



SOLUTIONS THAT MATTER. HEALTH CARE THAT WORKS.

TERMINAL ILLNESS: OPERATIONALIZING THE DEFINITION

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Death

Aim?



- ▲ To create a workable category of people allowed to access PAD (and hospice) while others cannot
- ▲ Three key components:
 - Competence,
 - Voluntariness, and
 - Terminally Ill – predicted to die within six months, sometimes modified as “with usual course”

What, exactly, is a prognosis to live for 6 months or less?



1. Nearly certain to die within six months
2. Very likely to die within six months
3. More likely than not to die within six months

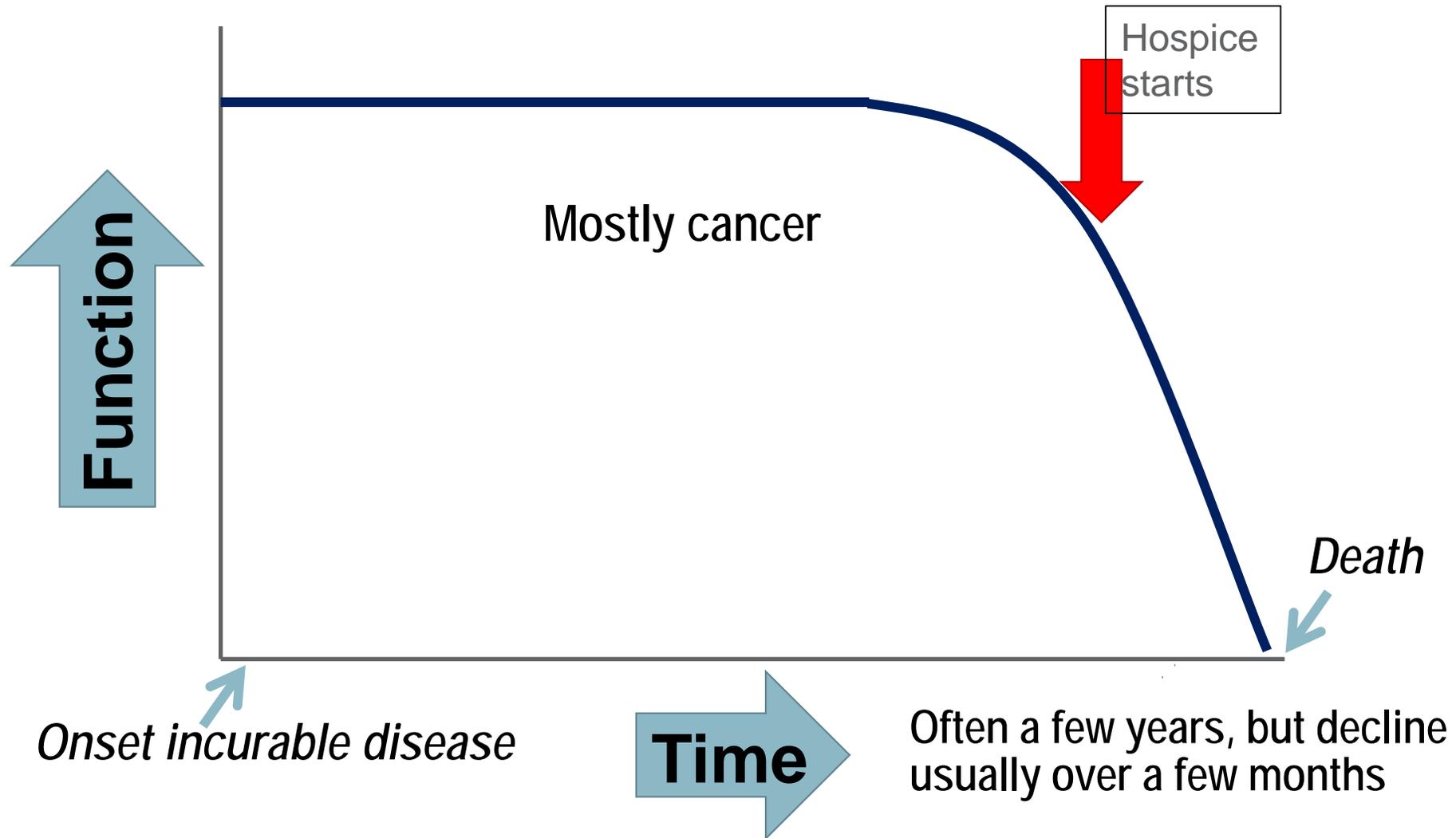
Sounds “academic” and trivial, right? – but the population with the third option is around 1000 times larger than the first, and stays in the category for many more months.

So – who did we really mean to include and exclude?

