

# Bioethics at the End-of-Life

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# Conflicts of Interest

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I have no financial conflicts relevant to this presentation

*However the practice of bioethics  
often leaves me very conflicted*



# Disclaimer

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I am a clinical bioethicist, not an ethicist

You may not agree with what I am going to tell you

Your hospitals may have much different policies & approaches to ethics at the end of life than mine

This presentation may not sound very patient-centric but please believe me if I tell you I am extremely patient-centric

# Educational goals for today

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Get a sense of what most patients want for themselves at the end-of-life

Appreciate what our obligations are in the care of patients approaching death (the intersection of Bioethics & Law)

Get some ideas about what to do for patients & families with unrealistic expectations at the end-of-life (the futility problem)



# What is Ethics?

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**A set of societal principles that define  
decent human conduct**



# The First Rule of Bioethics .....

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“It’s an issue of how wrong you’re willing to be .....”\*



“..... ‘cause there usually isn’t a completely right answer”

\*Ken Prager, MD, Chair, Columbia University Ethics Committee

# The 4 Key Principles of Bioethics

Adapted from Beauchamp & Childress

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Patients get to decide for themselves

**Autonomy**

**Beneficence**

Will there be benefit?

Treat everyone equally, fair distribution of scarce resources

**Justice**

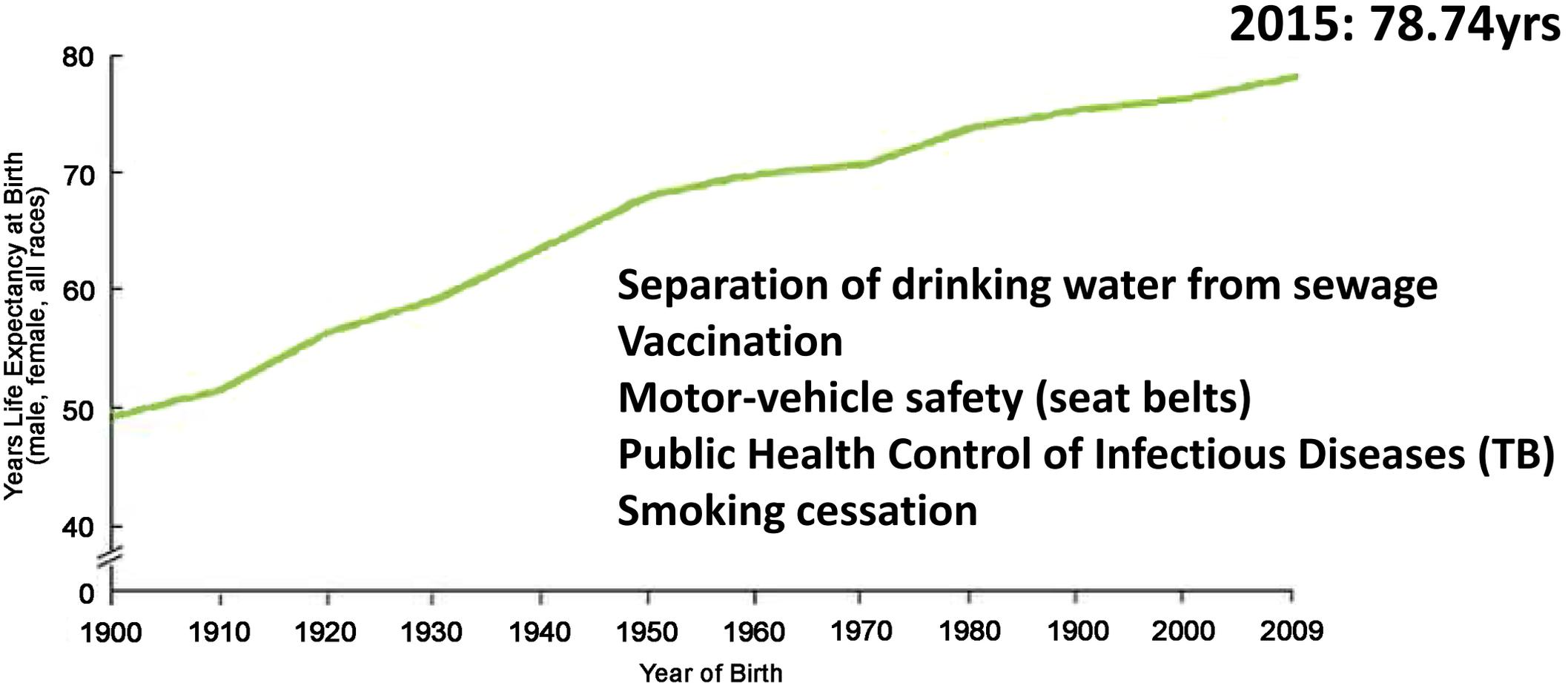
**Non-Maleficence**

... to not be the cause of harm

In some models there's more:

Respect for persons, Veracity (truth telling), Professionalism, Confidentiality

# Life Expectancy\* at Birth in the US, 1900-2009



**\*This is different than lifespan**

National Vital Statistics Reports 58, no. 21 Hyattsville, MD, National Center for Health Statistics, 2010, Table 11

# Modern Medicine is Amazing

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We now live eight years longer on average than we did 40 years ago,

Death rates are declining for many diseases

New technologies to keep us alive longer continue to flow forth ...



