
The justice of personalized medicine

Ethics / Medicine

- ❖ The Just Caring problem
- ❖ What is precision medicine
- ❖ Imprecision and uncertainty
- ❖ Who is paying?
- ❖ Limits and tradeoffs

Just caring problem

- ❖ What does it mean to be just and caring when we have limited resources?
- ❖ Practical implications
 - ❖ *Needs for limits on health care spending is unavoidable*
 - ❖ *Needs to make allocation decisions is unavoidable*
 - ❖ *Rationing means denying individual patients needing some care that care*
- ❖ Ethical implications
 - ❖ *Human life is not priceless*

Just caring problem

What should be a benefit package that is guaranteed to all?

Among the emerging (costly) medical therapies, which should be included (excluded) in that package?

Some statistics

- ❖ In 1960, the US spent \$26 billion (== \$240 billion in 2022 \$) on health care, or about 5.2 % of GDP
- ❖ In 2022, the US spent \$4.4 trillion on health care, or about 18.2 % of GDP
- ❖ Canada, UK, and most European countries spend 8-12% of their GDP on healthcare

Some statistics

- ❖ In 1960, the US spent \$26 billion (== \$240 billion in 2022 \$) on health care, or about 5.2 % of GDP
- ❖ In 2022, the US spent \$4.4 trillion on health care, or about 18.2 % of GDP
- ❖ Canada, UK, and most European countries spend 8-12% of their GDP on healthcare
- ❖ In 2022, approx 37% of the total health expenditures were consumed by the 14% of the US population over age 65 (47 million people)
- ❖ In 2023, approx 21% of the US population will be over the age of 65

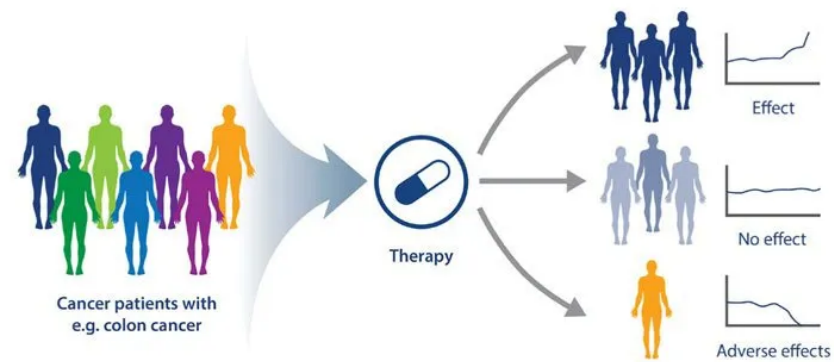
Justice / Ethics

How much health care are we ethically obligated to provide to:

- ❖ People with cancers
- ❖ People with hear disease
- ❖
- ❖ Patients with dementia
- ❖ Sick children
- ❖ Patients with disabilities?

Personalized medicine

Traditional Medicine One Treatment Fits All



Precision Medicine More Personalized Diagnostics



Where is the problem?