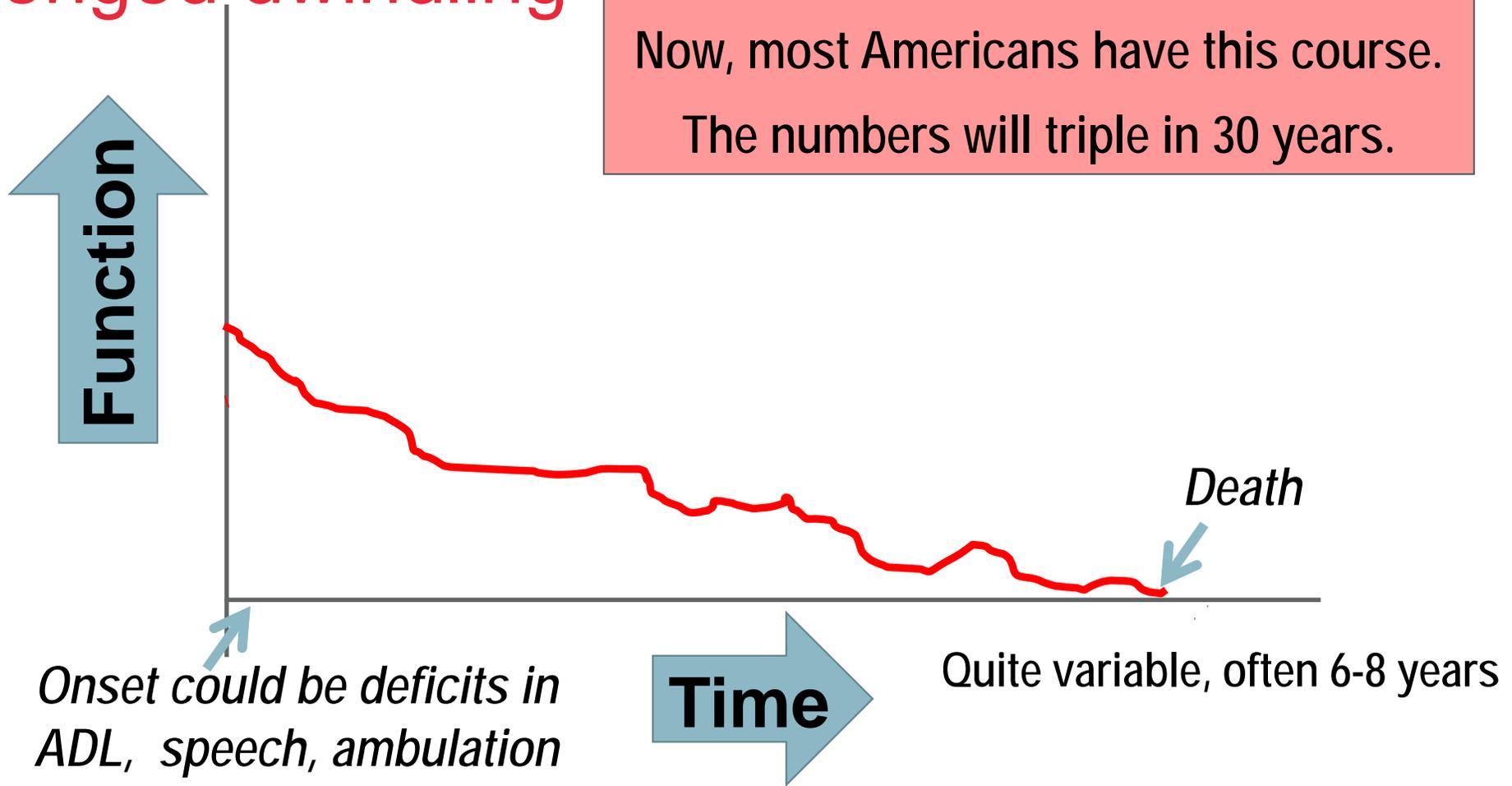
First, a little about the course to death



Single Classic “Terminal” Disease: “Dying”



