ONE LAST HABITAT, FOR US ALL.

FACING MORTALITY WITH HUMILITY, GRACE, AND COURAGE

A Model Home

Jimmy
Being Mortal
by
Atul Gawande MD
Or
The Book I Wish I’d Written!
Reviewed by
David R Grube MD
I see it now –
this world is swiftly passing.

- the warrior Karna, in the *Mahabharata*
Atul Gawande MD
Education

- was born in 1965 in NY; parents both physicians; moved to Athens, Ohio as a youth
- completed General Surgery residency, Brigham and Women's Hospital, (2003)
Political career

- was an early volunteer for Gary Hart’s presidential campaign (1984)
- involved with Al Gore’s campaign (1988)
- stopped medical school for two years to work on Bill Clinton’s campaign as *Healthcare Lieutenant* (1992)
Political career

- in 1992, after Clinton’s inauguration, he became a Senior Adviser in the Department of Health and Human Services. He directed one of the three committees of the Clinton Health Care Task Force; the committee’s charge was to define the benefits packages for Americans and subsidies and requirements for employers.
- He returned to MS in 1993
Writings

- Slate Magazine (online) articles on residency
- New Yorker Magazine, staff writer 1998
  - June 2009 article compared health care in two towns in Texas; it “argued that a revenue-maximizing businessman-like culture (which can provide substantial amounts of unnecessary care) was an important factor in driving up costs, unlike a culture of low-cost high-quality care as provided by efficient health systems (ex: Mayo Clinic).”

WIKIPEDIA
Books

- 2002 - Complications: A Surgeon's Notes on an Imperfect Science
- 2007 - Better: A Surgeon's Notes on Performance
- 2009 - The Checklist Manifesto: How to Get Things Right
- 2014 - Being Mortal: Medicine and What Matters in the End
Awards / Honors

- 2006 – MacArthur Fellow
- 2007 – Director of WHO’s effort to reduce surgical deaths
- 2009 – Hastings Center Fellow
- 2014 – Reith Lecturer (*The Future of Medicine*)
  (Boston/London/Edinburgh/Delhi)
Rare photo of Atul Gawande as a little boy....
8 Chapters (from The Independent Self .... TO ... Courage).

Medical facts juxtaposed with clinical stories and personal stories (esp. his father).

The SCIENCE vs THE ART OF MEDICINE

“HARD” technology vs “SOFT” technology
Being Mortal: Themes

- Technology has changed the way we die
- The default in US medicine is: **do everything**
- ODTAA (the body’s inevitable decline)
- How do we (and will we) deal with unwanted care?
  - Safety for others vs Autonomy for ourselves
- Personal stories matter; every story has an ending (his father’s story) and it matters as well
(...and esp. for educators)

When I die, I hope it is at a faculty meeting or teacher inservice because the transition from life to death would be so subtle.
Introduction: Medical School

• The Death of Ivan Ilyich:
  • “the failure to offer comfort … was (only) a failure of character and culture.”
  • “we took for granted that honesty and kindness were basic responsibilities”
  • “What worried us was knowledge. While (we thought) we knew how to sympathize, we weren’t at all certain that we would know how to properly diagnose and treat.”
“Modern scientific capability has profoundly altered the course of human life. But scientific advances have turned the processes of aging and dying into medical experiences, matters to be managed by health care professionals.”

In the U.S. everyone must die with a ICD-9* code.

(*INTERNATIONAL CLASSIFICATION OF DISEASES – NINTH ED.)
CHAPTER 1 –
THE INDEPENDENT SELF

- Family stories (wife’s grandmother; father; paternal grandfather)
- Tradition of caring for elders (India vs US)
- Increased life expectancy; fewer children
- Separation: 1910: 60% of seniors lived with a child; 1960 = 20%; 1975 = 15%
- Reality: SOONER OR LATER, LIVING INDEPENDENTLY WILL BECOME IMPOSSIBLE
CHAPTER 2 – THINGS FALL APART

- Why?
- Only 3% explained by family history
- Genetics or “wear and tear”?
- Is there a reproducible pathway or cause for aging?
- “No, we just fall apart.”

