actual genetic shape for less than 100,000 years. You make the connection (you the man!)

In other words, if a monkey uses a stick to draw a few lines in the dirt, it would not make another monkey think of a representation of (for example) another monkey (or animal) as is the case with humans. Otherwise it wouldn't be long until they proclaim their own Valentine's Day and fill zoological gardens with graffiti, among others.

Yet the monkeys have forms of communication and social traits that allowed them to survive and thrive in their environment.

Finally, if the increase in brain volume from monkey to man was the result of more usage and knowledge, how come that during the past 10,000 years, while the fund of human knowledge and brain functioning grew exponentially, the brain volume remained constant? Will the "brainman" replace the outdated man? Any sightings of these "brainiacs" in Silicon Valley? So far they're no claims.

Or will natural selection yield something with a Michael Jordan/Mark Spitz physical traits, the brain of Einstein/Mozart, the looks of Mel Gibson/ Brad Pitt and the spirituality of a religious leader? Given the way society rewards its winners nowadays, this

would be an obvious direction for natural selection.

Sounds improbable? Would it be easier to accept this idea if through the same process we'll have somebody with the looks of a female supermodel, an immeasurable IQ and the heart of Mother Theresa?

It would be very difficult indeed to cram "all the qualities you can handle" in one person.

To understand better how efficient and simple in dealing with complex situations is God's work, yet way too overwhelming for man's brain using today's knowledge and technology, a recent example is given by a IBM project to make a supercomputer for simulation of protein folding.

This supercomputer (projected date of completion is sometime in 2004) that is 500 times faster than the fastest supercomputer in use today, while it's able to process in real time the information that simulates a nuclear bomb detonation, on the other hand to simulate the creation of a protein from the genetic information (DNA and RNA) existent in every cell, using software that was not yet written will take about a year. For comparison, in every cell at any given instant a new protein molecule is produced; the human body has about one million different kinds of them. So we still have a long way to go just to reproduce the bearings supporting life; and still much longer to claim some control over these processes which happened long before any of us knew there is such a thing that we call today a protein.

I think this is a good development, as I am a great fan of medical research including bioengineering, but I hope that I'll never be the subject of technology that is attempting to reinvent or replace life. For now, it would be similar to me trying to make or repair a space shuttle.

To think that the arrangement of the 3 billion base pairs that make the human genetic book is due to chance is a scary thought.

And to copy this book billions of times with only about 3 million different “mistakes” (there are about 3 million SNP’s to date) is also mind-boggling.

Using a comparison, a book is more than a succession of characters on paper. First, it is the expression of someone’s thoughts by the means of a defined vocabulary. One can get by decently using an alphabet and a thesaurus of 5-10,000 words. All living matter is written using an alphabet of 5 letters (C, A, T, G, U) which by repetition make a different number of genes (words), about 80,000 to 100,000 in man’s case.

So far, our attempts to imitate life make use of an alphabet comprising of only two letters: the binary code of the computer, which are much simpler and therefore more versatile, but require much more computational effort.

The five letters of the genetic alphabet also have a relatively simple backbone; so that from more than 100 elements to chose (the chemical periodic table) it was made from only five elements: carbon, oxygen, hydrogen, nitrogen and phosphorus (molecules other than DNA, such as proteins, enzymes and so on have other elements in small quantities– calcium, iron, magnesium, chloride, sulfur, manganese, selenium, cobalt, etc).

When we read a book it’s more than just the words that we register, and sometimes more than an idea impresses our brain. Some books can influence the way we think and subsequently our lives. Maybe humans’ genetic book was written as the book with most meaning, a Bible of genetic code. But it has to make sense for somebody. SOMEBODY.

It took three centuries for church to admit (although the opposite is not specifically mentioned in the Bible) that Earth is not the center of the Universe.

And as much as it is difficult to prove God’s presence, it’s not easier to come up with material proof of speciation.

One of the ironies here is the scientists’ mind, which would readily accept a theory as evolution, which cannot be materially proven and is being challenged by genetics, but fits very well in the scientific puzzle of self-sufficiency, but not something equally mental

and difficult to prove like faith. The only suggestion I have here is that if this scientist would take the time to seriously read the Bible, there are at least the same number of mental arguments in favor of life as a gift from God, as there may be observations and inferences that led to development and general acceptance of evolutionism.

Considering that science prides itself as being much more logical, should we expect a move on its part any time soon?

Whassup, Doc?!

Medicine, when seen as the act of providing care to a person in need is one of the oldest professions known to mankind. And although no ancient archeological site shows representations of people wearing white coats, it is safe to say that herbal potions and various concoctions administered with or without a magical element is older than the earliest representations of engineers, economists, and lawyers among others.

This long and glorious history not only creates prestige and pride, but on the flipside it also created a lot of conservative attitude among its professionals.

With this in mind it is safe to say that no profession had to deal with a comparable intense assault of technology directed at its very core as medicine has been subjected in the past six decades. Beginning with the discovery of penicillin, description of DNA and continuing with the very contemporary human genome project, medicine had to re-write a lot of its rules on the go and adjust substantially.

To get a better idea of this very impressive resilience, I'll mention that until 17th century and the majestic contribution of William Harvey (*De Motu Cordis...*1628) who ended a centuries-old dogma on the principles of circulation of blood and functioning of heart, blood was believed to flow through pores in the heart septum connecting the left and right side of the heart. A doctor's main treatments were phlebotomies, enemas, purgatives and the occasional mercury salts. This is perhaps the time when medicine defined itself as an art, probably because the doctor had to rely mostly on his subjective perceptions, common sense and intuition rather than scientific arguments which were practically reduced to gross anatomy.

Making serious science with the human body as the object of study has always been difficult due to what's at stake. Systematic anatomical studies with a medical purpose were only started during Renaissance and it took centuries to complete an accurate anatomical description of the human body, sometimes with dramatic sacrifices.

Michael Servetus was burned alive after his major contribution to human anatomy that turned out to be a big sore in the academic eyes of his French colleagues. By describing the minor (lung) circulation he dare to challenge the centuries-old medical dogma developed by Galen and in the ultra-conservative world of medicine this was perceived by the doctors of his time as a heresy and effectively doomed.

Another illustrious example is that of Andreas Vesalius, the doctor who revolutionized the study of human anatomy by publishing in 1543 one of the best-known anatomy books of all times (*De Humani Corporis Fabrica*). But after finding numerous points of contention with the current medical doctrine of Galenus in numerous ways, he found himself at great odds with his colleagues and had to seek the protection of various cardinals and the emperor, abandon his studies and limit his activities to being a court physician.

As a parenthesis, we all know that medicine has a lot of syndromes and body parts named after the many outstanding doctors and scientists, but for me it's mind-boggling and discombobulating at the same time if I may say so to see so many people honored while Servetus (who even lost his life over his discovery) and Vesalius contributions are a mere footnote by comparison and time does not seem to run in their favor.

There were many important contributions in the advancement of medicine; I'll mention only the discovery and development of the microscope by Antoni van Leeuwenhoek in the 18th century, which brought in a new dimension of life and was relatively rapidly followed by new contributions. Although this may be regarded more as a technical achievement, I consider this a milestone because it opened research from dealing with systems and organs to smaller units like cells and concurrent with developments in chemistry and physics pointed the knowledge horizon in a new area which culminates today with the attempt to describe letter by letter the genetic book from which every human being was written: the human genome project.

It is not very obvious to realize its importance for mankind

today (mainly because of the lack of historical perspective and lack of immediate applications to translate in therapeutics), but I have no hesitation in placing this endeavor above achieving the splitting of the atom and the man landing on the moon.

Another important achievement is that for the first time in humankind history a project of such magnitude and importance was done through the collaboration of scientists across the borders of many countries: universities from US and Europe, US federal agencies and private, for-profit companies were working together (for the most part) on this project for more than a decade. It is an extraordinary achievement and hopefully a precedent that will be amply continued.

One would think that given the fact that the human body is a finite entity, by now most controversies related to it should have been resolved given the extraordinary advances in science and technology. Yet paradoxically the more advanced the knowledge and research gets, the bigger are the dilemmas facing healthcare and medical ethics. The struggle of Leonardo da Vinci, Andreas Vesalius and others (let's only mention that for fear of persecution by church who was not allowing dissection on humans, Da Vinci was digging fresh graves at night for dissection material and was using an encryption method for his manuscripts) seems to pale in contrast to the controversies and limitations that are placed today on genetic research (one thorny issue is the use of embryonic stem cells) which although is very promising, also has potential for producing disasters if important aspects are not controlled. But if history is of any help here, one can only say that time alone will give us the right answer and if undue restraints are being set on a good research path, sooner or later the good results will prevail.

An old medical adage says: "treat the patient, not the disease", yet for the many billion different people today we have only a few thousand medications and treatments available. The hope is that after the human genetic map is finalized and new, more efficient and safer techniques of intervention at the gene level are developed, everybody will have the "silver bullet" for a body close to

perfection.

And maybe we'll discover that the way to perfection doesn't include the creation of a "superhuman", but instead is the effort to improve everyone's imperfect life, which is already the biggest gift that was mysteriously granted to us.

We may also have the answer on whether genes can define life. As we are getting closer to find the minimum combination of genes, which can yield a viable organism, there is a strong temptation to think that genes equal life. We should not forget though that present studies already place important question marks on this equation. Monozygotic twins, having the exact same genetic endowment, are still different when it comes to behavior and predilection for certain diseases, especially when they are raised in different environments.

Anyhoo, after this short immersion in the evolution of medicine, I'll fast-forward to today's medicine and the way we all know it: the healthcare industry.

With the massive implementation of technology, over time medicine became much more a science than an art. Probably during the 70's this combination was very well balanced, but then things went beyond this point and today we stand at a different conjecture.

Many different factors are at work simultaneously: the pressure of lawsuits, the way of rendering healthcare within the constraints of insurance companies requirements and well-defined therapeutic pathways. All this and more have made the medical profession much more standardized in its practice and today what was once an art and a science was transformed in a service industry with more than a trillion dollars annual budget.

From a consumer's viewpoint, the use of the most impressive techniques lead many of us to believe that anything can be done for an ailing body, tending to forget the millions of people who under the current system cannot afford to see a doctor. But more on these aspects on the next chapters, for now I'll focus on my own experience within the industry with a few stories that I hope you'll find interesting.

Everybody knows that there are quite a few differences between what is being preached in school and real life. For me, the difference between the idealism of the medical school years and the harsh reality of healthcare delivery was immense, but looking back it was a well-worth experience.

One patient that I distinctly remember as making me think beyond the letter of the textbook was this thirty-something year old woman with a thyroid gland problem. She was my patient during her in-hospital treatment for hyperthyroidism (over-active thyroid gland). She was admitted with symptoms of “thyroid storm” which included a rapid heartbeat that put extra strain on heart muscle. The anti-thyroid medication that she received, although efficient in treating her hormonal excess problem was also affecting her heart through direct action as a side effect and she subsequently developed cardiac “insufficiency”. She was walking on a thin line with her medication: cutting on the anti-thyroid meds would have improved the heart function by eliminating the direct negative effect on the heart muscle but left the root of her problems unresolved which meant that her heart will get “tired” by beating too fast because the thyroid gland was unchecked; on the other hand increasing the thyroid meds would effectively solve her thyroid problem but would cause direct damage to her heart, with death being very probable outcome. Those of you who have dealt with hyperthyroid people know that such patients are difficult to manage due to some psychic changes that are being experienced, and she was no exception by being hyperactive, irritable and not good at following indications given by the medical staff. Not rarely she was going to secluded areas of the hospital for smoking while she was supposed to stay in bed with legs elevated because of edemas (a weak heart makes fluids accumulate in the lower parts of the body). Dealing with her was always an exercise in patience and I felt a bit lucky when she left the hospital on her feet; she promised to follow-up in the clinic, which given her non-compliance, I didn’t expect to happen.

Soon I found my profiling quite inaccurate when she was back in my care with a vengeance. As a bonus she developed the “give-the-intern-a-hard-time syndrome”, a contagious disease afflicting

nurses in teaching hospitals which she devilishly adapted to the “patient-is-your-master-to-the-point-of-tyranny” situation by making it self-rewarding and difficult to diagnose (one hint I got was that at times she harbored a mischievous smile).

But I digress. She was giving everybody a hard time (her first visiting nurse quit in frustration after a couple of weeks). Without being asked first (and by a completely unreasonable reason which to this day continues to obscure my intellect), I was given the role of mediating between her and the other people involved in her care: the endocrinologist, the cardiologist, the visiting nurses, later the gynecologist and so on.

Later on, because I seemed to have become immune to her abuse, and having no other practical explanation for my persistence in this hazardous situation for one’s mental health, people were starting to suspect some personal involvement on my part (“maybe he likes her, what do you know!”). This was like telling me I’m a masochist and enjoying every minute of it. OK, wait, it’s getting better.