Prolonged dwindling

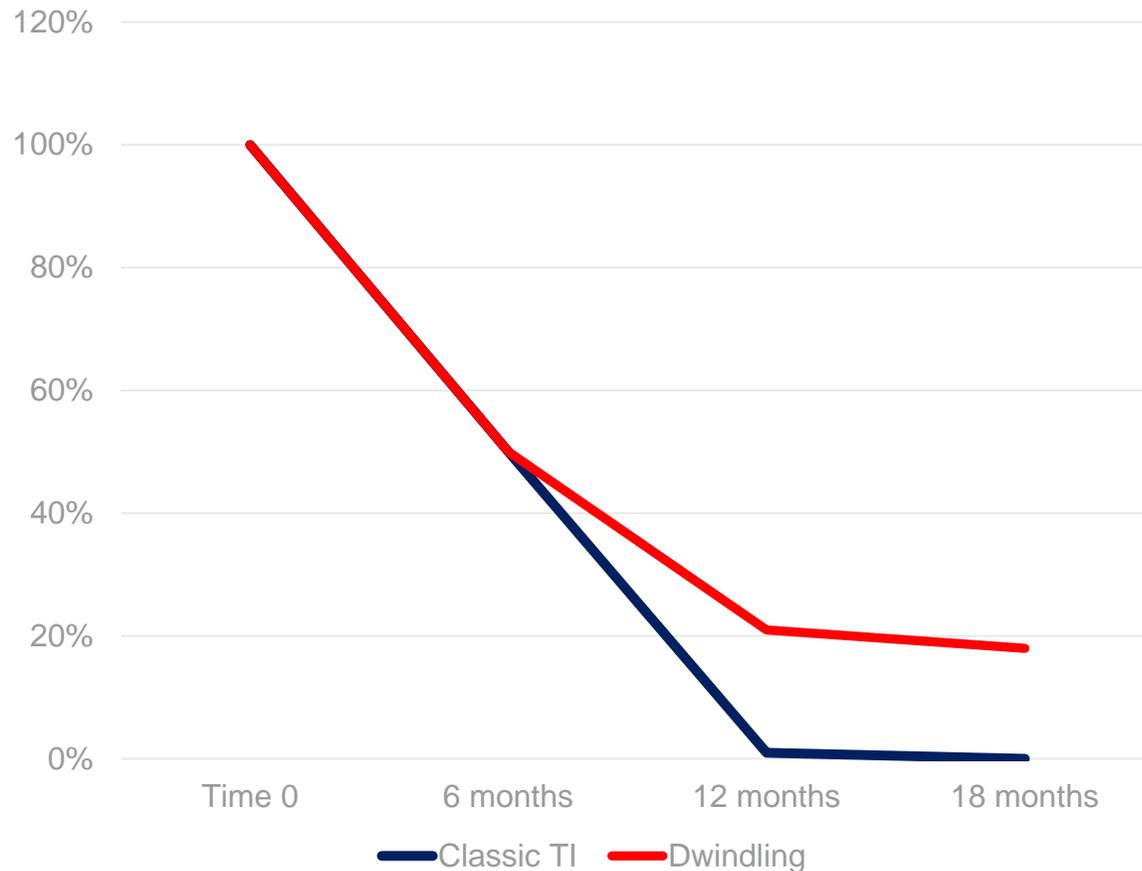


Comparing these two courses



Course to death	Major illnesses	Self-care disabled	“error “of >1 yr actual survival	Lead time to know nearly certain death in <6mos.
Classic	Many Cancers	Last weeks	Nearly zero	Few weeks or months
Dwindling	Dementia, Parkinsons, Frailty, strokes, ALS, organ system failures	Average >2 years	25% or more	Few days or weeks

Survival curves



Assuming we are aiming for “more likely than not,” and we identify a population of lung cancer patients with 51% dead at 6 months
And a population of frailty patients with 51% dead at 6 months –
Almost no lung cancer survivors will be alive at one year.
But 20% or more of the frailty patients will be alive at one year.

Does it matter? Is the answer different for hospice and for PAD?

Comparing these two courses



Course to death	Major illnesses	Lead time to know “nearly certain” death in <6mos.	Lead time to know “more likely than not,” death in <6 mos.	Prevalence: N eligible with “nearly certain”/ N eligible with “more likely than not”
Classic	Many Cancers	Few weeks up to a couple of months Time = A + B	Few additional weeks or months Time = A+B+C	X /10X
Dwindling	Dementia, Parkinsons, Frailty, strokes, ALS, organ system failures	Few days up to a week or two – Time = A	Many months Time = A+B+C+D	<X/ 1000 X

Again – who do we mean to include and exclude, and is it different for hospice and PAD?

What, exactly, is a prognosis to live for 6 months or less?



1. Nearly certain to die within six months
2. Very likely to die within six months
3. More likely than not to die within six months

In addition – usually made with (at best) inadequate predictive models by physicians with personal biases and little instruction as to what they should do

And it depends some on choices, supports, and treatments

Some important research questions:



- ▲ Why do policymakers link PAD to “reliably” dying “soon?” – long term suffering seems to have moral weight, and time near death can be precious. And why does policy link hospice to dying soon? – comprehensive supportive care aligned with the patient’s priorities would be a good benefit to have earlier while living with advanced illnesses.
- ▲ What standard do we mean to use, or are there very good reasons why the stakeholders have resisted defining it?
- ▲ What entities would support making statistical estimations of prognosis readily available?
- ▲ How will the “in practice” definition evolve if never defined? And why?
- ▲ “Debility” and “frailty” were overused in hospice eligibility and are now banned, but they are common reasons for very old people to die. How does that history apply to PAD? Is it sustainable in either case?

Contact info



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