# *‘Desperation Oncology’: When Patients Are Dying, Some Cancer Doctors Turn to Immunotherapy*

By GINA KOLATA APRIL 26, 2018



**Dr. Sartor: “Do you want to try an immunotherapy drug before you die?”**

# Life spans with no upper boundaries

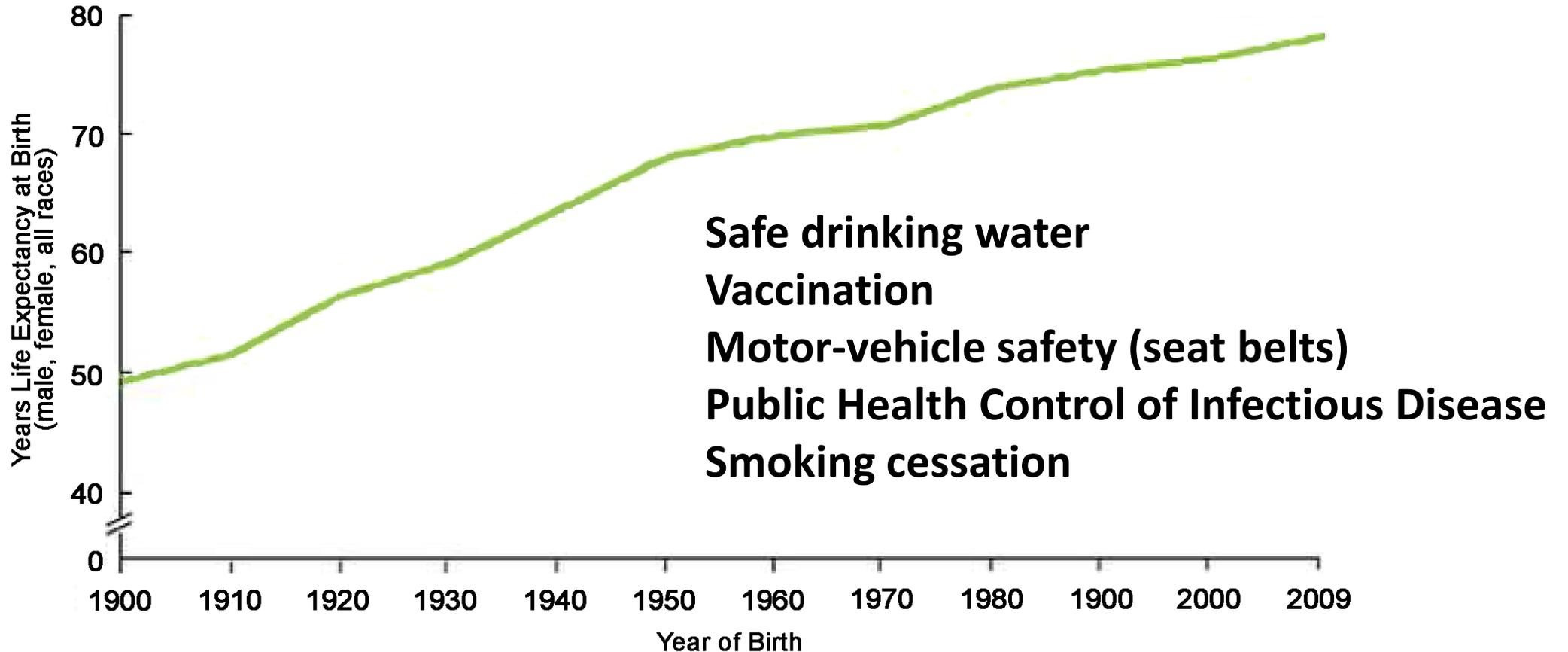
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There is almost always something that can be done technologically to give a dying person a few more hours, or days, or even weeks

What “progress” *has* given us is an amazing ability to keep sick people alive



# Life Expectancy at Birth in the US, 1900-2009



**What's missing from this list?**

# Is what most people get what they want?

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Neurologically devastated 2 year old with prolonged PICU stay whose father had an “unyielding refusal to consider” DNAR.

His son’s inevitable and unsuccessful cardiac arrest included innumerable, unsuccessful attempts to place central venous and intra-osseus lines.

While viewing his son’s body after the code the father looked at all the puncture wounds and bruises from failed attempts and said, “I want to thank you. I can see from this that you really tried.”