At some point, with her thyroid still being a problem, her heart still not back at 100% and our ongoing fight with her for taking (or not) her medications (which she admitted of skipping for days or pausing with no particular reason), the gynecologist needed to do a procedure to rule out cervical cancer. But for this she had to get medical clearance, which implied that somebody guaranteed (possibly with her/his medical license) that her heart can get through surgery with the associated anesthesia and implied risks without causing illness or death.

Although her previous EKG’s were OK, considering her thyroid and her recent episode of heart trouble, nobody wanted to take chances and she was told to have an echocardiogram done. I felt relieved that after two missed appointments she came in with the good news (just having something done was good news on her) that she had the echo performed and the results were due soon.

Meanwhile, the gynecologist was writing nervous notes in the chart about her missing the procedure, which could detect an eventual cancer, and delaying the eventual treatment was not a good

prospect...

So at the next visit in the clinic, after the routine exam and short history, I was on the phone with the Cardiology assistant and very happy to get the results of the echo, which were showing a heart in normal limits. A very short-lived joy, that is. As I was ready to write the result on the consult paper recommending the procedure with no hesitation, she then considered appropriate to disclose a minor detail: It was not her who had that echo done. "What do you mean", I inquired, totally confused, hoping that she was not having an episode of depersonalization. "It was not I. It was my sister. She had the echo done instead of me," said she with candor and a smile.

At that time I didn't know whether my jaw dropped because of amazement or frustration as in a moment taken out from "Candid Camera", but instead of trying to figure it out I picked up the phone and arranged for another echocardiogram. This time I wanted to make sure that she won't reach into her bag of tricks, so I had her promise that she will not try to surprise me again. Fortunately her heart turned out OK, the procedure was performed and it was no cancer. And no, I do not miss her as a patient or in any other way!

From a doctor's perspective, fighting a patient's death and losing the battle is the most unforgiving, irreversible happening, the biggest fiasco possible, and the worst imaginable outcome, The Disaster. So what would the doctor's doctor recommend in such an unfavorable circumstance?

The circulated wisdom on a doctor's emotional well-being is that the best protection is emotional detachment. Young doctor, be advised: try to act professionally and do not feel anything. Otherwise, emotions will cloud your intellectual prowess and worse, you'll get hurt if things don't go well. While this may work in many cases (and I have seen some using it so efficiently it was scary), as is the case with many theories there are shortcomings, too. Problems occur when some bonding happen through the cracks and pure denial is not enough to overcome the eventual loss, even for the ones who pretend that are very tough and nothing gets to them. In fact, it

is for sure that during any doctor's career such bonding will occur sooner or later and they will remember at least a patient very fondly. But the biggest problem that I see with this emotional isolation theory is that it is cutting short the doctor-patient relationship, and this only aggravates today's problems within the managed-care environment. Indeed, the time the doctors spend with patients today is at a big premium, and combining this with the emotional detachment, the result is that the patient is seeing a very rushed doctor who is a bit on the cold side, leaving the patient with the feeling that doctors today don't care for their patients any longer, but only for the material compensation of their effort.

In some situations, this may be right. After all, it's not easy to forget that today more than half of doctors go into practice with loans in excess of \$100,000 and the sword of a lawsuit hanging above their head, waiting for the right time to drop. On a different level, all of us have had unpleasant encounters with a healthcare practitioner. Someone said that even regular drinking water when prescribed by the doctor will have a bitter taste.

From my experience, I can say that there is good and bad in each and every one of us, and nobody is 100% all good or all bad. (yes, this rule applies to doctors, too) and we shouldn't categorize somebody based on a single encounter in a given set of circumstances, which can be very partial. We all have our imaginary index with "good" and "bad" people, only to be surprised when things don't turn out as expected, at least not as "black and white". Call me a hopeless romantic, but we are surprised to find out some morals and generosity in some thieves or when notoriously mean people do things that save the day. We also heard of "good people" doing very mean things, shattering reputations and leaving people wandering who and what to believe in anymore.

And no matter how well you think you know people, you can still have surprises. I lived through one such experience during my internship, which involved one of the attending physicians, Dr. B the gastroenterologist. The first time I got to know him was during the in-hospital stay of one of his nursing-home patients. Seventy-something, lethargic, with a feeding tube inserted through the skin in

her stomach and a lot of decubitus ulcers (skin lesions), she was admitted and being treated for an infection, when her feeding tube got clogged up and had to be replaced. After repeated attempts to reach him, Dr. B told me that I should replace the tube myself, which seemed overwhelming for me, so I asked for my senior's assistance. The third-year resident was surprised, saying that residents don't do these things, so I asked another attending, a nice gastroenterologist, for his help. He easily solved the problem after mentioning that he is NOT doing this favor for Dr. B.

Now mind you, over centuries medicine has coined such a term as "invidia medicorum", which is the Latin for "doctor's envy" (that is professionally, among themselves) but something seemed not right here, and although it was so unlike me, I started paying attention to the gossip on Dr. B, as the only source of intelligence on him. (To make it more objective, I asked different people and I kept for myself only the stories confirmed by multiple sources).

He had an intriguing history to say the least, and I'll only mention that he is the only doctor that I know of that was shot by one of his patients. At first it was difficult for me to believe, for this was far from the image of a doctor that I was cultivated in my mind throughout more than a decade in the field. But everybody confirmed the fact and I had to accept it as a sad truth. Simply, a patient asking for his assistance got so frustrated with his attitude that at one office visit he gave Dr. B his feedback on the matter in a very straightforward manner: a bullet from close range. Not your usual office visit, I reckoned.

Nobody told me if he started wearing a bulletproof vest or if he was getting a "hazardous conditions" bonus for working in such dangerous circumstances, but some speculate that he became somehow disinterested in his patients, except for the financial part or legal obligations. There were colleagues saying that he was in competition with another gastroenterologist in Queens for who is doing more procedures (in their case being upper endoscopies, flexible sigmoidoscopies and colonoscopies). It was a close race and Dr. B was trying his best, not losing time with patients who did not require a procedure and at the same time trying to make the procedure more popular among his patient population.

I had to take care of two or three more of his patients; the last one was a ninety-something year old lady who was sent from the nursing home for admission in the hospital because of persistent anemia. Most probably a remarkable woman a few decades prior, not much was left of her now: a wasted, very thin body seldom covered by the hospital gown because of her agitation, a gray, wiry hair in disarray, blue eyes in constant motion and a thin-lipped mouth which was her most used body part because she was always shouting and screaming or voicing her constant discontent of the care received and her many fears, including that of dying soon (which did not happen). This pathetic picture was not telling the same story for everybody, and while I have seen her son at her bedside with tears in his eyes, for other people she was just another difficult elderly patient.

It was obvious that nutrition was far from adequate for her. To make her swallow a cup of milk and cereal would take at least 15 minutes, and as the nurses were too busy, the task was delegated to volunteers and student nurses, all of whom didn't last too long on the assignment. One can easily imagine that she was not eating well in the nursing home.

A feeding tube was not yet inserted mainly because she was conscious and able to swallow; but also she was very non-tolerant about needles and tubes stuck in her, eliminating this option unless adequate sedation was to be administered. Although we tried to keep medication to a minimum for reducing the side effects, we had to administer her sedatives, and even so she still had her wrists tied from time to time. Her veins were thin and fragile, and I was happy to have a line inserted in her femoral vein upon admission, after the nurse and myself poked her unsuccessfully a few times in her arms and hands. The next morning though, the line was not there. The nurse told me that the patient pulled out the line herself despite the stitches, which were torn but still in place. A second line was then inserted and after the history repeated, wrist restrains and sedation were an important part of treatment.

Anyhow, getting back to Dr. B, he decided that the patient should undergo a thorough evaluation and (you guessed) the customary upper endoscopy. To prepare her for the procedure was

easy: nothing to eat from midnight before, and although it may not have been easy to perform, the result said that the stomach lining was somehow shrinking (mucosal atresia) with mild irritation. Not an explanation for her anemia (not to mention that one expects to find something at a ninety-something year old). So for the next step in diagnostic, an assorted colonoscopy was ordered.

I have to mention to the uninformed reader that in the event of finding a polyp (a growth of tissue in the intestine) the biopsy or excision that follows means an added payment. Also, the probability for such a thing to happen is increasing with age.

Now the preparation for colonoscopy is not as much fun: added to the no-eating order is the needed enema the night before, which of course was a no-no for our rebellious lady. The nurse did her best and prepared the patient, but after the patient returned from the procedure room, all I could read in the chart was that the colonoscopy was only partially completed, because of poor preparation. (euphemism for feces in the patient's colon). A messy job indeed.

I was happy thinking that the patient's gastroenterologic adventure will end here, but well... the call of the polyp was still there and to everybody's horror, the patient was scheduled again for a colonoscopy. I was starting to see Dr. B as a monster with dollar signs instead of pupils, but I couldn't do anything but talk to colleagues and nurses and wait for the result.

And on the day of the procedure after the patient was wheeled back into her room from the endoscopy suite a little too quick, I took the chart to read the findings... to my surprise I found out that the procedure was not performed due to poor preparation. Again? No, not again, the nurse explained to me with a wink: Dr. B did not even attempt the procedure this time.

Ta-taa. Ladies and gentlemen he was not a monster after all.

Going back to a doctors' image, I may add that when the patient judges the doctor, there's a lot of perception involved: I have seen patients frustrated after seeing excellent doctors, mainly because of miscommunication: the doctor is very busy and the patient very anxious and things go out of control easily. And I have seen patients

being happy with sub-mediocre medical advice just because it was presented in a confident and nice manner to them.

Overall though the medical field is not different than any profession, with different people of different natures. It resembles a forest in the sense that while there is some dead wood, it is impossible not to see the beauty of the living trees, which make a majority and define the word.

In my short time as a practicing physician I have come across and tried to avoid doctors who regard patients as materials for professional use, unable to give something from within their human nature which in some cases may have had salutary effects for the patients. I was also fortunate and have nice memories of working with many doctors exuding with warmth, understanding and genuine care for their patients. And contrary to the circulated opinion, this was no obstacle for them being excellent professionals on the technical side, too.

It has been always a pleasure seeing Dr. N the cardiologist during his morning rounds within the cardiac step-down care unit rotation: his bedside manners impeccable, his presence filling the room more than the herd of young doctors trying to learn the secret of practicing medicine (me included), his distinct English accent acquired during his postgraduate training reverberating with clarity and transcending everything with inimitable warmth. He had the peace and understanding of somebody who has been through many combined with a degree of respect for the patient regardless of status, that for others was difficult to understand. The patient felt right away and responded by trusting and respecting him. This may be also a reason why I do not remember him getting in awkward situations with either patients or staff, which cannot be said about all doctors that I've known at that hospital.

But enough with mercilessly throwing compliments at others. Hey, maybe the guy won't even like it, and besides there's always me, readily available for dissection and starving for your attention.

Talking about doctors' emotional isolation in my case and my bold attempts to get this "human teflon coating", I remember that I could do it in every circumstance before. I did it in my first year of medical school during cadaver dissections, while learning to think of the corpse as a didactic material and no more. And later with the physical exam, while learning to educate my senses previously used for different purposes, in a purely professional manner. And yet again after finishing medical school when dealing with my relatives, eager to test and benefit of the fresh doctor within their reach; I had to learn to look at them as patients and try to get over my subjective stereotypes. No problem with these. But I still couldn't get over this helplessness in face of death. Then again, maybe it's normal to feel that way when you're in battle with an enemy that you know that sooner or later will win and you can't do anything really significant to keep it from happening.

I remember Albert, the prostate cancer patient. He was admitted to the regular floor in my care in the midst of my internship. He was speaking little, very polite and at the same time weakened by his chronic illness, thin but not fragile, far from giving up. He had these silver-rimmed reading glasses on and he looked like he was getting a lot from this seemingly important book that he was reading when I was entering his room. He was also very alone; the only visitor who showed up in a while was his daughter, a nice person but also busy with her own problems at work, her kids and husband. After a few days of struggling and constant deterioration, which was regarded as normal for a patient with terminal metastatic prostate cancer, it was obvious that he was going to leave us. I had his daughter sign the DNR "Do Not Resuscitate" order that night, trying to explain the futility of efforts; I told the second-year resident that most probably Albert won't be there in the morning. For a while the "human teflon coating" worked. Come morning though, after learning of his death, somehow I felt the need to see him. Probably because it was for the last time. Or probably because somewhere I secretly hoped that he would forgive me for not fighting more for him after he trusted himself to me. Forget about the senior residents, attending; I felt that I was his closest ally and his last line of defense

in his fight with death. I couldn't let go; so I went to the hospital morgue, and getting past suspicious and surprised people I had one last look at him. I could barely hold back my tears, but although I knew I was pathetic I didn't have any room for feeling embarrassed.