The example of cancer

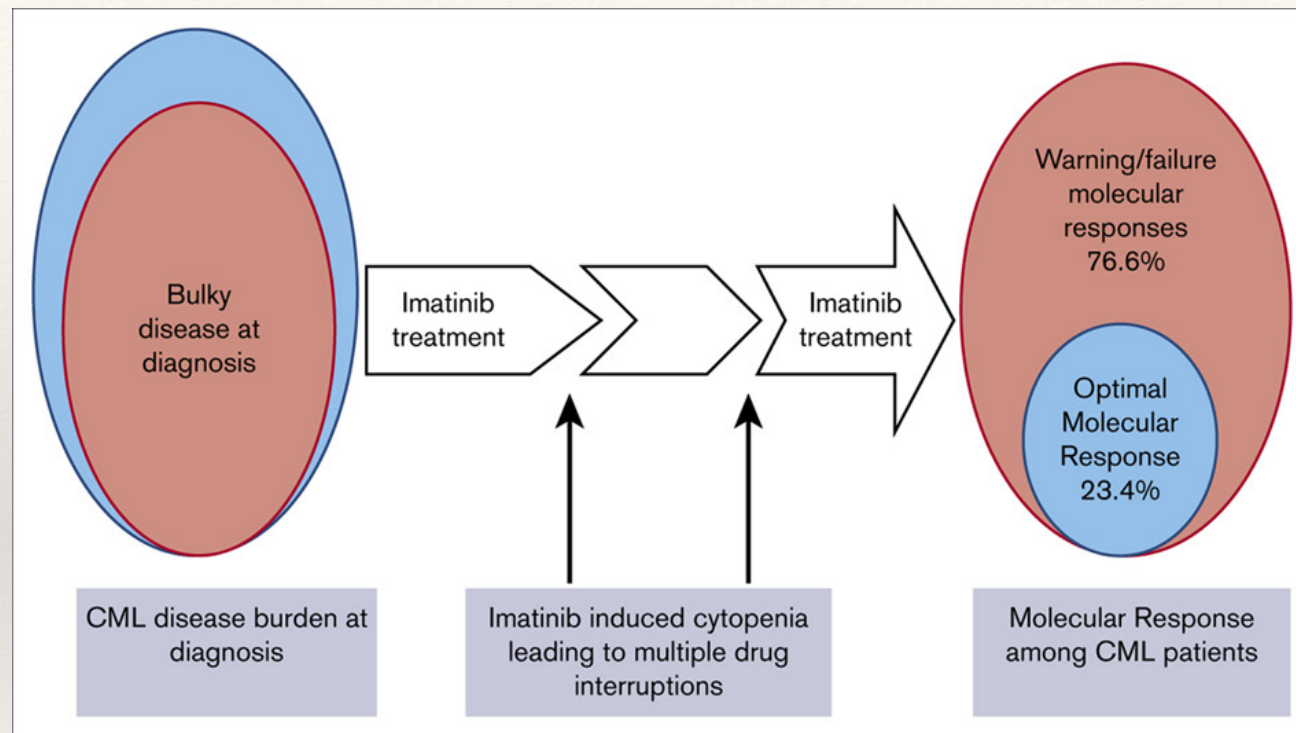
- ❖ 1.8 million Americans were diagnosed with cancer in 2021
- ❖ 610,000 Americans die of cancer each year (projected to be 1 million in 203)
- ❖ Cancer is largely a disease of older people (87% of cancer deaths are in individuals > 50 years old)
- ❖ Most cancers are treatable, if caught early
- ❖ Cost of cancer treatment is VERY expensive and increasing, in part as cancers are heterogeneous

Imatinib: success...

- ❖ Chronic Myelogenous Leukemia (CML) is caused by a mutation affecting an enzyme, tyrosine kinase ABL
- ❖ The mutation gives rise to a constitutively active kinase, which causes leukemia.
- ❖ Imatinib is a tyrosine kinase inhibitor.