FELIX SILVERSTONE MD, SENIOR GERIATRICIAN, PARKER JEWISH INSTITUTE, NY
HISTORICAL MODEL OF SURVIVAL
PATTERN OF DECLINE FOR CHRONIC ILLNESSES
A CURRENT PATTERN OF SURVIVAL –
“the dwindles”
Our fantasy of survival (DRG)
CHAPTER 2 – 
THE “RECTANGULARIZATION” OF SURVIVAL

- Throughout history, society’s population had formed a pyramid based upon age
- 1950 –
  - Children under 5 y.o. = 11% of population;
  - Adults 45-49 = 11%;
  - Over 80 = 1%
- 2015 - # of 5 year olds = # of 50 year olds
- 2045 - # of 5 year olds = # of 80 year olds!
CHAPTER 2
(MEDICINE IS NOT KEEPING UP)

Geriatricians

- Total # has decreased by 25% in last 15 years
- Among lowest paid specialties in US medicine
- Less than 300 doctors a year are being trained in geriatrics (more than 300/year are retiring!)
- 97% of medical students take no course in geriatric medicine (?) (LCME: 92% of medical schools have required courses in geriatrics)
DIED FROM
NOT FORWARDING
THAT EMAIL
TO TEN PEOPLE
The elderly have many, and chronic, problems.
- US Medicine has focused upon technology.
- It is not ‘glamorous’ or financially rewarding to care for the elderly.
- There is no “automatic defrailer”.
- The ‘art of medicine’ vs the ‘science.’
Chapter 2 – THINGS FALL APART

- Median income of people over 80 is $15,000/yr
- Average retirement community rent is ~ $35K
- More than ½ of elderly living in long-term-care facilities run through their entire life savings
- The average American spends a year or more of old age living is assisted living or a nursing home
CHAPTER 3 – DEPENDENCE

- 1935 – Social Security
- 1946 – Hill-Burton Act
- 1954 – Amendment to finance Nursing Homes
- “Nursing homes were never created to help people facing dependency in old age. They were created to clear out (expensive) hospital beds.”
- By 1970 – 13,000 Nursing Homes
CHAPTER 4 – ASSISTANCE

- 1980’s - Keren Brown Wilson
- Park Place, Portland, Oregon
  - “the key word in her mind was “home”
  - Your own priorities hold sway
  - You decide how you spend your time
  - You decide how you share your space
  - You decide how you manage your possessions
CHAPTER 4 — ASSISTANCE

- The Hierarchy of Needs. As we age:
  - We focus on ‘being’ rather than ‘doing’
  - We focus on the present rather than the future
  - We find living to be more emotionally satisfying
  - PERSPECTIVE: “As your horizons contract your focus shifts to the here and now, to everyday pleasures, and the people closest to you.”
  - And perspective is what matters.
2010 – The number of people in assisted living equals the number of people in nursing homes

“ ‘We want autonomy for ourselves, and safety for those we love.’ That remains the main problem and paradox for the frail.”

“The language of (US) medicine, with its priorities for safety and survival, is taking over, again.”
“We all seek a cause beyond ourselves” (LOYALTY)
Loyalty is the opposite of individualism
We all require devotion to something more than ourselves for our lives to be endurable.
MEANING: “The only way death is not meaningless is to see yourself as part of something greater: a family, a community, a society.”
CHAPTER 5 – A BETTER LIFE

- AUTONOMY: different concepts; contexts

- “All we ask is to be allowed to remain the writers of our story. That story is every changing. This is why the betrayals of body and mind that threaten to erase our character and memory remain among our most awful tortures. The battle of being mortal is the battle to maintain the integrity of one’s life.”
CHAPTER 6 – LETTING GO

- 25% of all Medicare spending is for the 5% of patients who are in their final six months of life
- “The most likely time you will have surgery is in the last week of your life.”
- 2008 COPING WITH CANCER Study: Terminally ill patients who were put on a mechanical ventilator, given electrical defibrillation, or admitted to the ICU had a much worse quality of life than those who had no interventions
CHAPTER 6 – LETTING GO

- Seriously ill patients’ desires:
  - Avoid suffering
  - Strengthening relationships (w/ family and friends)
  - Being mentally aware
  - Not being a burden on others
  - Achieving a sense that their life is complete

These do not align with American medicine’s desires for the seriously ill.

But the default is DO EVERYTHING
“Well, good news! We think we got it all!”
Medical science has rendered obsolete centuries of experience, tradition, and language about our mortality and created a new difficulty for mankind: how to die.
CHAPTER 6 – LETTING GO

Physicians views may be unrealistic:

- 63% of MD’s overestimated their patient’s survival time
- 17% underestimated survival time
- The average estimate was 530% too high
- The better the doctor knew the patient, the more likely they were to err
- > 40% of oncologists offer treatments they know are unlikely to have any benefit
CHAPTER 6 – LETTING GO

- Discussing EOLC w/ your doctor
- Those who saw a palliative care specialist
  - ... stopped chemotherapy sooner
  - ... entered hospice far earlier,
  - ... experienced less suffering at the end of their lives
  - ...and they lived 25% longer!
- Zen: You live longer only when you stop trying to live longer
Not an EOL option....