And there was George, who I would only see for one intense night; asthma patient admitted on the regular floor after one exacerbation. Well built (around 250 lbs.), about 70 years old; who would imagine that his heart will stop beating during his nebulizer treatment around 2 a.m., freaking out the respiratory therapist and the nurses on the floor? Nobody saw it coming. And yet nobody in that room expected him to recover so quickly after CPR. We were looking at him in disbelief: his heart was not beating for minutes in a row, yet half an hour later he was fighting us (and he was fighting like a wounded bull) shouting that he did not need our help in the first place and his rescue came from God. Nobody could argue with that, and we were left treating him like a stubborn kid, under his verbal and physical abuse; there to help him as we could, but against his will at times. Bitter victory, but what a memorable night!

Then I remember standing in ER very early one morning towards the end of the shift, in a zombie-like state and watching a nurse trying to give the treatment to a patient who was cursing her, spitting and fighting. I didn't ask her, but I wonder if she ever thought about that patient as her kid or if she was trying to compensate with her own heart what doctors could not offer.

And lastly from this series of memories I'll mention a short story that illustrates how easily is to make mistakes just by following the established guidelines while not paying attention to the actual patient.

This happened during the Critical Care Unit rotation. We were doing the morning rounds and the second year residents were presenting the overnight admissions for the attending who that day was the director of the unit, and their colleagues. The intern (me that morning) by tradition was a negligible quantity supposed to do the

mundane functions: arterial punctures, insertion of naso-gastric tubes, paperwork for radiology and otherwise observe and keep out of the way of “real” doctors.

The patient presented to the attending and colleagues by the second-year resident was a male in his sixties admitted for gradual onset of “altered mental status”, which for him manifested as feeling weak, dizzy, with slow thinking and speech progressing to lethargy; left untreated this could lead to coma and subsequent death. There was no clue about the cause of his problems, but after the analyses taken at admission indicated that his blood sodium was low, he was given perfusion with “normal saline”, which is supposed to bring sodium in the bloodstream and hopefully correct the deficit. Not for him, though; latest tests indicated that the blood sodium stubbornly stayed at low levels, prompting the resident to present as probable causes (and tentative diagnostic) a hormonal anomaly (over secretion of antidiuretic hormone), a renal problem, and a whole list of other potential problems for which the testing and treatment was ongoing. After the resident’s presentation, the attending started to examine the patient for herself; first step being a short interview, punctuated with questions from anybody who felt that something ought to be addressed. Anybody but the intern, I may add. And the questions started pouring, supporting any diagnoses and not showing any progress.

Well, in retrospect I wish this question had come from somebody else, but after waiting in vain for it and exasperated that things were going in the wrong direction (after all, one of the chief residents was wondering aloud during a morning report “how come patients are admitted walking, talking and then die within 48 hours of hospital admission?”), I lost control of my oral sphincter (my mouth that is). Without any introduction I asked the patient straight how much water was he drinking daily. The answer came very promptly and with dramatic effect: he was getting two or more gallons per day for the past couple of weeks. And probably seeing the expression on the faces of doctors and feeling that an explanation was needed, he gave it to us: somebody advised him that drinking more water will help eliminate the body toxins, thus make him healthier and eventually live longer.

Needless to say that under the circumstances the opposite was closer to reality, prompting the attending to stop the normal saline perfusion on the spot. The patient was transferred afterwards to regular floor instead of CCU and discharged soon. And my popularity among the senior residents was again starting to soar, this meaning that everybody loved to hate me.

The main reason I was bothering you with this rather self-centered storytelling is for you to understand that somewhere in their hearts most doctors care, although not always they care to show it.

At the end of this section I have to confess that the selection of stories that happened during my internship may not include the moments when my performance was not as good (for example when I was tired during calls to the point of getting irritable and my failures in getting blood from patients that I considered would be needlessly punctured). Also, the occasional propping of my boss's self-esteem (kissing-up) as an essential tool in the intern's survival kit. And of course the mistakes that I'm not aware of; at least I'll be excused from mentioning these!

...well I may say in my defense that I did this in an effort to be liked (...loved, if I'm not asking too much, but in any case, trying to speak the same language) by the people to whom control and power is the most important thing in the universe and others' mistakes may mean a major throw-off (for themselves, it is expected they make a few errors every now and then, which comes especially handy when it's on other's expense and may result in an advantage for them). This is the kind of people for whom 2 and 2 may equal 3 or 4 or 9 or -12 or whichever depending on the situation, as long as the result assures that they are still in control and sole possessors of the powers. And if you know somebody around you who's acting this way, you'll understand why I didn't put much emphasis on my own mistakes. By the same token, I have no problem sharing my own bad experiences with people who show genuine care and understanding.

Cover this! (...medically speaking)

So the doctor sees you because your pain in the...(wallet is the first word really coming to mind) and without delay orders a few tests which if you're lucky are scheduled all the same day. Then you begin to get more comfortable with the idea that something may be really wrong with your aging body and will eventually be picked up by some cold machine and hopefully unhampered by some unfortunate error. Then somebody lets you know that *the test* is not covered by your insurance. Or you need a written approval. Or another referral or another piece of paper or just another signature from a very busy person. All too familiar, isn't it?

The following section may offer some hope; please have patience while I'll gradually introduce you to a new type of insurance (and what's even better, I promise I won't make you buy it!)

Besides the kind of limitations mentioned above that make the patient's life miserable, there are other important reasons why a lot of people are unhappy with the current medical insurance coverage, including healthcare providers, economists, politicians, etc.

If you're willing to listen to doctor's side of the story, they are very unhappy because of HMO's interference with the way they practice medicine; nurses are unhappy with the surreptitious cuts in budgets that mean that they have to do less for more patients; HMO executives are unhappy because (and despite good retribution) they couldn't deliver on their most important promise: reducing medical costs.

Another important aspect that is worrisome today is that it will become increasingly difficult for the insurance companies not to discriminate against who they are covering for medical expenses as we usher in a new era of medicine where genetic testing will be part an important of a patient's medical work-up. There is a fundamental contradiction between trying to contain costs by approving what and when can be done to a patient and having access to the information

that leads to this decisions, which will eliminate some patients from coverage.

For now, the COBRA act makes continuous health coverage easier for patients while putting more strain on the insurers and having as consequence an increase in premiums. But with the development of new capabilities of genetic diagnostic, which most probably will precede the capacity to correct these by therapeutic procedures it's safe to say that some patients will have a harder time getting coverage under the current system. By the same token it is not the best idea to try to slow the progress in genetics by assuming that the progress of medical ethics and insurance coverage are unable to keep up.

Not as the last reason, healthcare budget has risen dramatically in the past decades and strains the economy to the point that major changes in policy were needed. Trying to contain costs while maintaining a satisfactory level for delivery of healthcare is definitely not an easy task if status-quo is maintained in the way medical services are delivered and paid for today; cuts in Medicare budget are being felt seriously and led to corrective actions recently.

So it becomes imperative that the current medical coverage practice be changed. But how?

To start with, there is an excellent paper on the principles of health insurance (17), which I strongly recommend to the thorough reader.

Among other important observations, it is suggested that even the use of the word "insurance" may be inappropriate, as health care is a need, covering very common occurrences as well as unpredictable disasters, while insurance is supposed to shelter one only against the rare and catastrophic circumstances.

We start with what is working already and try to be practical to the hilt:

1. universal coverage: What is the effect of universal coverage on health expenditures on a national level? (30), (32). Accounting for the extra care needed for uninsured at the beginning of their coverage, an estimated \$20 billion would cover the costs. This represents about 5% of the current Medicare budget and some studies suggest is not an

impossible demand to be met.

2. third-party control (as in HMO's): More responsibility and control of the resources on the individual level will lead to better utilization of the resources. Adding a third component that controls resources to the patient-healthcare provider equation instead of natural market laws is a sure prescription for increasing costs over their normal fair market value (not to mention the cost of managing these resources and making a profit in doing so).

3. choice: We like to choose and we do it for most things in our lives; we choose our stereos, our cars, our homes, our friends and partners. However, when it comes to choosing the way we are cared for or what we want to be done to us by a healthcare practitioner, most of us are limited to the point of taking up on someone's suggestions without blinking, thinking that no other option is out there for us.

To make the above talk easier to understand to somebody who was not directly involved with healthcare or healthcare financing, I'll try the following practical example:

You are the head of your household, working hard for a good salary and you're making more money than anybody you know. You and your family have every material need fulfilled, which makes everybody happy and yourself more productive; everything seems fine until you realize that the pace at which the family expenses are escalating far exceeds the increase in revenue and if no changes are done soon you'll be bankrupt in no time.

The way you were handling the expenses so far was that the person overseeing the finances – your spouse – was giving all family members from the common budget everything they asked for, even if it meant buying the same thing three times and throwing it the same number of times. So after a thorough analysis you decide that you have basically three options:

a) establish a budget for each category of expenses (food, clothing,

gasoline, entertainment, etc.) that will be used by all family members and plan spending among them by trying to estimate everyone's needs and ensure a reasonable fulfillment of their wishes;

- b) pay somebody to manage your family expenses, and to make that person directly involved s/he will get a bonus if some savings are achieved, regardless if it comes with drastic rationing
- c) after common expenses are paid for (mortgages, insurance premiums and other fixed expenses) the family agrees for each member to be given a certain amount of money to manage for themselves (an individual monthly allowance)

If you chose b) you are the perfect executive for an HMO, because you believe in the principle. If you chose a) you'll spend endless nights trying to figure out what are the needs and what is a "reasonable wish" and you'll still be unable to avoid some resentment and arguments. If you chose a combination of the above options then you should think about a career in politics. And if you chose c) something tells me that you'll enjoy what you're about to read.

Here are some facts that one may want to consider to put in the equation that yields the new insurance formula.

A savings plan for medical expenses is nevertheless a good idea, as is the tax-exempt status of medical expenses; but it has the great shortcoming of not being able to cover for accidental occurrences that require large amounts of money in a short time frame.

For somebody in good health, the estimated lifetime costs of preventive medical care is between \$5,000 and \$18,000 (29), which can be easily covered by the medical savings accounts. Everybody thinks that the tax-sheltered medical savings account with limited annual maximum that was recently introduced by the government is a great idea (31).

On the other hand, it is estimated that 91 million Americans have at least a chronic medical condition, which require constant medical care. For them a medical savings account in today's form will not

cover for their health needs.

Also, most people cannot afford to live without insurance because of the imminence of spending a few thousand dollars or even more without blinking in the event of an accident or after being diagnosed with a new disease, which so far is very difficult to predict with enough warning time.

With these in mind, probably the best option will be a compromise.

Going again on the way of analogy, we all know how much car and how much car we can afford by estimating our revenue and distributing it for different expenses. If we see health insurance from an economical standpoint, as a commodity, then purchasing it should not be much more different than other big purchases that we're making in our lifetime, for which most of us pay monthly premiums.

Also, as in the example given, if the amount that a person can use for medical expenses is limited, one can think that if the person will have a say on how to allocate resources, then he or she will be interested in using that budget more efficiently. This means less doctor-shopping, less redundant or otherwise unnecessary testing and hospitalization, definitely less misuse of funds.

For example, if one knows that he or she has to spend a fixed amount on diagnosis and treatment, it is likely that the person won't agree to have an echocardiogram performed on her/him-self three times in two years (as I have seen myself, and not as an isolated case).

This will also add new meaning to the expression "informed consent". Having direct control over the financial aspect of the healthcare received, more patients will want to know and understand more of the ramifications and implications of any act that is being delivered. Some of this information may come from providers, some from other patients and yet some from counselors (HMO decision-makers may offer some expertise in this area).

With all these in mind, a new model of insurance would look like this:

One should pay a monthly tax-deductible premium beginning

with the adult life. The minimum coverage, which should be mandatory and universal, will provide for necessary emergency assistance and outpatient primary care visits (1 per year, for example), then a stratified pay level will cover more specialized medical care. Federal programs like Medicare and Medicaid can cover the necessary for the indigent and elderly.

The patient will have then a lifetime maximum that he or she will actively manage, by choosing how and when to spend the money.

The role of the insurance companies would be primarily in maintaining the accounts of patients (including payments to providers in due time), making sure that no errors or frauds are committed with the payments of providers, recruitment of more patients and eventually participating in negotiations involving the pharmaceutical industry, various healthcare providers, government, patient groups for costs and benefits. By not handling medical data on patients, the privacy issue is put to rest.

So instead of dealing with HMO's, PPO's, POS's, different groups of providers and methods of management, referrals, authorization and so forth, there will be only health insurance companies, the patients and the providers.