Imatinib: ...failure

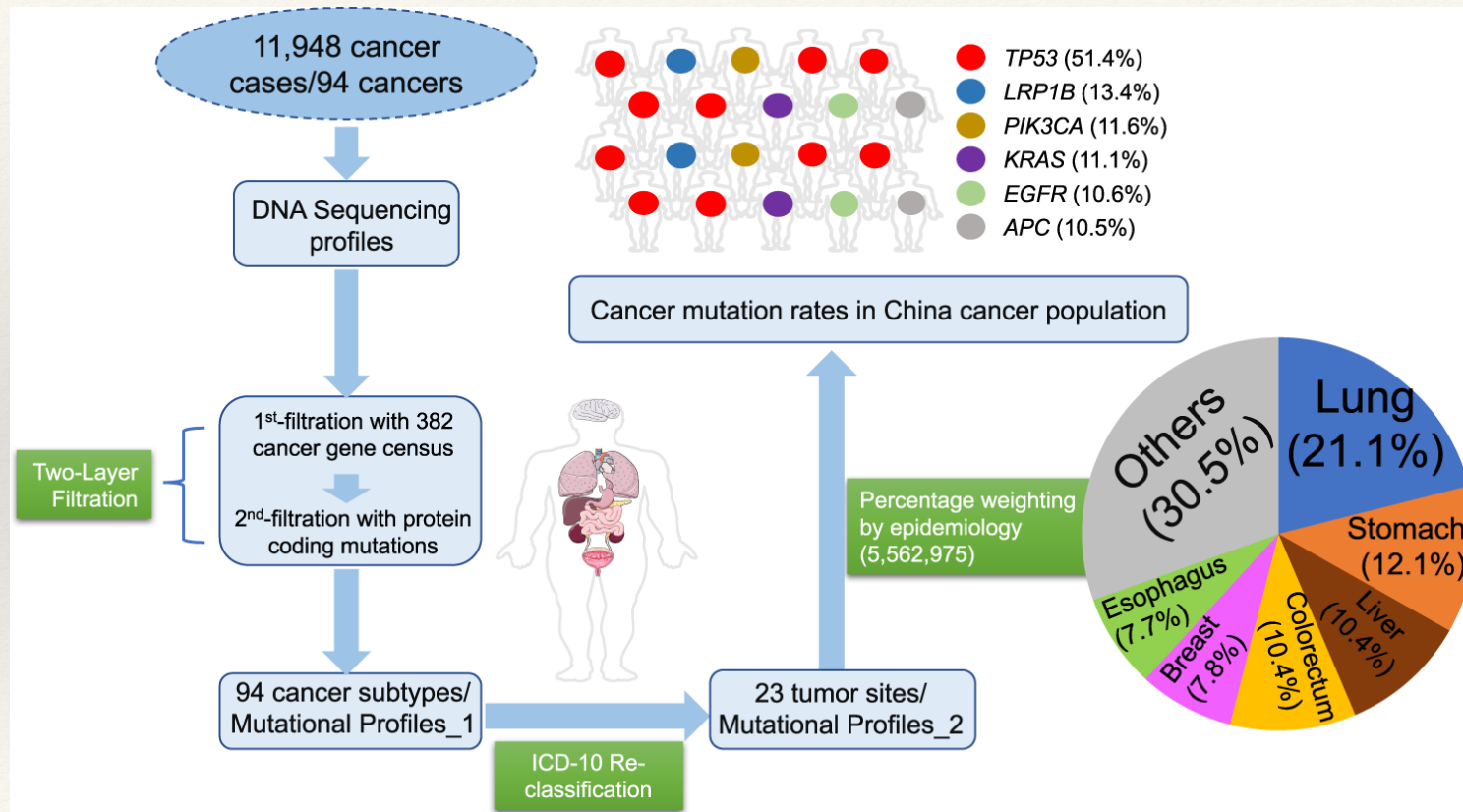


Nasser et al, Blood advances, 2021

Cancer treatments

- ❖ 150+ cancer drugs approved by FDA since 2000
- ❖ Cost: \$100,000 — \$200,000 for a course of treatment
 - ❖ Extreme case: Kimtrak for uveal melanoma, a type of eye cancer; single-use vial given by infusion once every week. It was launched at \$18,760 / vial, i.e. an annual cost of \$975,520.
- ❖ None of the drugs are curative
- ❖ Median gain in life expectancy for patients measures in months