# The Hastings Center Report (2003)

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***“...too many Americans die unnecessarily bad deaths—deaths with inadequate palliative support, inadequate compassion, and inadequate human presence and witness. Deaths preceded by a dying marked by fear, anxiety, loneliness, and isolation. Deaths that efface dignity and deny individual self-control and choice.”***<sup>1</sup>

*We have traded off earlier, quicker deaths for later, drawn-out deaths. That bargain needs to be reconsidered.*<sup>2</sup>

# What most people want for themselves at the End of Life

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*“To die a natural death at home without being a burden, financially or emotionally, on their families”*

To be free of emotional & spiritual burden, including the fear of dying

To be treated with respect & dignity and to be safe in the presence of loved ones

Their family’s needs are met

Their Healthcare team listens to their needs, feelings and experiences

Comfort through good pain and symptom management



# Wishes of the Common Man

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Multiple nationwide surveys report that the majority (70-87%) of Americans prefer not to be kept alive with machines if in a persistent vegetative state<sup>1</sup>

This includes cessation of fluids and nutrition

**Surrogates commonly fail to correctly predict what their loved ones want in regard to CPR vs. DNR and prolongation of life vs. comfort care when/if critically ill<sup>2,3</sup>**

# Why does this happen?

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Fake News

Clinical Inertia

Failure of communication amongst everyone  
but especially docs & patients and their families



# The War on Death

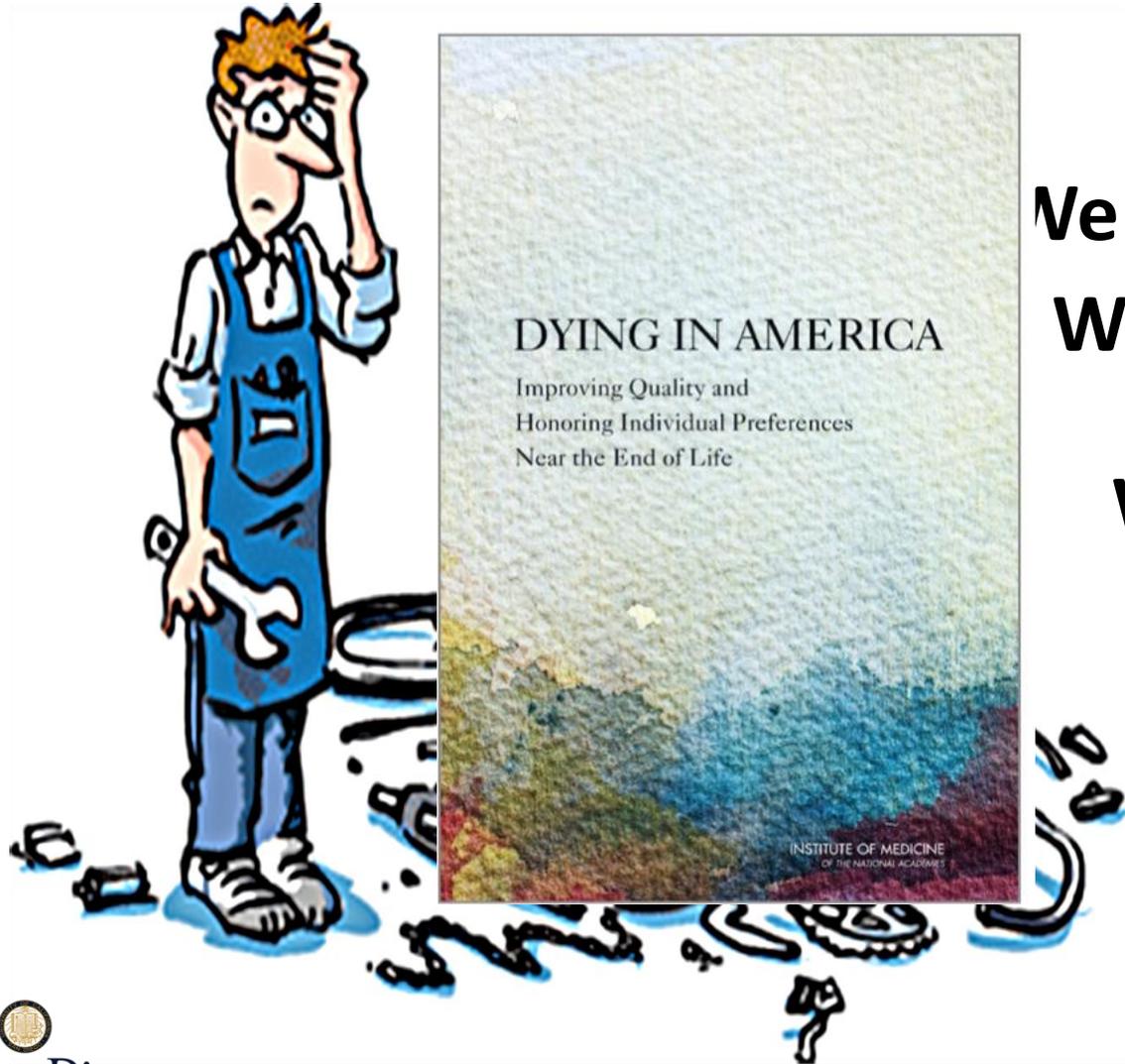
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**Death is something to be overcome**