A simple way to do it would be probably that everybody should pay tax deferred monthly premiums to insurance companies for a certain amount of time (like life insurance). For \$150 per month for 40 years, the value of the insurance policy could probably be \$150,000 (or more, preferably), for which the person will get an account with a checkbook for all medical expenses incurred during that time frame. For any medical care received, the person will pay on the spot with the checks provided and will have the balance to spend for the remainder of the time frame when the monthly premiums will be paid. If there is a need for surgery valued at \$3,000, then from the total of \$150,000 \$3,000 will be spent and that person will have \$147,000 left in the medical expenses account until the 40 years end. If the person estimates that the \$147,000 will not last that long, additional insurance can be bought, for example for an additional \$50 per month, \$50,000, worth of health insurance, which

will increase the account balance to \$197,000. But if the person waits twenty years before buying the additional insurance (that means that monthly premiums will be paid only for 20 years for the latter insurance), then the monthly premium for this second insurance would be \$100, which will add to the initial \$150. So one can buy more health insurance initially for less monthly premiums, with the only caveat that it may be exceeding the diagnosis and treatment needs of that person. What to do with the balance? A portion could be given for research or to various health organizations or simply donated to the insurance company if no option is expressed.

It may seem strange, but it is easier to calculate insurance premiums for a population as a whole than for segments of that population. On a national level, statistical data can be used for a much better approximation of the premiums needed for the individual health insurance than by using dispersed data and estimates of different groups.

An important aspect of this kind of health insurance is specificity, both for individual and type of expense, which means that the funds can be used only by the person for whom are issued (non-transferable), and only to pay for medical expenses.

Natural market laws (competition being an essential part) will assure more reasonable pricing of services.

And although anybody can have any type of care he or she desires (including any plastic surgeries or alternative medicine, as long as the person is willing to pay for that treatment), in many situations after an initial spending spree (which may not outspend the actual level of annual cost per person), spending the “health monies” will be judicious.

The patient will think twice about the need to see a specialist if the same treatment can be provided by the primary care doctor, but at lower cost. Also, the number of unnecessary visits to emergency rooms will decline, also due to economics: a visit to ER is about \$250, while a visit to the primary care doctor is much less. And knowing that you're on a budget, you won't waste resources, but try to get the best care that your money can buy. This way it will be achieved

effortlessly what HMO's tried for long time with artificial rules: having the general practitioners providing more of the medical care.

There will be no need for co-payments, deductibles, co-insurance, etc. as the payments will be made in full by the patient through his insurance at the time that the medical services are provided.

There will be more flexibility in spending so any patient will be able to see providers anywhere in the country, east coast or west coast.

Generally speaking, there will be no need for somebody to cut on unnecessary spending, (as in HMO) or any kind of financial incentives for cost-cutting since everybody will watch his or her own account. Some people may need counseling for properly spending their healthcare money, and people who work for HMO's probably may expertly do this. This will be probably of limited extent (after all, not many pay an expert to tell them what kind of car or house they may buy).

Considering that estimates for 1998 make the average cost of health insurance per insured employee at about \$4,000 for the year, that will be about \$330 per month for the average employee (this includes both the employee's premium and the employer's contribution).

In this newly proposed insurance model, in the minimum setting, someone 21 years or older and employed should pay probably \$50 monthly, tax-deductible, to his insurance company, which will get that person a \$50,000 account for use mostly on ER and primary care doctor's visits.

The indigent and the elderly would receive this kind of coverage from federal programs, similar to today's Medicare and Medicaid. People may also choose to support various research or health groups or organizations with money from their health insurance accounts.

On top of this minimal but universal insurance coverage, anybody could buy an unrestricted amount of personal insurance for additional monthly premiums and different amount of times (20, 50,

70 years, etc.).

A downside to the model above is that all adults will be *required* to buy insurance, which means new law, and also added pressure for those who barely make ends meet and think they cannot afford the extra cost of medical insurance. To make everybody happy in “the land of free” while having everybody insured, there’s also a way.

Perhaps an even better model will be one in which EVERY US citizen receives at birth from the government a check for \$120,000 exclusive for personal medical expenses (including medications), non-transferable and non-renewable (“health money”). How did I get to this figure? As a minimum coverage I figured \$1,000 per year of life, multiplied by the potential human life span of 120 years.

For some children this amount may not outlast the first year of life and the parents will need to buy extra private personal insurance for their kid (maybe sometimes with the help of the community, church, philanthropists or special programs designed by the government). By the same token, some people may live 100 years and not use even half of it. The important thing here is the size of the insured population: 270 million and growing, which is a factor of success. Also, at the same time, people who are anywhere between 1 and 111 years of age at the time of implementation of this model should get the difference between their potential and actual age in years multiplied by 1,000: for example the one year-old should get \$119,000, the 60 year-old should get \$60,000 and the 115 year-old should get \$5,000 from the government. Of course, \$1,000 per person per year is an estimative figure; ideally the government should afford to pay much more and hopefully not less.

And sure enough on top of universal coverage everybody could buy time-limit insurance by paying monthly premiums. This type of model may be able to replace Medicare and Medicaid. There will certainly be a need for government assistance for people who cannot pay premiums for extra insurance and cannot find support from community, church or philanthropists, but the volume of these programs will be much smaller than today’s Medicare and Medicaid.

My Choice

You know that you're dealing with an incurable optimist when the person starts his or her testament with the words: "If one day I will die..."

There were many frustrations as well as many satisfactions during my internship, but no doubt that the most consuming thing for me was dealing with patients who were a few heartbeats away from death, most of them gathered in the cardio-pulmonary care unit (CPCU) or the dreaded 6W. A short walk through the CPCU unit will give anyone the primer: the ubiquitous ventilators, the worried, worn-out faces of the staff, the frequent blue codes, the cynicism, and the unhappy relatives. All the shortcomings of hospital care in a nutshell.

You're left trying to figure out how all the wrong things are happening in one place. Why are the nurses non-cooperative, sometimes downright aggressive, with low morale and some sort of resignation in their attitudes? Or why doctors feel so uncomfortable talking to the patient's relatives? Can anybody be accused of wishful thinking for treating a patient that only a miracle can save from death? Or is it better to allocate the resources to others who can benefit more visibly? Is it good to make the patient a pincushion and try to "do everything" in the book knowing that there is no guarantee of success? Or try to make the patient comfortable knowing that he or she won't live too long? Fortunately, you're not expected to make up your mind this time; experts have tried to come up with a conclusion for decades and no one can say something that can be applied always for everybody. And maybe this is an important part of the answer.

To begin with, it would have been easier for everybody if there were advanced medical directives for those terminally ill patients. Indeed, it is much easier to follow directions than trying to "wing it" on your own, sometimes with no map and nobody to ask. And if you agree with me on this one, then many questions arise, starting with: when to get these directives?

One nurse more involved with the administrative side and during a short conversation suggested that this should be addressed when we're seeing patients in the clinic, as outpatients. She may be right in that something, which may go wrong, is best addressed before it happens, a good guideline that we get from preventive medicine. The problem is that most people come to clinic for a specific complaint or ailment and is probably not the best idea if the doctor, after examining the patient for that issue to start asking him or her questions pertinent to end-of-life. They will freak out, and with a good reason. "Doc, is it that bad? Is it something that you're not telling me, doc?" Definitely not the best setup for talking such important matters. Besides, time is so limited for all visits that it would be impossible to squeeze in as a matter-of-fact collateral something as important as medical directives.

One study (3) calculated that patients completing an advance directive paper containing well-defined scenarios ("standardized" if you want) need a median of 14 minutes to give the answers in the questionnaire, not including the explanations and eventual questions that may need clarification. This is half the time of a usual follow-up medical visit (which sometimes can be as short as 20 minutes). And an entire visit dedicated to advanced medical directives is not covered yet by health plans.

Then what is being done now?

Another recent study (5) shows that the issue of advance medical directives is not addressed appropriately during a regular outpatient visit, with the doctor-patient conversation on the subject averaging 5.6 minutes.

Considering only the patients that are already seeing a doctor in an outpatient setting, only about a quarter have written advance directives (23). Even with this low percentage, after being admitted in a hospital, just a fraction of the patients who have written advance directives get them recognized upon admission, therefore rendering them useless.

Probably the closest I got to talking about advance directives

with a patient in the Brooklyn clinic where I've been working that year was during one of my strangest consults there. The patient was a man in his late twenties and very worried that he may die soon, as it happened recently to a friend and a third degree cousin. He got so worried that for the first time in his adult life he wanted to see the doctor, although he could not offer any specific complaints other than feeling a little weak sometimes. I examined him and as there were no negative findings from the physical exam and no "alarm signs" in his medical history, I reassured him that he had no reason to think of imminent death. He was in better spirits when the consult was over, visibly relieved. I knew then that he won't see a doctor too soon (he had no health insurance, either), so do you think that it would have been appropriate at that time to ask him what he wants to be done to him in case his heart stops beating? Please don't blame me if I didn't.

From a financial standpoint, medical costs incurred in the last years of life make up for a significant percentage of the Medicare budget. A study published in 1993 (24) showed that the Medicare payments for decedents were relatively constant between 1976 and 1988, representing between 27-30% of the total Medicare budget. A study from 1995 (15) reveals again that Medicare payments are concentrated in the years just before death, and about 2/3 of all expenses incurred for people dying at 80 are made in the last 5 years before death.

In a more recent publication -1996 (1), it is mentioned that medical care at end-of-life consumes an estimates 10-12% of the total health care budget and 27% of Medicare budget. For 1997 the health care budget was close to 1.1 trillion dollars, while Medicare expenses were in excess of 400 billion dollars. This percentage is likely to increase in the next decade, as the average life expectancy increases and the proportion of elderly people of the general population increases too.

I am sure that if given the option, a lot of people will want to use the same resources spent for life-support earlier in life for prevention, better lifestyle and research for a better treatment. Many insurance companies have a lifetime benefit per person limited to \$1,000,000. It would be interesting to find out what percentage of this

amount one wants to be spent on diagnosing and treating his/her problems, what percentage should be dedicated for research on these problems which include ways for prevention and better lifestyle, and what percentage for life support in the event of terminal illness.

More responsibility and control of the resources on the individual level can lead to better utilization of the resources, as mentioned in the previous chapter.

Getting back to the real world and to the life-or-death battle that was in question before I started this dream presentation of your next type of health insurance (let's call it "the millenium insurance" as is the trend nowadays for anything new), every single life saved makes all expenses worthwhile, and nobody can predict who will survive and thrive and who will be lost in these trials.

Try to imagine now how it is to be like that patient, unaware of himself or surroundings, not knowing whether is day or night, unable to breathe, eat, see, not responsive to noises and sometimes not even to pain. This reminds me of a Metallica song, "One" when a Vietnam war veteran is shown in a infirmary, imprisoned in his own body on a hospital bed, while the lyrics are:

***"I can't remember anything
Can't tell if this is true or dream
Deep down inside I feel to scream
This terrible silence stops me [...]"***

***Fed through the tube that sticks in me
Just like a wartime novelty
Tied to machines that make me be
Cut this life off from me***

***Hold my breath as I wish for death
Oh please God, wake me
Now the world is gone I'm just one [...]
Oh please God help me [...]"***

I cannot live, I cannot die..."

Some of us may have seen a friend or a relative in this situation

and live the difficult experience, and maybe some of us have already asked themselves how would they fare in such circumstances. It is not a nice use of imagination, but it sure is useful.

If we could only realize how important is that we make our choices, and not put ourselves and the loved ones through painful, agonizing experiences by simply making a choice ahead of time. It could be yes or no, good or bad from others point of view, in short, debatable, but the most important issue is that it is our own, personal choice and it will be first taken into consideration when a decision will be made by doctors and family of how we'll spend maybe the last moments of our life.

What comes to mind here is the story of a TV reporter, a man in his forties, beloved husband and father, yet unfortunate enough to be the victim of a car accident when nobody expected. He was in a coma for two years, and as the chances of recovery grew slimmer by the day, an agonizing battle was mounting between his family, wanting closure and discontinuation of life support, and local authorities, which were invoking his best interest for continuing the life support. But who will ever know what he really wanted? A simple statement from him could have solved this dilemma for good and forever.

It is important to have answers to some straightforward, unavoidable questions. Would you accept to be intubated if you cannot breath? Would you like to be resuscitated if your heart stops beating? What if you were terminally ill, with only a few months to live? What kind of treatment would be appropriate? Would it be OK being on mechanical ventilator for the rest of your life? Or having a gastrostomy tube inserted in your belly that will allow feeding because you cannot swallow and have no gag reflex? Or what will you prefer: having your limb amputated because of a life-threatening infection or risking dying with all members on? What if a second member gets infected? And how long are you willing to stay unconscious, dependent on artificial breathing and tube, being constantly prodded with needles? Would you want only help with breathing, eventually dialysis, antibiotics for infections, feeding via

tube or through the vein? In short, how much help is too much?

Sometimes, due to unforeseen circumstances, we may end up in a hospital we've never been before, treated by doctors that never knew us, surrounded by people who try their best to guess what will make us more comfortable or happy. It would be much easier for everybody if there will be information on what we want to be done to us in predictable, unfortunate situations.