If I am ever on life support, unplug me...
Then plug me back in. See if that works...
CHAPTER 7 – HARD CONVERSATIONS

- Doctor patient relationships
  - Paternalistic
  - Informative
  - Interpretive
  - Shared-decision making (is it theoretical?)
- Sub-specialization of medicine and technology
- ODTAA
Cindy W.
Aug. 20, 1954
Sept. 30, 2013
“I told you I was sick”
Plato, in “The Laches” asks What is courage?

- “Courage is strength in the face of knowledge of what is to be feared or hoped. Wisdom is prudent strength.”
- “One has to decide whether one’s fears or one’s hopes are what should matter most.”
Suffering

- Daniel Kahneman: Thinking, Fast and Slow
- The “Peak-End” rule:
  - An “experiencing self” vs a “remembering self”
  - The worst moment and the last moment
  - The last moment is more meaningful

- “Life is meaningful because it is a story. In stories endings matter. The peaks are important, and so is the ending.”
“I never expected that among the most meaningful experiences I’d have as a doctor – and, really, as a human being – would come from helping others deal with what medicine cannot do as well as what it can.”
Epilogue

- His father’s story
  - ODTAA
  - His mother call 911!
  - “mud brain” at the end

- “If to be human is to be limited, then the role of caring professions and institutions ought to be aiding people in their struggle with those limits.”
“The waning days of our lives are given over to treatments that addle our brains and sap our bodies for a sliver’s chance of benefit. They are spent in institutions – hospitals and nursing homes - where regimented, anonymous routines cut us off from all the things that matter to us in life. Our reluctance to honestly examine the experience of aging and dying has increased the harm we inflect on people, and denied them the basic comforts they most need.”
What matters....

- What is your understanding of the situation and its potential outcomes?
- What are your fears and what are your hopes?
- What are the trade-offs you are willing to make and not willing to make?
- What is the course of action that best serves this understanding?
Critics

“Being Mortal uses a clean, illuminating style to describe the medical facts and cases that have brought him … to the understanding how wrong doctors can be if they let their hubris and fear of straight talk meld with a patient’s blind determination to fight on, no matter what.”

JANET MASLIN, NYT, OCT 2014
“In his newest and best book, Atul Gawande lets us have it right between the eyes: no matter how careful we are or healthful our habits, like everyone else, we will die, and probably after a long period of decline and debility.”

“There is no way, of course, to make old age and all its infirmities disappear; it is what life deals us. But what Gawande shows us in this admirable book is that we could handle it a lot better.”

MARCIA ANGELL MD, NYT, JAN 2015
“As (doctors) we (too often) deal with the pain and grief of loss (death) of our patients. But it is through these struggles with critical and difficult conversations that we also focus on what is truly important in our lives. As we become mortal, grief breaks our hearts, and we become more human. And perhaps better at doctoring. Thank you, Dr Gawande, for giving a voice to that experience.”
In sum....

“I learned about a lot of Things in medical school, but mortality wasn’t one of them. ....the purpose of medical schooling was to teach us how to save lives, not how to tend to their demise.”
Summary

- Technology has changed how we live and how we die. It will not get easier.

- We will all die, and we can determine some things, but not all.
  - Patient autonomy; unwanted medical care

- Shared decision making is important

- There is unwanted medical care and suffering

- Advance Directives are most important
  - What REALLY matters? (…not in a vacuum)
Summary

- The role of the physician is not to ensure health and survival (for that is impossible): medicine’s purpose is to enable well-being.
- All of us will die; we should talk with our loved ones and our physicians about what we want.
- Stories, stories, stories….. and endings matter.
"We’ve all got a lot of dying ahead of us. We might as well learn how to go about it."

Ken Kesey
We’re all just walking each other home.

-Ram Dass-
Resources:

- Can’t We Talk About Something More Pleasant (Roz Chast)
- How We Die (Sherwin Nuland MD)
- The Conversation (Angelo Volandes MD)
- Knocking on Heaven’s Door (Katy Butler)
Dying: the Last Chapter

How do you want your story to end?

Tell me, what is it you plan to do with your one wild and precious life?

Mary Oliver

Compassion and Choices and Imagine Coffee welcome you to this conversation on September 23, 2015 at Imagine Coffee from 7-9 P.M.
Random Review

October 14, 2015 (noon – 1 p.m)

ALL THE LIGHT WE CANNOT SEE
Anthony Doerr

Reviewer: Penny Brassfield