**Most of this post-WW2 cultural shift can be attributed to the healthcare apparatus**



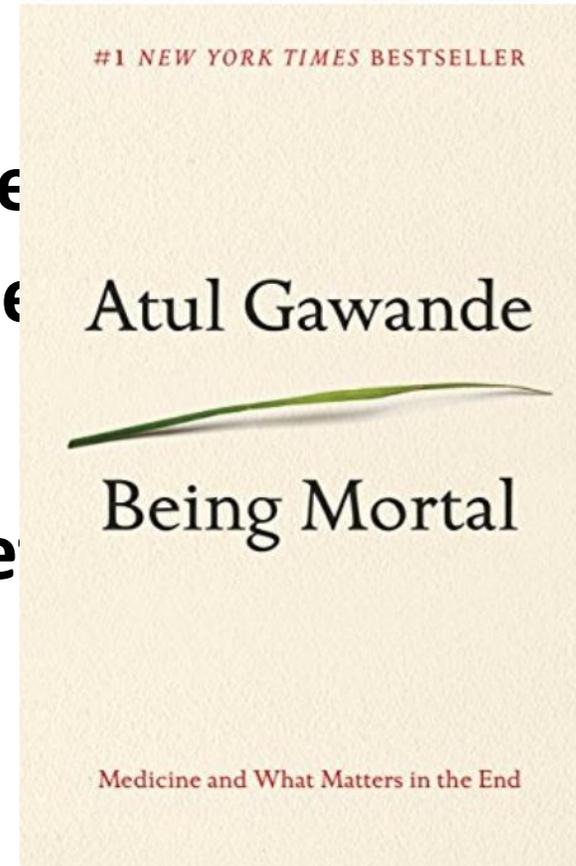
# How are we going to fix this?



We need

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*We need to change us*



# How are we going to fix this problem?

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"Couldn't we just hire a do-it-yourselfer?"



# Mrs. G.

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Mrs. G is 93 year-old woman with moderate dementia admitted with sepsis, acute renal failure, altered mental status. Prior to admission Mrs. G. was living with her adult son and required assistance with most ADLs likely due to dementia. She had not seen a physician since delivering her children.

Mrs. G's hospital course was very stormy, sepsis quickly progressed to multiple organ system failure requiring vasopressor support and mechanical ventilation for more than 3 months. Her ICU stay included several hospital acquired infections, a pressure ulcer, severe malnutrition, and a lower extremity DVT. She remained obtunded despite discontinuation of sedatives and analgesics.



# Mrs. G.

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Mrs. G's son's sole focus in life was his mother, he had never married, hadn't worked in many years so he could take care of her, and he had no social contacts other than his mother.

Numerous family meetings were held with the son & the ICU team. The son insisted that everything be done including CPR should her heart stop but he steadfastly refused tracheotomy and feeding tube placement. The ICU team felt that Mrs. G. was in constant pain.

Bioethics was consulted because of discordance about goals of care, and frustration on the part of the ICU team.

***What should we do?***



# *“Overmastered by Disease”<sup>2</sup>*

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*“Whenever the illness is too strong for the available remedies, the physician surely must not expect that it can be overcome by medicine ... To attempt such treatment is to display an ignorance that is allied to madness”*

1. Reiser SJ, Dyck AJ, Curran WJ, editors. Ethics in medicine: Historical perspectives and contemporary concerns. Cambridge: MIT Press; 1977. p 6–7.
2. From: Hippocratic Corpus, found in N Engl J Med 2010; 363:1988-1989