A story that I remember reading is one of a young man who was saved from death after a devastating car accident during a vacation away from home. The surgeon telling the story bragged about the very successful reconstruction of chest, face and arms, with a minor caveat (when compared to the patient's presentation after the accident): limitation of motion in fingers of both hands after repeated surgeries. What could be the big deal after saving the patient's life? It turned out that he was a concert pianist, and he lost completely his ability to play the piano, which until that point meant his life. If this information could have been found somewhere by the doctors, this disaster could have been avoided.

Maybe we should go and see for ourselves how it is like in a CCU unit or step-down unit, how care is provided for people in this situations; what means to come back after CPR, breathing through ventilator tubes, developing decubitus ulcers, feeding by gastric tube. Getting poked with needles at least twice a day for tests, to the point that blood can be drawn only from arteries, laying in your own feces because you cannot do anything about it and you have to wait until you are cleaned, and so on.

Don't get me wrong now; I am not a partisan of assisted suicide. The way I see it is that the gift of life is given to us without our invocation or consent and it cannot be us the very ones to throw it away. And while it's true that to live is not always easy, maybe the tough moments we are going through at times are just the price for our wiser, more fulfilled ulterior existence.

So assisted suicide is an action too extreme.

But the other extreme is trying to keep a body "alive" at any

price. And sometimes without even knowing whether the patient wants to go through all this.

To complicate matters a little and shying away on being firm on this issue, one can give the example of a thirty-something depressed woman who thinks suicide is her only way out of her troubles, only to find out that with treatment she can very well continue a very meaningful life. But this is very different from the elderly patient who already has accomplished most of his lifetime goals and knows that the tubes connected to his body are merely a useless, meaningless extension of his struggle with death. What can be done then to help somebody contemplating suicide from achieving this goal? First, if somebody is diagnosed with depression then that person should not be allowed to change the advance directives made prior, and if there are no prior directives, then either should wait until after the depressive episode is resolved or a psychiatrist should make sure that the severity of depressive does not affect that person's choice while under treatment. Another implication may be that before somebody wants to change the advance directives s/he should have the approval of a psychiatrist or psychologist, certifying for the absence of depression.

There are numerous publications (2), (3), (8), (14), (19), (27) documenting that many patients (more than 40% in all the studies consulted), in some situations making the majority, would want less than "everything" done to them when the end is close.

Which prompts me to the next question: is all the medical treatment that is given to us absolutely necessary? Absolutely not. There are a lot of examples of unnecessary medical care ranging from surgeries (cesareans, hysterectomies, appendectomies, and so on) to non-urgent medical care given in ER's, to unneeded physical rehabilitation for elderly patients from retirement or nursing homes.

Besides, the main reason for being of the HMO's (this is how it started, remember?) is to cut on unnecessary procedures (there are strong indications that they are overdoing it, though).

In an effort to make spending during the last year of life more reasonable, it was proposed that elderly people in need of chronic

care and assistance with daily activities should be taken care of in hospices, which are more cost efficient. Although I'm sure that many people would prefer to die in their home rather than in a hospice, the very existence of hospices rises another question: who and when should go there? There are guidelines for admitting patients in hospices, but in a recent study addressing this issue, namely the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) it was concluded that there are no clinical prediction criteria for indicating survival of 6 months or less (8). If one is to stick to data that is available today for the physician's use, more often than not the prognosis for one's death will be wrong. There is no mention though of the many situations when the doctor is adding to this data his own experience, intuition and common sense, which although cannot be precisely quantified, in many situations can make night-or-day difference.

Extrapolating the results and using a hint from real world, one may say that statistics and mathematical models that use today's measurable data cannot yield an accurate prognosis.

To give an example of how subtle signs can be, I remember one of the patients I had on the regular floor. Slightly overweight woman in her late forties, she was admitted to the hospital for a rather unusual complaint: a few days before she started limping her right foot, making walking hazardous as she seemed to be unable at times to lift her foot enough off the floor. The physical exam was within normal limits; the only abnormality was this episodic walking problem for which some neurological testing was done, as well as keeping the patient under observation. Then as we were preparing to discharge her, during a routine exam for writing my progress notes while on call I've noticed a positive neurological sign (positive Babinski), which was new. For the uninformed reader, the Babinski sign is a ridiculously simple maneuver (basically implies scratching the sole of feet with a sharp object and observing whether the toes extend or curl); but I have distinctly remembered that day a small story that our 4th year Internal Medicine professor shared with us and it involved exactly that: a unilateral positive Babinski as the sole positive finding, followed after a few days by a stroke. Corroborated

with some complaints of tingling, this triggered a big alarm sign that prompted me to call the neurologist on call. Not really knowing what's going on, blood tests were ordered which showed abnormalities present in a few disorders; getting the right diagnostic started to be a challenge. Also, because no specific diagnosis was established, the therapeutic action was tentative and minimal. Meanwhile, the patient's status took a steep turn for the worse: she was gradually losing function over her leg and arm and later had difficulty speaking. By this time and as you probably guessed, a full-blown stroke was diagnosed with the help of an angiogram, which showed an arterial blockage within one of the arteries at the base of her skull.

This is not the most pleasant memory, but hopefully it shows how complex and delicate can our body be and how difficult it is to see clearly the warning signs to disaster and take action before extensive damage occurs.

There are examples of people coming out of coma after many years. It's great to give everybody a chance; then again what was the age and overall health of the person before the accident? Not to mention that if one is lucky enough to come back after a yearlong coma, he will probably pass out again when seeing the bill.

Again, I am not advocating euthanasia, which goes against The Ten Commandments and the Hippocratic oath. And for the science-minded people, there is good argument against it, too. So far, nobody can create an independent living being from scratch. Cloning – the closest we can get for now - uses existing DNA and existing animals (it's like making a photocopy, you can't make one unless you have an original that you can't produce).

So it makes no sense to kill (trash) something that you don't fully understand. Would the scientist dispose of the car with a broken transmission, which is rendering it useless, but he knows it can be repaired? Probably yes, if the amount spent for the repair exceeds the value of the car; no otherwise. But science cannot put a price on the human life for the reasons mentioned above. (A lawyer could, but

that has to do more with ethics, and we discussed the ethics in the beginning).

By the same token, keeping someone alive at any price, as a result of technology advancement is working against nature. An analogy that comes to mind is having a flat tire and no efficient way to patch it, so the decision taken is to keep pumping air in the punctured tire for the sake of keeping it inflated. The tire is inflated all right, but you can't do anything else and also the tire is of no use.

There are statistics that may help with decisions. Around 10% of the successfully resuscitated patients (CPR after heart stops beating) make it to be discharged from hospitals in stable condition. This is an example of reasonable risk-taking; not all decisions though are this simple and there are plenty of books on situations that make bioethics more agonizing than the chicken-or-egg question.

Ultimately, we cannot take any answers for granted for anybody. Who would think that some people would not accept a thing as common and simple as blood transfusions, even in critical, life or death situations? Yet there are such people – Jehova's Witness – and nobody can say that they are doing the wrong thing. One can only have respect for somebody who sticks with his or her choice to the end; that is a true measure of character.

In a related paper (21) is given the example of two Jehovah's Witness patients, who despite the fact that they had written directives for not allowing blood products to be given to them, they were transfused.

To make matters more complicated, when it comes to the kids of a Jehovah's member, doctors are free to give them life-saving blood transfusions against their parents will, a right that was earned in court. I am wondering how that parent will feel, torn between his faith and the love of his child. The only comparison that comes to mind is Abraham.

So what is the conclusion?

We can be convinced that the doctors will fight for us by

default and will try everything to keep somebody alive and give that person the chance to recover, sometimes against all odds and maybe against common sense. It's the way they are trained and the way the laws are written. So there is not much to fear on this side, one can never say that the doctor is interested in terminating us prematurely.

This is to expect when we cannot decide.

The important, variable part is thus us, the patient.

In a bold move, Congress passed in 1991 the Patient Self Determination Act, which emphasizes patient autonomy in the medical setting. This way sad controversies as Mrs. Cruzan's right-to-die episode in 1990 will probably not repeat.

Studies performed before and after 1991 confirm the usefulness of the advanced directives (12), (11), (2) and the general positive attitude towards them (3), with the downside being the relatively small percentage of patients who actually have them (less than 30% of any random sampling of a patient population). Some patients chose the easy way out; instead of specifically mentioning their preferences for life-sustaining treatment, they let every decision on the shoulders of a relative or friend through the power of attorney for health care forms (2). And while this may be of help in the event that a new technique is developed in the future that is not specified in today's documents, today's questions still remain unanswered, not mentioning that general principles can be stated and acted upon. (as in mechanical ventilation, tube feeding, etc.)

With the examples given before in mind and the thought that misfortune can strike at any time, it may be better to not wait until one become disabled or put out of commission after an unexpected accident or tired of fighting a chronic illness, but think of the possibility in advance and make a decision while in good shape.

It is not possible today to make legal personal wishes regarding end-of-life choices for healthy young adults. But rules can be changed for the better. There are many reasons to argue in favor of this change.

What else can be practically done?

Talking with a friend on the issue, we concluded that it would be best if everybody will be given an option on the issues by the government, similar to organ donation on the driver's license.

The advance medical directives could be coded on the drivers' license and would include general information as well as special preferences (for example, the concert pianist would like special care to his hands and brain, especial motor areas).

Having the advance directive information widely available (as on the Internet) would make them vulnerable to attacks from ill-intended persons. But a database with limited access can be created that would be available for use by hospitals and probably the EMS throughout the nation which will help in taking the decisions wherever it may be needed.

By making a choice about the care received at the end of life it will be a good way to show responsibility as a young adult. And sometimes just contemplating end-of-life issues may have positive influence on one's lifestyle. Like in the diabetic patient or the stubborn smoker faced with the option of limb amputation or the young "invincible" driver asked to make a choice if in a possible comatose situation. Hopefully this "wake-up call" will give them a better perspective on the issues, and at the very least will make them more responsible toward themselves and ultimately to their loved ones.

There is the "when" question: what is the best time to take such a decision?

The answer seems to be the beginning of adult life; a simple argument being that if one can vote on who should be his community or nation's leader, the same person should be able to decide what he or she wants to be done to his/her body in certain situations. Another argument is that nobody knows exactly when and how one will exit to netherworld and all adults should be prepared to face this inevitable issue about end-of-life.

A pertinent question is how reliable are decisions made by a

healthy young person (how long they last?). There is a feared glibness of the young in the relation to illness and death (ii), which implies that the choice of advance directives made by somebody early in life may be lacking maturity and experience.

Going through the literature available on this topic, one can argue that this kind of choice is not much influenced by having experienced an illness or aging after reaching adulthood, but by one's personal system of values, view of life and his or her priorities, which for most people are defined with reaching the adult years and stay unchanged.

In support of this idea, this study done in 1997 (7) shows that for persons with diverse health status, treatment preferences are grounded in a consistent belief system and it was unchanged for 30 months, which was the duration of the study. Another publication (6) shows that the choice for advance directives (presented as 4 illness scenarios with 11 treatment alternatives) was moderately stable over 2 years (which coincides with the length of the study). This prompted the authors to conclude that for both healthy adults as well as for patients advance directives can be relied on 1 to 2 years to reflect patient's choices.

Yet another study (22) shows that over 2 years, 85% of patients who did not want life support were stable in their preference.

Other studies (25) take in consideration ethnicity when end-of-life decisions are made, showing that there is variation in patient's preference based on ethnicity.

In the system proposed above, anybody could change his option anytime for a fee, he or she will be issued a new ID with the new data recorded on it, or the person could make the change with the periodical renewal of his or her ID.

*

* *

Did you know of this ancient Greek legend of a monster called Procrustes? He was measuring all passers-by against his bed; if they were taller, he would shorten them by cutting what was hanging out the bed; if shorter, he would also adjust them. And of course, there were the very few lucky ones who were the same size. Unfortunately, too few. (And yes, fortunately, he was given what he deserved by Theseus, one of legend's heroes).

Meanwhile, the words I wrote were not intended to help you make up your mind in one way or another, or help create a standard, or in any way manufacture another Procrustes' bed against which you will be measured. There is no right or wrong when choosing how to receive your medical care. The trick is to say and get what you want. And this is probably the only time in life when you can confidently say: "It's my way or the highway".

PART TWO

Bibliography and quotations

The literature on the subjects discussed in the first part is very rich, and after launching a Medline search I found myself browsing through approximately 1,800 papers, which made a selection a necessary evil.

Considering that this form of censorship is already introducing a bias from the author, I tried to make it as objective as possible, by including mainly the publications who presented data obtained from a large number of patients in a multi-center setting and presenting different studies, some with contradicting results.

The first two citations explain the concept of advance directives, then different papers are dealing with different subjects, all being pertinent to end-of-life decisions or health insurance.

The source is given first in a journal format, then relevant parts from that publication are cited in the authors' original format and in some cases a comment is written.

This presentation was intended as a minimum-bias help for the reader to form his or her own opinion.