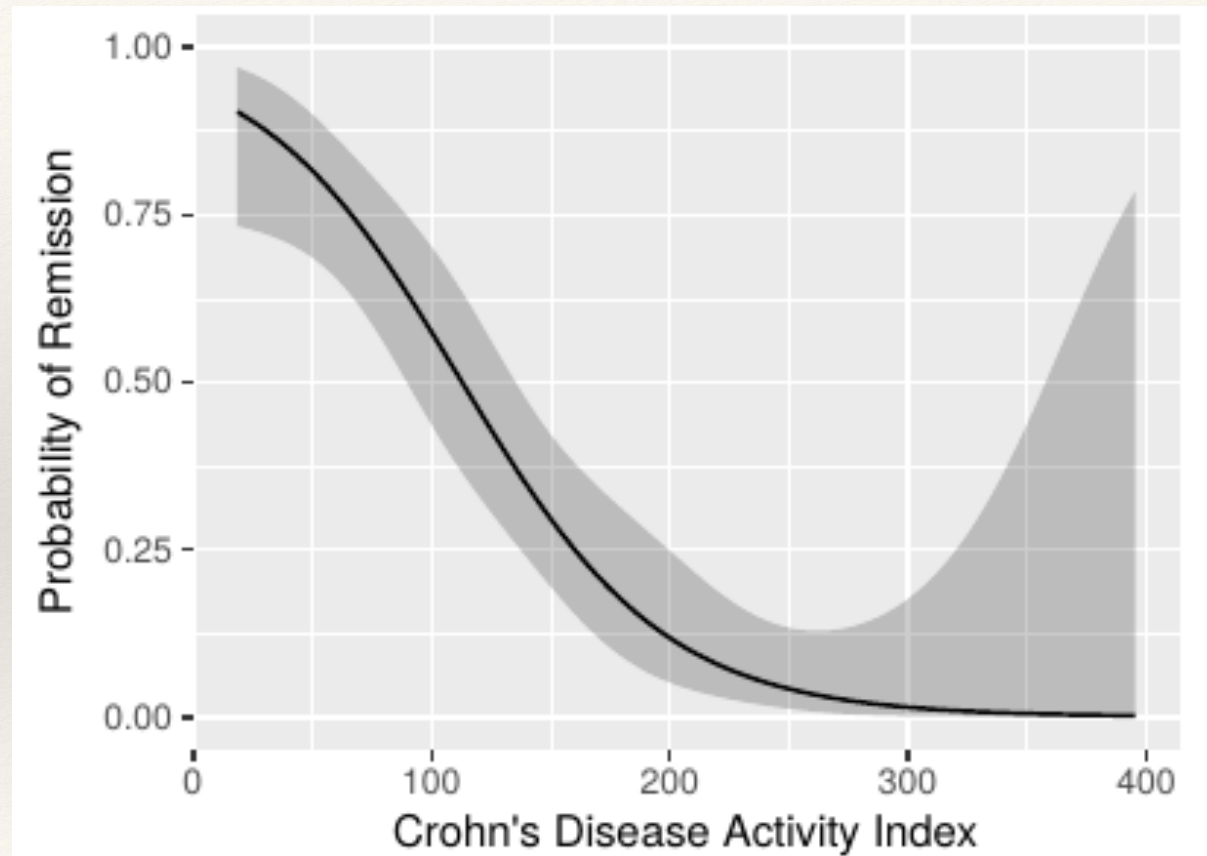
Cancer mutations



This is not just a cancer related problem

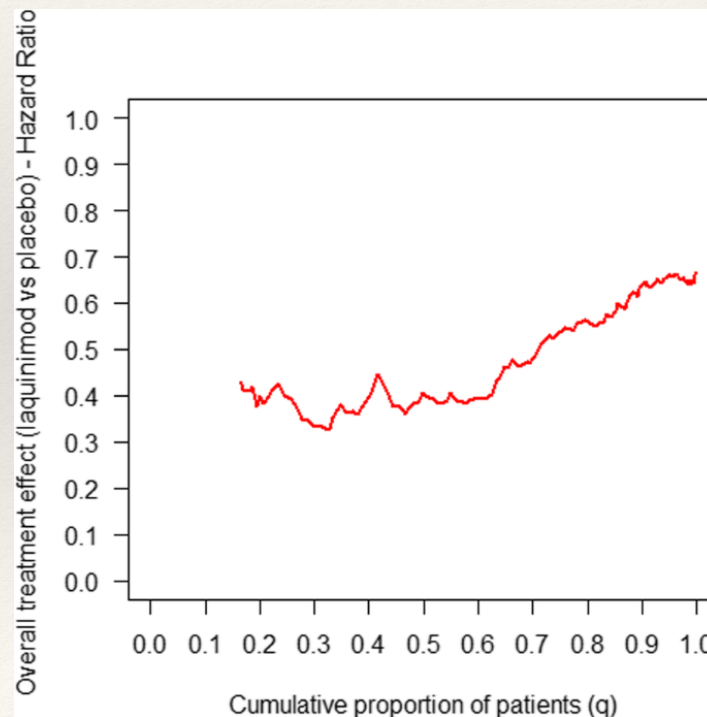
- ❖ Amyotrophic lateral sclerosis (ALS): 17300 diagnosed with ALS every year in the US
- ❖ Tofersen is a new drug that slows the progression of ALS.
- ❖ Only 2% of ALS patients who have mutations within the SOD1 gene can benefit from Tofersen
- ❖ Treatment is estimated to cost \$375,000 per year.
- ❖ ***Are we ethically obligated to find comparable drugs for the other 98% of ALS patients?***

Wicked problem #1: The ragged edge



Wicked problem #1: The ragged edge

There is no sharp line that distinguishes those patients who are strong responders to a drug, to moderate responders, to minimal responders, and to non-responders.



Wicked problem #2: Funding research

Should we fund research that is aimed at identifying biomarkers for patients who are likely to benefit from a certain therapy / drug, as it implies that we will deny those drugs to individuals who are unlikely to benefit from access to them?

Wicked problem #3: Comparators

- ❖ For HIV positive patients, four drug combinations cost \$35,000 per patient per year; As HIV positive patients can get up to 30 extra years of life, the aggregated cost is over a million dollars.
- ❖ For dialysis patients, we are paying almost \$90,000 a year in the US; there are 570,000 of those patients. They will get seven to 10 extra years of life. The aggregated cost of doing that is gonna be somewhere between 650,000 and 1.4 million.
- ❖ A left ventricular assist device (LVAD) cost \$250,000 to provide individuals with LVADs. And in the future for artificial hearts we'll pay half a million dollars, perhaps for as many as 50,000 Americans per year.

Justice?

- ❖ A utilitarian would say that only predicted super-responders should be treated /
- ❖ A libertarian would say that you have a right only to what you can pay for
- ❖ A deontologist or a virtue ethicist would be at loss as to what to think!

- ❖ *Questions:*
 - ❖ Are we equal when it comes to health?
 - ❖ Do we equalize resources, outcomes?
 - ❖ Should people with bad health habit have the same right as people that tempt to live healthy life?