# Clinical Inertia

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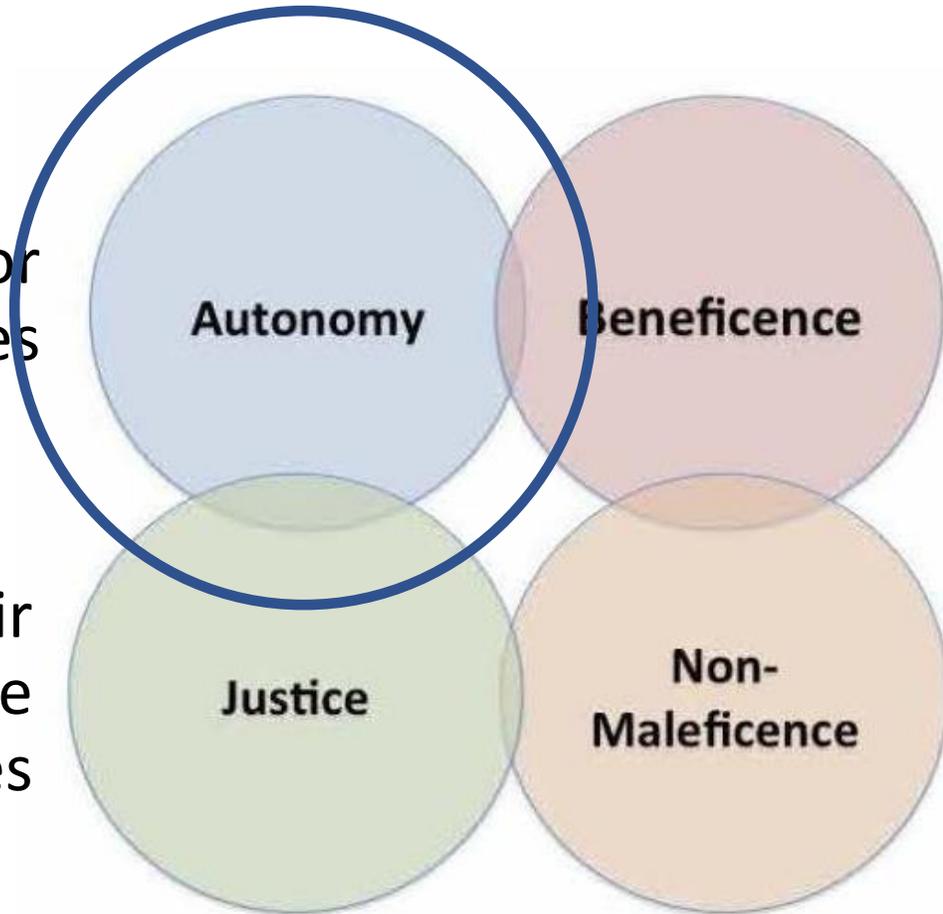
... as patients like Mrs. G. progress, there is a transition where providing life-prolonging and disease-targeted treatment is unlikely to be of benefit and increasingly conflicts with the goals of alleviating suffering and improving quality of life

*The problems is that once the ball starts rolling,  
we have trouble recognizing when to stop*



# The Big 4 Principles

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Patients get to decide for themselves

Will the patient benefit from our actions?

Treat everyone equally, fair distribution of scarce resources

... to not be the cause of harm

# Autonomy

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Care at the end of life should, whenever possible, respect personhood

Care at the end of life plan should be patient-centric and reflect the cultural and spiritual needs of the person

It should respect advance directives

It should intermingle with beneficence → the goal should be to achieve the best possible quality of life for as long as reasonable



# Is Respect for Autonomy the Problem?

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Whenever possible, autonomy must be promoted and protected by offering information and explanation in a manner and context appropriate for the patient

*Patients nearing the end of life are, once they know what goals are possible, experts in what they would choose but not in the means that can help achieve those goals*



**“Has autonomy become a kind  
of tyranny over end-of-life  
decision-making?”<sup>1</sup>**

**Are we afraid to say no?**

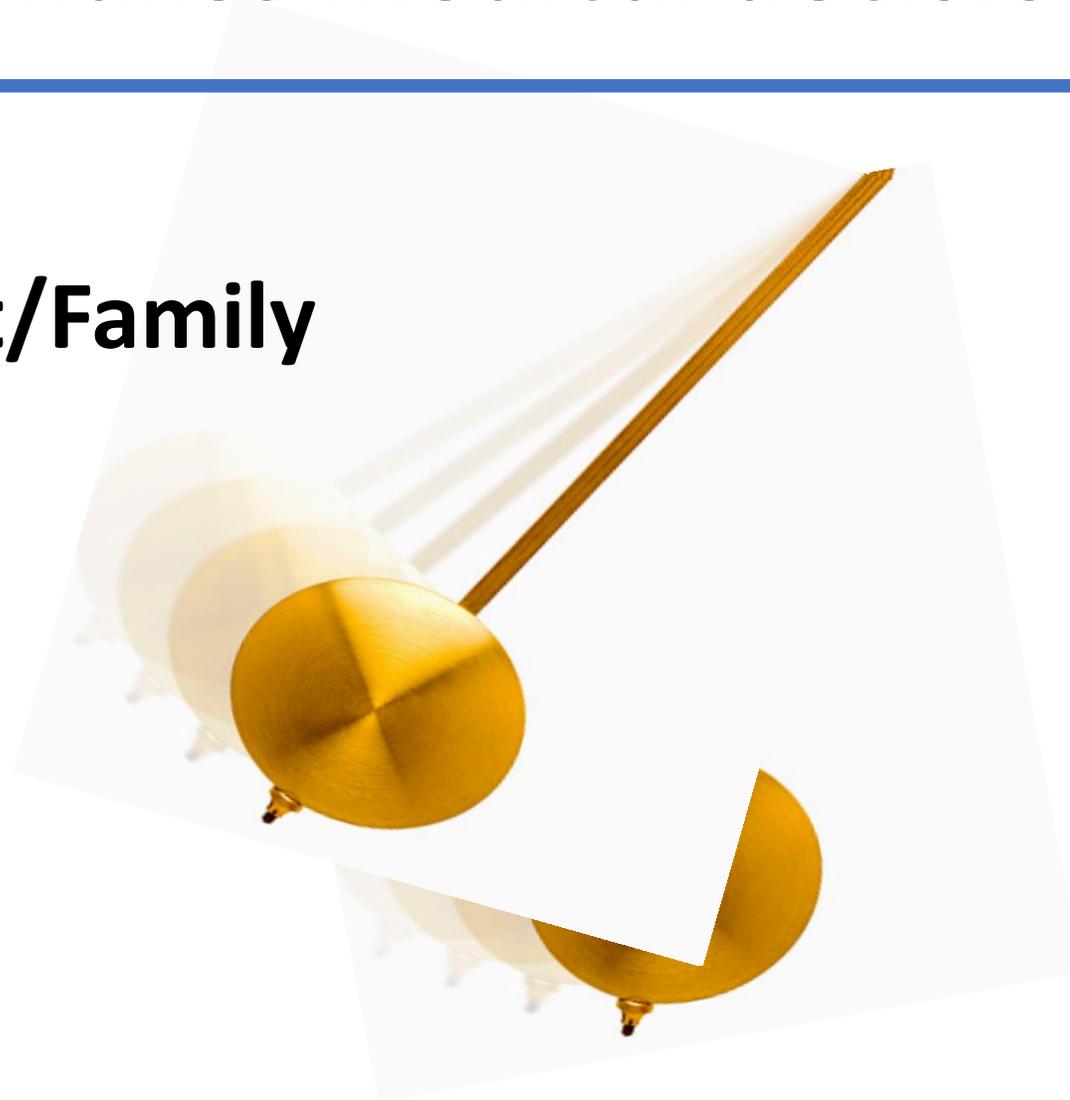
# Who makes medical decisions for patients?

