TERMINAL ILLNESS: OPERATIONALIZING THE DEFINITION

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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”

- Onset incurable disease
- Time
- Function
- Mostly cancer
- Hospice starts
- Often a few years, but decline usually over a few months

Mostly cancer
Onset could be deficits in ADL, speech, ambulation

Function

Time

Death

Quite variable, often 6-8 years

Mostly frailty and dementia

Now, most Americans have this course.

The numbers will triple in 30 years.
## Comparing these two courses

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

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

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?
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