(i) - Principles of Ambulatory Medicine, 4th Edition, 1995; L Randal Barker, John Burton, Philip Zieve, pg. 74,206

Highlights: “ Advance directives are intended to allow a patient to state in advance wishes about medical care in the event of subsequent incapacitation. These directives take two general forms: The first is exemplified by the living will: a patient states what treatments should, or should not, be withheld in the event of incapacity. The second form of advanced directive names an agent or proxy who will represent the patient if the patient becomes incapacitated. These directives are often called durable powers of attorney for health care. Laws about advance directives vary from state to state. In many, for example, patients must be terminally ill before the living will becomes valid. Requirements for witnesses and notarization, acceptability of directives from other states, determination of

patient capacity to make decisions and other technical aspects are variable from state to state. Utilization of advance directives has been officially encouraged by the federal government since the implementation of the Patient Self-Determination Act in 1991. Evidence for the effectiveness of advance directives is uncertain. [...] Making decisions for the many patients who are incapacitated and who have left no advance directives is a very difficult problem. [...] Physicians have been taken to court because they have withdrawn therapy from an incompetent patient at the family's unanimous request. Under almost identical circumstances, physicians have been sued because they have refused to discontinue therapy."

(ii) - Harrison's Principles of Internal Medicine, 14th Edition, 1998; Fauci, Braunwald et al, pg. 7,39 (Bernard Lo: Ethical issues in clinical medicine)

Highlights: " Advance directives: These are statements by competent patients to direct care if they lose decision-making capacity. They may indicate (1) what interventions they would refuse or accept or (2) who should serve as surrogate. Following the patient's advance directives respects his or her autonomy. Oral conversations are the most frequent form of advance directives. While such conversations are customarily followed in clinical practice, casual or vague comments may not be trustworthy. Living wills direct physicians to forego or provide life-sustaining interventions if the patient develops a terminal condition or persistent vegetative state. Generally patients may refuse only interventions that "merely prolong the process of dying." A health care power of attorney allows patients to appoint a proxy to make health care decisions if they lose decision-making capacity. It is more flexible and comprehensive than the living will, applying whenever the patient is unable to make decisions. Physicians can encourage patients to provide advance directives, to indicate both what they would want and who should be surrogate, and to discuss their preferences with surrogates. In discussions with patients, physicians can ensure that advance directives are informed, up-to-date, and address likely clinical scenarios. The federal Patient Self-Determination Act requires hospitals and health maintenance organizations to inform patients of their right to make health care decisions and to provide advance directives."

(1)-Emanuel EJ: Cost savings at the end of life. What do the data show? Journal of American Medical Association 1996 Jun 26; 275(24) pg. 1907-14

Highlights: "Medical care at the end of life consumes 10% to 12% of the total health care budget and 27% of the Medicare budget." / "A more definitive study that assessed patients' end-of-life care preferences, use of

hospice and advance directives, and direct and indirect costs would be desirable. In the absence of such a study, the existing data suggest that hospice and advance directives can save between 25% and 40% of health care costs during the last month of life, with savings decreasing to 10% to 17% over the last 6 months of life and decreasing further to 0% to 10% over the last 12 months of life. These savings are less than most people anticipate. Nevertheless, they do indicate that hospice and advance directives should be encouraged because they certainly do not cost more and they provide a means for patients to exercise their autonomy over end-of-life decisions.”...”CONCLUSION: Americans strongly believe that we are wasting significant health care resources and that by simply cutting this waste we can provide universal care – or reduce medical costs or reduce the federal budget deficit – without compromising patients’ quality of care. Because so much is spent on care at the end of life and because most Americans claim they do not want aggressive high-technology care at the end of life, there has been a hope that significant savings can be achieved by cutting end-of-life costs. Because they reinforce our hopes, studies reporting large savings from hospice and advance directives are widely and uncritically publicized. But careful review of all studies on cost savings at the end of life suggests that this savings is likely to be small, 10% or less during the last 12 months of life. This does not mean that we cannot achieve huge medical savings near the end of life. Such savings would require Americans to drastically reduce their use of medical tests and technology over many months before death. And this, in turn, necessitates a radical transformation in American culture and values about the importance of youth and health toward the acceptance of death as a natural and inevitable part of life. The difficulty of getting more Americans to enroll in hospice and use advance directives, which by comparison are relatively modest changes in values, should make us skeptical that Americans will rush to embrace these changes to realize tremendous medical costs savings. We can achieve savings only with more systematic changes in our health care system rather than by tinkering with care of the dying.”

(2)-Gross MD: What do patients express as their preferences in advance directives? Archives of Internal Medicine 1998 Feb 23; 158(4) pg. 363-5

Highlights: “For inpatient admissions during the calendar year 1994, of 8727 questionnaires completed, 11% of patients indicated that they had executed an advance directive (AD). For outpatients, the corresponding figures are 22,966 and 15%. [...] Of the 328 medical ADs, 86 (26%) were living wills, expressing the wish that if the individual had an incurable disease or irreversible injury that he or she not be given any treatment that would only delay death. There were 210 power of attorney for health care forms completed; these were 64% of all the medical ADs. Of these, 7 did not specify any preference that patients wanted their proxy to follow. The

remaining 203 forms were divided as follows: 189 individuals requested that they did not want life-sustaining treatment if the burdens of treatment outweighed the expected benefits; 12 wanted their lives to be prolonged unless they were in an irreversible coma; and 2 wanted their lives to be prolonged to the greatest possible extent regardless of the chances for recovery or the cost. There were 32 do not resuscitate forms executed exclusively by residents of nursing homes that specified that they did not want cardiopulmonary resuscitation or artificial feeding. Conclusions: The overwhelming desire expressed by the patients in the ADs was not to have their lives prolonged if their medical condition were such that treatment would merely delay death. Only a minuscule number of patients, less than 0.7%, wanted everything done to prolong life regardless of the chance for improvement or the cost. Because such a small percentage of patients have ADs, it is recommended that each hospital appoint a committee on AD's to do everything possible to encourage patients to execute an AD. A second mission of this committee would be to do everything possible to encourage physicians to pay close attention to their patients' wishes for medical care at the end of life.

(3)-Emanuel LL, Barry MJ, Stoeckle JD, Ettelson LM, Emanuel EJ: Advance directives for medical care – a case for greater use; New England Journal of Medicine 1991 Mar 28:324(13)pg. 889-95

Highlights: “We surveyed 405 outpatients of 30 primary care physicians at Massachusetts General Hospital and 102 members of the general public in Boston and asked them as a part of the survey to complete the Medical Directive. RESULTS: Advance directives were desired by 93% of the outpatients and 89% of the members of the general public (P greater than 0.2). Both the young and the healthy subgroups expressed at least as much interest in planning as those older than 65 and those in fair-to-poor health. Of the perceived barriers to issuing advance directives, the lack of physician initiative was among the most frequently mentioned, and the disturbing nature of the topic was among the least. The outpatient refused life-sustaining treatments in 71% of their responses to options in the four scenarios (coma with chance of recovery, 57%; persistent vegetative state, 85%; dementia, 79%; and dementia with a terminal illness, 87%), with small differences between widely differing types of treatments. Specific treatment preferences could not be usefully predicted according to age, self-rated state of health, or other demographic features. Completing the Medical Directive took a median of 14 minutes. CONCLUSIONS: When people are asked to imagine themselves incompetent with a poor prognosis, they decide against life-sustaining treatments about 70% of the time. Health, age or other demographic features cannot be used, however, to predict specific preferences. Advance directives as part of a comprehensive approach such as that provided by the Medical Directive are desired by most people, require physician initiative, and can be achieved during a regular office

visit.”

(4)-Malloy TR, Wigton RS, Meeske J, Tape TG: The influence of treatment descriptions on advance medical directive decisions; Journal of American Geriatric Society 1992 Dec; 40(12) pg.1255-60

Highlights: *“Subjects (201 community-dwelling elderly in Omaha, Nebraska) were asked whether they would accept or reject three life-sustaining interventions: cardiopulmonary resuscitation, mechanical ventilation, or tube feeding in three separate hypothetical case scenarios. The three life-sustaining interventions were each described positively, negatively, and exactly as they are worded in a widely used advance directive. Subjects reviewed each scenario three times with three different descriptions of the three interventions. RESULTS: For the three interventions presented in three scenarios, subjects opted for the intervention 12 percent of the time when it was presented negatively, 18 percent of the time when it was phrased as in an advance directive already in use and 30% of the time when it was phrased positively. 155 of the 201 subjects (77%) changed their minds at least once when given the same scenario but a different description of the intervention. Of these 155, 33% changed decisions 1-3 times, 33% changed decisions 4-7 times and another 34% changed decisions 8-17 times based solely on the description of the intervention. CONCLUSION: The decision patients make about whether to accept or reject life-sustaining treatments are affected by the descriptions of the treatments. These findings emphasize the critical importance of doctor-patient consultation when patients execute advance directives.”*

Comments:

- the study may be only representative for the selected population (exclusively made up of elderly people in Omaha, Nebraska)
- 67% of the participants changed their mind more than 4 times (4-17) for only three scenarios suggesting that more than description of intervention could be involved

(5) – Tulskey JA, Fischer GS, Rose MR, Arnold RM: Opening the black box: how do physicians communicate about advance directives?; Annals of Internal Medicine. 1998 Sep 15; 129 (6): 441-9

Highlights: *“PARTICIPANTS: 56 attending internists and 56 of their established patients. Eligible patients were at least 65 years of age or had a serious medical illness. MEASUREMENTS: Two raters coded transcripts of audiotaped discussions about advance directives to document how physicians introduced the topic of advanced directives, discussed*

scenarios and treatments, provided information, elicited patient values, and identified surrogate decision makers. RESULTS: Conversations about advance directives averaged 5.6 minutes; physicians spoke for two thirds of this time. In 91% of cases, physicians discussed dire scenarios in which most patients would not want to be treated, and 48% asked patients about their preferences in reversible scenarios. 55% percent of physicians discussed scenarios involving uncertainty, typically using vague language. Patients' values were rarely explored in detail. In 88% of cases, physicians discussed surrogate decision making and documents to aid in advance care planning. CONCLUSIONS: Although they accomplished the goal of introducing patients to advance directives, discussions infrequently dealt with patients' values and attitudes toward uncertainty. Physicians may not have addressed the topic in a way that would be of substantial use in future decision making, and these discussions did not meet the standards proposed in the literature."

COMMENT: This is making the case for the advanced directives to be more standardized and not subject of variations due to factors other than the individual wishes and ideals. Therefore, the options and the explanations should be written and the person given time to reflect on the issues before reaching a conclusion. The doctor's input can be solicited, but should not be made mandatory. This is also justified by the cost; it will be more efficient to print the best explanations than to have at least 10 minutes of doctors' time, which is much more expensive and not always more efficient.

(6) - Emanuel LL, Emanuel EJ, Stoeckle JD, Hummel LR, Barry MJ: Advance directives. Stability of patients' treatment choices; Archives of Internal Medicine 1994 Jan; 154(2):209-17

Highlights: "In a prospective cohort study of 495 of 495 outpatients and 102 members of the public, we studied the stability of scenario- and treatment-specific choices. Subjects completed an advance directive, which included four illness scenarios with 11 treatment choices in each, as part of a questionnaire. A second interview was completed by 296 patients and 78 members of the public after 6 to 12 months; 154 patients completed a third interview after a further 6 to 12 months. We assessed stability by comparing each choice between interviews. RESULTS: Stability of choices was moderately high among patients and the members of the public. Patients had a wide range of personal stability levels (0% to 100%), but individuals starting out stable rarely became less so (93% of the patients with 85% to 100% stability maintained this level of stability on the third interview). Hospitalized patients showed no significant difference in stability at the second interview, but their stability was not improved at the third interview. CONCLUSIONS: Our findings generally support the use of advance directives. Most people made moderately stable decisions using

scenario- and treatment-specific directives, and stability improved after they reviewed the decisions, especially among those who had discussions with their physicians. Recent hospitalization did not decrease stability, although it appeared to reduce the improvements that others achieved with repeat interview. These findings suggest that advance directives can be relied on 1 to 2 years after completion to reflect patient's choices."

(7) - Patrick DL, Pearlman RA, Starks HE, Cain KC, Cole WG, Uhlmann RF: Validation of preferences for life-sustaining treatment: implications for advance care planning; *Annals of Internal Medicine* 1997 Oct 1;127(7):509-17

Highlights: "PARTICIPANTS: Younger and older well adults; persons with chronic conditions, terminal cancer, or AIDS; stroke survivors; and nursing home residents. CONCLUSIONS: Prospective life-sustaining treatment preferences show high convergent validity. For most persons, treatment preferences are grounded in a consistent belief system. Concordance and discordance between treatment preferences and health state ratings offer clinicians the opportunity to explore patients' values and reasoning."