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**Patient/Family**

**Physician**

**Shared Decision Making**



# Who makes medical decisions for patients?

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## Shared Decision Making

A model that implies that the physician has a say in making a decision about the plan



# Are you any good at delivering bad or sad news?

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## SPIKES—A Six-Step Protocol for Delivering Bad News: Application to the Patient with Cancer

**WALTER F. BAILE,<sup>a</sup> ROBERT BUCKMAN,<sup>b</sup> RENATO LENZI,<sup>a</sup> GARY GLOBER,<sup>a</sup>  
ESTELA A. BEALE,<sup>a</sup> ANDRZEJ P. KUDELKA<sup>b</sup>**

<sup>a</sup>The University of Texas MD Anderson Cancer Center, Houston, Texas, USA;

<sup>b</sup>The Toronto-Sunnybrook Regional Cancer Centre, Toronto, Ontario, Canada

# A Fundamental Operational Rule of Bioethics

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1. If you disagree with the asks & expectations of the patient and/or family – you should step aside and transfer care to someone else.
2. If the entire care team (the doctors & nurses) feels similarly then call a Bioethics Consultation.

The most common reason for discord is failure to establish realistic expectations with our patients and their families

Most of these cases are due to poor communication on our part by not having a well orchestrated family conference



# Mr. P

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Mr. P is 53 y/o Sudanese gentleman with in a persistent vegetative state attributed to cardiac arrest from spice intoxication in the fall of 2014.

The Univ. of Arizona Bioethics Committee was asked see Mr. P in January 2015. The committee recommended that Mr. P. be made AND and that new medical problems not be addressed when they arise. Subsequently a long lost brother was located in Minnesota with help of the Sudanese consulate. His brother came to Tucson and after substantial discussion and vacillation and with support from the Sudanese community a decision was made to keep Mr. P's AND status but proceed with tracheostomy and institutionalization to provide more time for him to declare his functional state.



# Mr. P

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Mr. P. returned to hospital in early 2016 with polymicrobial sepsis from pneumonia, pancreatitis, severe malnutrition, contractures, pressure ulcers, and uncontrolled diabetes. His hemodynamics improved in the first 48 hours permitting discontinuation of pressors but he continued to require mechanical ventilation.

The MICU team, with some effort, contacted Mr. P's brother who indicated that he could not make "difficult decisions" for his brother such as establishing limits of care. As a result Mr. P. was made "full code" and his ICU team began tackling his many medical issues.



# Mr. P

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The MICU team requested input from the Bioethics Committee because they felt that Mr. P's condition had not improved after more than 1 year of support and that continuation of aggressive treatment would do little more than facilitate recurrent cycles of acute hospitalization for conditions stemming from his bed bound state and inability to care for himself, they are asking if care can be unilaterally withdrawn.

**Can we do that?**

# Futility

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“It is futile to try to define futility”

Non-beneficial Care

# Non-Beneficial Care in Texas

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“Provision of medical care or treatment to a patient when there is no reasonable hope of benefit from that treatment”



Texas Health & Safety Code, Section 166.046, Subsection (e): “... a health care facility may discontinue life-sustaining treatment ten days after giving written notice if the continuation of life-sustaining treatment is considered futile care by the treating medical team.”

# What Do We Mean by Futility?

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Physiological futility	Treatment that cannot achieve its physiological aim
Quantitative futility	Treatment that has <1% chance of succeeding
Qualitative futility	Treatment that cannot achieve an acceptable quality of life treatment that merely preserves unconsciousness or fails to relieve total dependence on intensive medical care
Imminent demise futility	An intervention that will not change the fact that the patient will die in the near future
Lethal condition futility	The patient has an underlying condition that will not be affected by the intervention and which will lead to death within weeks to months



# AMA Code of Medical Ethics

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“Physicians are not ethically obligated to deliver care that, in their best professional judgment, will not have a reasonable chance of benefiting their patients.”

..... But, make sure everyone caring for the patient agrees and inform the family

# Nonbeneficial Care at UC San Diego

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UCSD Health: “Any treatment without a realistic chance of providing an effect that the patient would ever have the capacity to appreciate as a benefit, such as merely preserving the physiologic functions of a permanently unconscious patient, or has no realistic chance of achieving the medical goal of returning the patient to a level of health that permits survival outside the acute care setting of UCSD Medical Center.

# How do we get ourselves into these situations?

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## **We are awful at prognostication**

Doctors sometimes object that uncertainty in prognostication means we should shy away from seeing a patient as needing end-of-life care



# Fairness & Urgency

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A decision to let a dying person wait for an end of life plan is effectively a decision not to act because the patient will have died before the action is taken.

*Get your Bioethics Committee involved early*



# Another Fundamental Rule of Bioethics

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Never, ever ask the patient or the family if they want everything done

This question is fundamentally unethical because it is uninformed consent – it is impossible in the setting of an acute crisis to meaningfully convey the risks and benefits of “everything”,

Ask “do you want what we think is most likely to help”



# Mr. B

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Mr. B is a 76 year-old gentleman who suffered an acute subdural hematoma while on anticoagulation for A-fib in June 2015 which was treated with a craniectomy followed by care in a series of post-acute care facilities.

During these admissions he developed numerous medical issues but did demonstrate some improvement in alertness such that he was able to feed himself with assistance as recently as fall 2015.



# Mr. B.

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Mr. B. was admitted to BUMC-T on Thanksgiving 2015 from a SNF with altered mental status, dehydration, and sepsis. He initially responded to treatment but over the course of a >2month admission experienced 2 additional episodes of septic shock, developed profound malnutrition worsened by refractory diarrhea attributed to intolerance to tube feedings, and anascarca.

Over the 24 hours prior to bioethics consultation he demonstrated hemodynamic instability, rising lactate, an uptrending WBC count, and worsening mental status causing his care team to restart broad spectrum antibiotics. He had numerous possible sources of infection including a tracheostomy, a chronic indwelling Foley catheter, a G-tube, and a PICC line.



# Mr. B.

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Mr. B's wife, son, and daughter were very involved & ever present at the bedside, they were well aware of his medical issues.

They described innumerable bad experiences with the care provided to Mr. B. during his stays at an LTAC and SNF but also at his current hospital. They clearly expressed that they felt things were often misrepresented to them, that the doctors caring for Mr. B. had hidden facts from them and withheld needed care, or refused to listen to them. They also indicated that they have been repeatedly and regularly asked to make Mr. B. DNR.



# Mr. B.

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At the time of Bioethics Consultation Mr. B. was again at the threshold of septic shock. His care team felt that this was happening despite the well intentioned efforts of many caregivers over a long hospitalization and was due to malnutrition, immunosuppression, and colonization with resistant organisms in a bed bound patient who is unable to care for himself.

They perceived that addressing another acute deterioration would only serve to perpetuate an uninteruptable cycle and prolong his suffering.

Mr. B's family insisted that "everything" be done for him, they did not want him to be DNR.

***What happened here?***

# A Very Angry Family

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- Limited health literacy of the family and many perceived & real failures of healthcare delivery and benefit led to mistrust of the hospital & providers by the family
- Family meetings were held at the bedside and in the hallway, no one sat down with all the parties
- Care givers weren't frank or effective at conveying that Mr. B was dying
- A point person to represent the family was not designated which resulted in different people talking to different members of the family every day
- Tension amongst the family limited effective communication opportunities

**Total Failure of Communication with a very angry family**

# Reasons to Set Aside Autonomy

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The Bioethics Committee felt that we weren't going to be able to help Mr. B., a decision was made to offer transfer to another hospital or remain to receive comfort care

Welfare of the individual

Unrealistic requests by patient and/or surrogates

The interests of other parties (e.g. children)

The interests of healthcare givers

Societal interests in allocation of scarce resources



# When is a unilateral DNR reasonable?

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Patients for whom CPR may not provide benefit (PVS/MCS)

Patients for whom CPR (if successful) would result in permanent damage, unconsciousness, and poor quality of life

Patients who have poor quality of life before CPR is ever needed and wish to forgo CPR should breathing or heartbeat cease but are unable to assent/consent

# Worried about litigation?

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“Increasingly, U.S. jurisdictions are imposing sanctions for providing overly aggressive end-of-life treatment...the message from legislative and adjudicative tribunals is that, in certain end-of-life circumstances, not only *may* patients’ autonomy be limited, but it *must* be limited.”