(8) - Fox E, Landrum-McNiff K, Zhenshao Z, Dawson N, Wu A, Lynn J: Evaluation of Prognostic Criteria for Determining Hospice Eligibility in Patients with Advanced Lung, Heart or Liver Disease; *Journal of American Medical Association* 1999, Nov 3; 282(17):1638-45

Highlights: "OBJECTIVE: To test the ability of currently available criteria to identify a population with a survival prognosis of 6 months or less among seriously ill hospitalized patients with 1 of 3 commonly fatal chronic diseases. SETTING and PATIENTS: Consecutive sample of 2607 seriously ill patients from 5 US medical centers. RESULTS: Seventy-five percent of the sample survived more than 6 months after hospital discharge; 44% expressed a preference for palliative care. CONCLUSIONS: These data indicate that for seriously ill hospitalized patients with advanced chronic obstructive pulmonary disease, congestive heart failure, or end-stage liver disease, recommended clinical prediction criteria are not effective in identifying a population with a survival prognosis of 6 months or less"

(9) - Weeks WB, Kofoed LL, Wallace AE, Welch HG: Advance directives and the cost of terminal hospitalization; *Archives of Internal Medicine*, 1994 Sep 26; 154(18): 2077-83

Highlights: "METHODS: This retrospective cohort study examined 336 consecutive patients who died in a university tertiary care medical

center: 242 without advance directives, 66 with a previously completed advance directive, 13 admitted for the express purpose of terminal care, and 15 who signed an advance directive during their terminal hospitalization. RESULTS: The group without advance directives had dramatically higher mean total (\$49,900 vs \$31,200) terminal hospitalization charges than the group with previously completed advanced directives, producing a charge ratio of 1.6. CONCLUSION: Patients without advance directives have significantly higher terminal hospitalization charges than those with advance directives. Our investigation suggests that the preferences of patients with advance directives are to limit care and these preferences influence the cost of terminal hospitalization.”

(10) - Teno JM, Licks S, Lynn J, Wenger N, Connors AF Jr., Phillips RS, O'Connor MA, Murphy DP, Fulkerson WJ, Desbiens N, Knaus WA: Do advance directives provide instructions that direct care? Support Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment; Journal of American Geriatric Society 1997 April;45(4):508-12

Highlights: “PATIENTS: A total of 4804 patients with at least one of nine serious illnesses were admitted to five teaching hospitals in the 2 years following implementation of the Patient Self-Determination Act. RESULTS: From the medical records of 4804 patients, a total of 688 directives were collected from 569 patients. The majority of these directives (66%) were durable powers of attorney; in addition, 31% were standard living wills or other forms of written instructions(3%). Only 90 documents (13%) provided additional instructions for medical care beyond naming a proxy or stating the preferences of a standard living will. Only 36 contained specific instructions about the use of life-sustaining medical treatment, and only 22 of these directed forgoing life-sustaining treatment in the patient’s current situation. CONCLUSION: Advance directives placed in the medical records of seriously ill patients often did not guide medical decision-making beyond naming a healthcare proxy or documenting general preferences in a standard living will format. Even when specific instructions were present, care was potentially inconsistent in half of the cases.”

(11)-Eisemann M, Richter J: Relationship between various attitudes towards self-determination in health care with special reference to an advance directive; Journal of Medical Ethics 1999 Feb; 25(1):37-41

Highlights: “A stratified random sample of 600 adults in northern Sweden was surveyed by a questionnaire with a response rate of 78.2%. The subjects were asked about their wish for control of their health care, their

concerns about health care, their treatment preferences in a life-threatening situation (both reversible and irreversible), and their attitudes towards the application of advance directives. RESULTS: Numerous relationships between various aspects of self-determination in health care (desire for control, fears of over-treatment, and choice of treatment level) in general and advance directives, in particular, were found. Those who wanted to have a say in their health care (almost 94%) also mainly supported the use of an advance directive. CONCLUSIONS: The fact that almost 30% of the respondents were undecided concerning their personal use of advance directives points to a lack of knowledge and to the necessity of education of the public on these issues."

(12) - Chambers CV, Diamond JJ, Perkel RL, Lasch LA: Relationship of advanced directives to hospital charges in a Medicare population; Archives of Internal Medicine 1994 Mar 14; 154(5):541-7

Highlights: "SETTING: Large (700+ beds), private university, tertiary care hospital. PATIENTS: ALL 474 patients who had Medicare listed as their primary insurer and who died in the hospital between January 1 and June 30 in 1990, 1991, or 1992. MAIN OUTCOME MEASURE: Total inpatient charges. RESULTS: The mean inpatient charge for the 342 patients without documentation of a discussion of advance directives was more than three times that of the 132 patients with such a documentation (\$95,305 vs. \$30,478). This relationship remained statistically significant after controlling for severity of disease, use of an intensive care unit, and number of procedures. Demographics, length of stay, admitting service, admitting diagnosis, and previous admissions to the study hospital did not contribute to the predictive model. CONCLUSIONS: During discussions of advance directives, patients often opt to limit the extent of care they desire in certain situations. Although the most appropriate setting for savings to society may be realized if such discussions take place while, at the same time, autonomous patient choice will be respected."

(13)-Schneiderman LJ, Kronick R, Kaplan RM, Anderson JP, Langer RD: Effects of offering advance directives on medical treatments and costs; Annals of Internal Medicine 1992 Oct 1; 117(7):599-606

"CONCLUSIONS: Despite claims that public demand for longer life accounts for rising medical costs, most surveys suggest that patients are calling for less, not more, of the expensive, high-technology treatment often used in terminal phases of illness. Executing the California Durable Power of Attorney for Health Care and having a summary copy placed in the patient's medical record had no significant positive or negative effect on a patient's well-being, health status, medical treatments, or medical charges."

(14) - Danis M, Mutran E, Garrett JM, Stearns SC, Slifkin RT, Hanson L, Williams JF, Churchill LR: A prospective study of the impact of patient preferences on life-sustaining treatment and hospital cost; Critical Care Medicine 1996 Nov; 24(11):1811-7

Highlights: *“PATIENTS: Hospitalized patients, at least 50 years of age, with short life expectancy due to end-stage heart, lung or liver disease, metastatic cancer, or lymphoma. INTERVENTIONS: None. MEASUREMENTS AND MAIN RESULTS: Patients were interviewed to determine their desire for life-sustaining treatment use and other characteristics and then were followed for 6 months to determine life-sustaining treatment use and costs during hospitalization. 244 patients were interviewed. 58 % of patients expressed a desire for life-sustaining treatments to prolong life for 1 week. During subsequent 245 hospitalizations, there were 20 episodes of mechanical ventilation, 63 episodes of intensive care, and 66 cancer treatments given. Bivariate and multivariate analyses showed no significant association between patient desire to receive treatment to prolong life and either life-sustaining treatment use or hospital costs. CONCLUSION: In a university teaching hospital setting, there is no systematic evidence that patient preferences determine life-sustaining treatment use or hospital costs.”*

(15) – Lubitz J, Beebe J, Baker C: Longevity and Medicare expenditures: New England Journal of Medicine, 1995 Apr 13, 332(15): 999-1003

Highlights: *“Medicare payments are heavily concentrated in the years just before death. About 2/3 of all payments for beneficiaries who die at 80 years of age are made for care in the last five years of life.”*

“METHODS: We used data from the Medicare program to estimate lifetime expenses for a sample of 129,166 beneficiaries, 65 or older, who died in 1989 and 1990, according to age at death. Spending for nursing home care not covered by Medicare was excluded. (Nursing home costs represent about 20 percent of total health care spending for the elderly and increase with age.) Through simulation, we assessed the lifetime payments by Medicare for enrollees who turned 65 in 1990 and those who will do so in 2020. RESULTS: Estimated lifetime Medicare payments (in 1990 dollars) ranged from \$13,044 for persons who died at 65 years of age, to \$56,094 for those who died at 89, to \$65,633 for those who died at 101 or older. The payments associated with an additional year of life and the average annual payments over an enrollee’s lifetime both decreased as the age at death increased. The estimated 7.9 % increase in life expectancy beyond 65 years that will have taken place between 1990 and 2020 (19.1 years past the age of 65 in 2020, as compared with 17.7 years in 1990) was associated with an

estimated increase of 2.0% in lifetime Medicare payments. Of the estimated \$98 billion increase in total lifetime payments (in 1990 dollars) from the 1990 group to the 2020 group, 74.3% was due to the larger size of the original birth cohort who will reach the age of 65 in 2020, 22.5% to an increase in the proportion of that birth cohort projected to survive to 65 years of age, and 3.2% to improved life expectancy beyond 65. CONCLUSIONS: The effect on Medicare spending of the increased longevity beyond the age of 65 may not be great. Total Medicare payments will be more substantially affected by the expected increase in the absolute number of elderly people.”

(16) – Silverman EM, Skinner JS, Fisher ES: The association between for-profit hospital ownership and increased Medicare spending; *New England Journal of Medicine*. 1999 Aug 5, 341(6): 420-6

Highlights: "RESULTS: Adjusted total per capita Medicare spending in the 208 areas where all hospitals remained under for-profit ownership during the study years was greater than in the 2860 areas where all hospitals remained under not-for-profit ownership (\$4,006 vs. \$3,554 in 1989, \$4,243 vs. \$3,842 in 1992, and \$5,172 vs. \$4,440 in 1995. Mixed areas had intermediate spending rates. Spending in for-profit areas was greater than in not-for-profit areas in each category of service examined: hospital services, physicians' services, home health care, and services at other facilities. The greatest increases in per capita spending between 1989 and 1995 were for hospital services (a mean increase of \$395 in for-profit areas and \$283 in not-for-profit areas) and home health care (an increase of \$457 in for-profit areas where all hospitals converted from not-for-profit to for-profit ownership grew more rapidly than in the 2860 areas where all hospitals remained under not-for-profit ownership (\$1,295 vs. \$866). CONCLUSIONS: Both the rates of per capita Medicare spending and the increases in spending rates were greater in areas served by for-profit hospitals than in areas served by not-for-profit hospitals.

(17) – American College of Physicians: Insurance Reform in a Voluntary System: Implications for the Sick, the Well, and Universal Health Care; 1996 Aug 1, 125(3), 242-9

ABSTRACT: "In the absence of universal coverage, carefully designed insurance reforms can make health insurance in the individual and small-group markets more affordable for those who need it most-the sick- and more secure for all subscribers. In this position paper, the American College of Physicians calls for specific strong reforms at both the state and federal levels. Substantial reform of the insurance marketplace is a necessary step toward achieving universal coverage. It should reflect the

view that providing quality health care is in the best interests of the community and that health care financing should be a community responsibility.”

Highlights: “As an economic good, all insurance is a vehicle for reducing risk and increasing peace of mind. As such, it carries a price.” ... “On the other hand, health care coverage is considered so vital that much of US society believes that everyone must have at least partial access to this coverage. Unlike other forms of insurance, health coverage is directly related to survival, to life and death.” ... “The social welfare view of health insurance also derives from the fact that individual control over health status is much more limited than individual control over other risk factors, such as those for fire or automobile loss. Although lifestyle choices certainly contribute to health status, many other factors – including genetic, biological and environmental influences – are beyond the control of the individual.”...”The American College of Physicians reaffirms its commitment to universal health care coverage. To that end, the College recommends reforms of the private insurance market that 1) harness the benefits of economic principles, including competition based on price and quality but not risk selection and 2) spread risk, financing and access broadly across communities.”...”Substantial reform of the insurance marketplace is a necessary step toward achieving universal coverage. It should reflect the view that providing quality health care is in the best interests of the community and that health care financing should be a community responsibility.”

(18) – Hofmann JC, Wenger NS, Davis RB, Teno J, Connors AF Jr., Desbiens N, Lynn J, Phillips RS: Patient preferences for communication with physicians about end-of-life decisions. SUPPORT Investigators. *Annals of Internal Medicine*, 1997 July 1, 127(1): 1-12

Highlights: “SETTING: Five tertiary care hospitals. PATIENTS: 1832 (85%) of 2162 eligible patients completed interviews. MEASUREMENTS: Surveys of patient characteristics and preferences for end-of-life care; perceptions of prognosis, decision making, and quality of life; and patient preferences for communication with physicians about end-of-life decisions. RESULTS: Fewer than ¼ (23%) of seriously ill patients had discussed preferences for cardiopulmonary resuscitation with their physicians. Of patients who had not discussed their preferences for resuscitation, 58% were not interested in doing so. Of patients who had not discussed and did not want to discuss their preferences, 25% did not want resuscitation. [...] CONCLUSIONS: Among seriously ill hospitalized adults, communication about preferences for cardiopulmonary resuscitation is uncommon. A majority of patients who have not discussed preferences for end-of-life care do not want to do

so. For patients who do not want to discuss their preferences, as well as patients with an unmet need for such discussions, failure to discuss preferences for cardiopulmonary resuscitation and mechanical ventilation may result in unwanted interventions.”

(19) – Lynn J, Teno JM, Phillips RS, Wu AW, Desbiens N, Harrold J, Claessens MT, Wenger N, Kreling B, Connors AF Jr.: Perceptions by family members of the dying experience of older and seriously ill patients. SUPPORT Investigators; Annals of Internal Medicine, 1997 January 15, 126(2): 97-106

Highlights: “SETTINGS: Five teaching hospitals. [...] RESULTS: 4124 of 9105 seriously ill patients died. The patients’ family members were interviewed after 3357 persons (73%) had died [...] In the last 3 days of life, 55% of patients were conscious. Among these patients, pain, dyspnea, and fatigue were prevalent. Four in 10 patients had severe pain most of the time. Severe fatigue affected almost 8 in 10 patients. More than 1 in 4 patients had moderate dysphoria (discomfort). 63% of patients had difficulty tolerating physical or emotional symptoms. Overall, 11% of patients had a final resuscitation attempt. A ventilator was used in ¼ of patients, and a feeding tube in four tenths of patients. Most patients (59%) were reported to prefer a treatment that focused on comfort, but care was reported to be contrary to the preferred approach in 10% of cases. CONCLUSIONS: Most elderly and seriously ill patients died in acute care hospitals. Pain and other symptoms were commonplace and troubling to patients. Family members believed that patients preferred comfort, but life-sustaining treatments were often used. These findings indicate important opportunities to improve the care of dying patients.”

(20) – Morrison RS, Olson E, Mertz KR, Meier DE: The inaccessibility of advance directives on transfer from ambulatory to acute care settings; Journal of American Medical Association, 1995 August 9, 274(6); 478-82

Highlights: “ RESULTS: 26% of patients who had previously executed advance directives had their directives recognized during hospitalization. Of the subgroup of patients who were judged not to have the capacity to make medical decisions during their admissions, 26% had their directives recognized. When the advance directive was recognized, it appeared to influence treatment decisions in 12 (86%) of 14 cases. CONCLUSIONS: Previously executed advance directives are not accessible when patients are admitted to hospitals for acute illness. When such directives are recognized, they are used to influence medical treatment decisions. Further research is needed to define and overcome barriers to this inaccessibility.”

(21) –Kleinman I: Written advance directives refusing blood transfusion: ethical and legal considerations; American Journal of Medicine, 1994 June, 96(6):563-7

Highlights: *"This paper examines two cases involving Jehova's Witnesses who signed cards refusing blood transfusions and who were subsequently transfused. In the Canadian case, the physician was found liable for battery. In the American case, the courts upheld the appointment of a guardian who authorized the transfusion. In the American case, the courts upheld the appointment of a guardian who authorized the transfusion. In the emergency situation, if there is a reasonable doubt about the validity of a treatment refusal, the presumption must be to render life-saving treatment. The author believes, however, that a written advance directive could be developed that respects the religious convictions of Jehova's Witnesses and the ethical and legal responsibilities of physicians."*

(22) – Danis M, Garrett J, Harris R, Patrick DL: Stability of choices about life-sustaining treatments; Annals of Internal Medicine, 1994 April 1, 120(7): 567-73

Highlights: *"PATIENTS: Medicare recipients (2536). INTERVENTION: Participants were asked about demographic characteristics, health status, well-being, depression, social support, use of a living will, and desire for life-sustaining treatment if they were to become terminally ill. These questions were repeated 2 years later (2073 patients, 82% follow-up). RESULTS: The population tended to choose to forego one or more treatment at follow-up than they did at baseline. A choice to forego treatment was twice as stable as a choice to receive treatment. Patients with a living will were less likely to change their wishes (14%) than those without a living will. (41%). Persons were more likely to want increased treatment at a later time if they had been hospitalized (23% compared with 18%), had had an accident (29% compared with 19%), had become more immobile (23% compared with 19%), had become more depressed (25% compared with 15%), or had less social support (25% compared with 14%). CONCLUSIONS: Most patients (85%) who had chosen to forego life-sustaining treatments did not change their choices. Nonetheless, these data suggest that it is important to review patient's preferences for life-sustaining treatments rather than to assume the stability of their choices."*

(23) – Emanuel EJ, Weinber DS, Gonin R, Hummel LR, Emanuel LL: How well is the Patient Self-Determination Act (PSDA) working?: an

early assesment; American Journal of Medicine, 1993 December, 95(6): 619-28

Highlights: *“RESULTS: In the pre-PSDA cohort, 60.9% of the patients had some kind of advance care planning, whereas in the post-PSDA cohort, 72.6% did. However, there was not a significant increase in the proportion of patients who had advance care planning “in a written document” (19.8% of the pre-PSDA cohort compared with 25.5% of the post-PSDA cohort). [...] CONCLUSIONS: The PSDA was associated with significant effects on general advance care planning issues, increasing the proportion of patients who had (1) some kind of advance care arrangements and (2) general discussions of end-of-life issues with their proxies. However, the PSDA did not appear associated with significant increases (1) in the use of formal, written advance care documents, (2) in the frequency of discussions between patients and their physicians on advance care documents or end-of-life issues, or (3) in the frequency of discussions about specific treatment preferences between patients and their proxies.”*

(24) – Lubitz JD, Riley GF: Trends in Medicare payments in the last year of life; New England of Medicine, 1993 April 15, 328(15): 1092-6

Highlights: *“RESULTS: Reflecting the large overall increase in Medicare spending, Medicare costs for decedents (dying patients) rose from \$3,488 per person-year in 1976 to \$13,316 in 1988. However, Medicare payments for decedents as a percentage of the total Medicare budget changed little, fluctuating between 27.2 and 30.6% during the study period. Payments for care during the last 60 days of life expressed as a percentage of payments for the last year also held steady at about 52%. Furthermore, the pattern of lower payments for older as compared with younger decedents also prevailed throughout the study period. CONCLUSIONS: The same forces that have acted to increase overall Medicare expenditures have affected care for both decedents and survivors. There is no evidence that persons in the last year of life account for a larger share of Medicare expenditures than in earlier years.”*

(25) – Blackhall LJ, Murphy ST, Frank G, Michel V, Azen S: Ethnicity and attitudes toward patient autonomy; Journal of American Medical Association; 1995 September 15, 274(10): 820-5

Highlights: *“A stratified quota sample of 200 subjects aged 65 years and older self-identified as being from each of the four ethnic groups: European American, African American, Korean American, or Mexican American. MAIN OUTCOME MEASURES AND RESULTS: Korean Americans (47%) and Mexican American (65%) were significantly less likely than European Americans (87%) and African Americans(88%) to believe that a patient*

should be told the diagnosis of metastatic cancer. Korean Americans (35%) and Mexican Americans (48%) were less likely than African Americans (63%) and European Americans (69%) to believe that a patient should be told of a terminal prognosis and less likely to believe that the patient should make decisions about the use of life-supporting technology (28% and 41% vs. 60% and 65%). Instead, Korean Americans and Mexican Americans tended to believe that the family should make decisions about the use of life support. CONCLUSIONS: Korean-American and Mexican-American were more likely to hold a family-centered model of medical decision making rather than the patient autonomy model favored by most of the African-American and European-American subjects. This finding suggests that physicians should ask their patients if they wish to receive information and make decisions or if they prefer that their families handle such matters.”

(26)- Greco PJ, Schulman KA, Lavizzo-Mourey R, Hansen-Flaschen J: The patient Self-Determination Act and the future of advance directives; *Annals of Internal Medicine* 1991 Oct 15; 115(8):639-43

Highlights: “Unfortunately, the law does little to promote discussion or preparation of advance directives before hospitalization. Additional efforts to promote the use of advance directives can take place in the outpatient medical care system, in attorneys’ offices, or through health insurers.”

(27) - Alpert HR, Emanuel L: Comparing utilization of life-sustaining treatments with patient and public preferences; *Journal of General Internal Medicine* 1998 Mar; 13(3):175-81

Highlights: “167 inpatient cases met review criteria for the scenario coma with a small chance of recovery. Hospital patients received medical interventions that were not consistently greater or less than the preferences of the surveyed outpatients or members of the general public. Resuscitation, the most frequently withheld treatment (94% of cases), was withheld more often than surveyed preferences to decline it (56% of outpatients). 4 treatments – mechanical breathing, artificial nutrition, major surgery, and hemodialysis – were utilized comparably to surveyed outpatients’ preferences (...) CONCLUSIONS: This study does not support the assumption that, collectively, patients’ advance care preferences are less interventionist than actual practices for patients in corresponding scenarios. Nevertheless, these results do support the assumption that life-sustaining treatment decisions do not conform well to individual patients’ specific preferences. Progress in end-of-life care should focus on shared decision making at the patient-proxy-physician level rather than overall life-sustaining treatment utilization.”

(28) - Teno J, Lynn J, Connors AF Jr, Wenger N, Phillips RS, Alzola

C, Murphy DP, Desbiens N, Knaus WA: The illusion of end-of-life resource savings with advance directives. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment; Journal of American Geriatric Society 1997 Apr;45(4):513-8

Highlights: *“RESULTS: Chart documentation of existing advance directives at the time of study admission increased with both the Patient Self-Determination Act and the SUPPORT intervention. We found that intervention patients were more likely to have pre-existing advance directives documented. Despite this increase, there was no corresponding change in hospital resource use for those who died during the enrollment hospitalization. Replication of analyses from published studies using data from the block randomized controlled trial found that advance directives (AD) documented by the third day of serious illness were associated with a 23% reduction in hospital resource use among control patients (\$21,284 with Ads documented compared with \$26,127 without) However, this association was not observed among intervention patients, who had more pre-existing Ads documented in the medical record. (...) CONCLUSIONS: Increasing the documentation of pre-existing ADs was not associated with a reduction in hospital resource use. ADs documented without further intervention by the third day of a serious illness were associated with decreased hospital resource use. However, we did not find this association with an intervention that increased AD documentation.”*

(29) - Filak AT Jr, Ricer JS, Ricer RE: Lifetime costs for preventive medical services: a model; Journal of Family Practice; 1999 September, 48(9): 706-10

Highlights: *“Cost effectiveness and other issues relating to preventive health services have been widely discussed, but a computer search of the literature elicited no reports in which the lifetime cost of a patient’s preventive services was calculated. The purpose of our study was to calculate the total lifetime costs of preventive medical services for idealized versions of male and female patients. METHODS: We used the preventive screening recommendations of the US Preventive Services Task Force as our standard. We developed a model using idealized patients, had no risk factors, and lived healthful lifestyles. We determined the typical charges in a specified marketplace for the office visits, procedures, laboratory tests, and purchases required to comply with the screening recommendations. RESULTS: Lifetime charges ranged from \$5432.60 to \$7529.60 for men and from \$15,307.10 to \$18,525.10 for women. CONCLUSIONS: Knowledge of the lifetime costs of preventive services may influence the decisions of patients, physicians, and insurance plans when purchasing or providing these services.”*

(30) - Short PF, Hahn BA, Beauregard K, Harvey PH, Willets ML: The effect of universal coverage on health expenditures for the uninsured; Medical Care, 1997 February, 35(2): 95-113

Highlights: *“OBJECTIVES: Universal coverage will trigger an increase in health-care spending, because the uninsured will use more services after they are insured. The effect of insurance status on expenditures is estimated here from a multivariate statistical model. RESULTS: Expenditures for the full-year uninsured increase by approximately \$700 per person in 1994 as a result of universal coverage. Nearly half of the increase is because of a substantial increase in the likelihood of hospitalization. CONCLUSIONS: If the uninsured are enrolled in plans similar to those offered by employers currently, personal health-care spending increases by approximately \$20 billion in 1994. There are other costs associated with universal coverage that are not included in this figure.”*

(31)- Ozanne L: How will medical savings accounts affect medical spending? : Inquiry, 1996 Fall, 33(3): 225-36

Abstract: *“This paper estimates that if a cross-section of nonelderly adults switched from comprehensive insurance to a combination of catastrophic insurance and a medical savings account (MSA), they would reduce their medical spending by between 2% and 8%. The author constructs measures of the prices individuals pay for medical care under a typical comprehensive insurance policy and a particular combination of catastrophic insurance and MSA. The difference in prices paid in the two health plans is combined with price elasticity estimates from the Health Insurance Experiment to predict changes in spending. Several qualifications to the estimate are considered.”*

(32)- Long SH, Marquis MS: The uninsured ‘access gap’ and the cost of universal coverage; Health Affairs, 13(2): 211-20

Highlights: *“This study estimates the effect of universal coverage on the use and cost of health services by the uninsured. Adults lacking insurance for a full year have about 60 % as many ambulatory contacts and about 70 % of the inpatient hospital days they would have if they were covered by insurance. This “access gap” is only slightly smaller for children. Providing universal coverage would increase ambulatory contacts and inpatient days by less than 4% a year. The dollar cost of these new services is estimated to be \$19.9 billion – a 2% increase in health spending.”*