**Best protection: make sure the whole healthcare team is in agreement about nonbeneficial care, get Bioethics involved, and communicate with the family**

# If you don't agree with the asks of the patient

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*If this happens:*

1. If you disagree with the asks & expectations of the patient and/or family – you should step aside and transfer care to someone else.
2. If the entire care team (all the doctors & nurses) feels similarly then call Bioethics and offer transfer to another facility

*The most common reasons for discord are failure to establish realistic expectations with our patients and their families and poor communication*



# We don't preach what we practice

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In multiple survey-based studies 80-90% of physicians indicate that they would forgo high-intensity end-of-life treatment in a setting of incurable illness (cancer).<sup>1</sup>

“Physicians more often than other Americans chose to forgo chemotherapy and other forms of medical torture that give promise, at best, to give them a little time and a lot of suffering.”

“Physicians know enough to choose to be well—or well enough—for as long as they can”<sup>2</sup>

# Doctrine of Double Effect

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Thomas Aquinas:

*“it is morally legitimate to cause or permit evil in the pursuit of good”*

It is ethical to take actions with good intentions (pain control) even if unintended but foreseeable bad consequences occur (respiratory failure)

# The guy lacks capacity, now what?

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Forcing a patient to undergo treatments and procedures they decline is, in general, not practical.

For example restraining and sedating a patient to permit a skin graft when it is unlikely that they will comply with a post-op care program is not likely to be successful and should be carefully considered.

*Assessment of medical decision-making ability applies to medical decisions, not all aspects of life.*



# Hospice for the Homeless

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***"The homeless don't have a place to live,  
let alone a place to die."  
We want to surround them with comfort."***

**Hospice for the Homeless\***

# Phil's Summary

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End-of-life care is about living, not just about dying, good end of life care is an ethical duty.

Find ways to respect the preferences of those who can no longer speak for themselves

Clear, effective communication is paramount

Think about personhood - listen to the patient and those close to them, try to understand the importance of their goals and values and how they mesh with your medical plans & recommendations

***Your ethical obligation is to do what you think is best for your patient***



# Its not just us & its not new .....

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Dylan Thomas, 1938

**Do not go gentle into that good night,  
Old age should burn and rave at close of day;  
Rage, rage against the dying of the light**

**pfactor@ucsd.edu**



**Thank you**

**pfactor@ucsd.edu**

# It's a conspiracy

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Fee-for-service medicine, rewards physicians for their use of medical technologies not for talking with patients



# Understanding Phil's Approach to Ethical Decision Making

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A place to start

**Hueristic**

Something to aspire to

**Iterative**

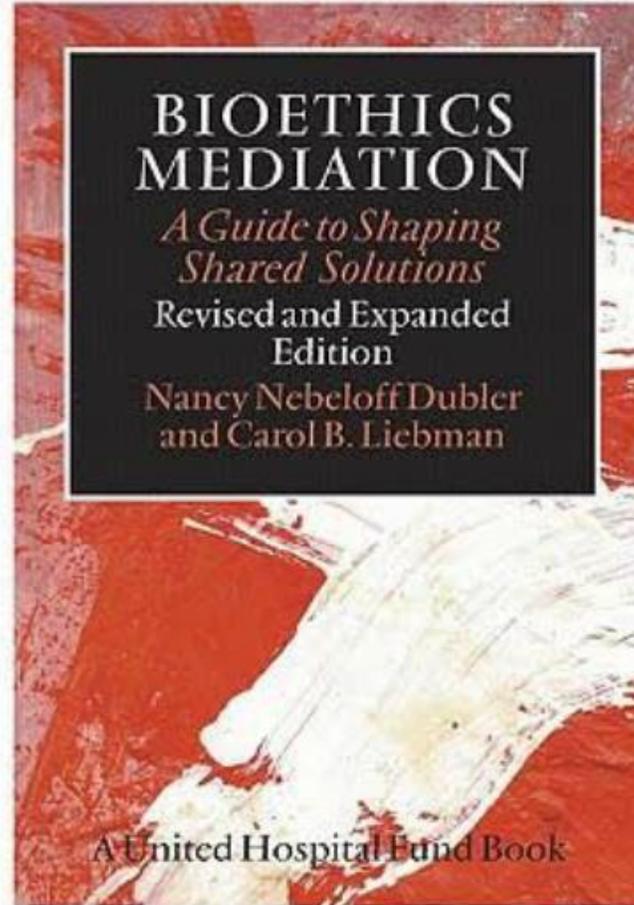
**Experiential**

# A Better Way

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**B**

Sit down conferer  
(and/or patient) a  
when possible,



**1**

that gives the family  
heir issues and then,  
nable to everyone

