Capacity Assessments during the COVID-19 Pandemic

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A word of caution/comfort

- Decision-making capacity assessment are often difficult even in the absence of a pandemic.

- Making high-stakes decisions in the face of incomplete information is difficult.

- There may not be an absolute right answer, and different physicians may make different determinations

- This presentation is meant to provide a framework to guide your thinking in these difficult situations.

Part 1: Capacity Basics

What is capacity and why is it important?

Capacity assessment ensures a patient is of sound mind and understanding to make a specific medical decision

Capacity assessment balances two pillars of medical ethics: patient autonomy and beneficence

Two phases of decision-making capacity assessment

1) Determine the capacity threshold based on the clinical scenario

2) Based on your discussion with the patient, evaluate whether the patient meets the appropriate threshold for all four functional elements of capacity

Capacity Threshold

The level of capacity required to make a decision is proportional to the gravity of the situation, based on risk/benefit analysis.
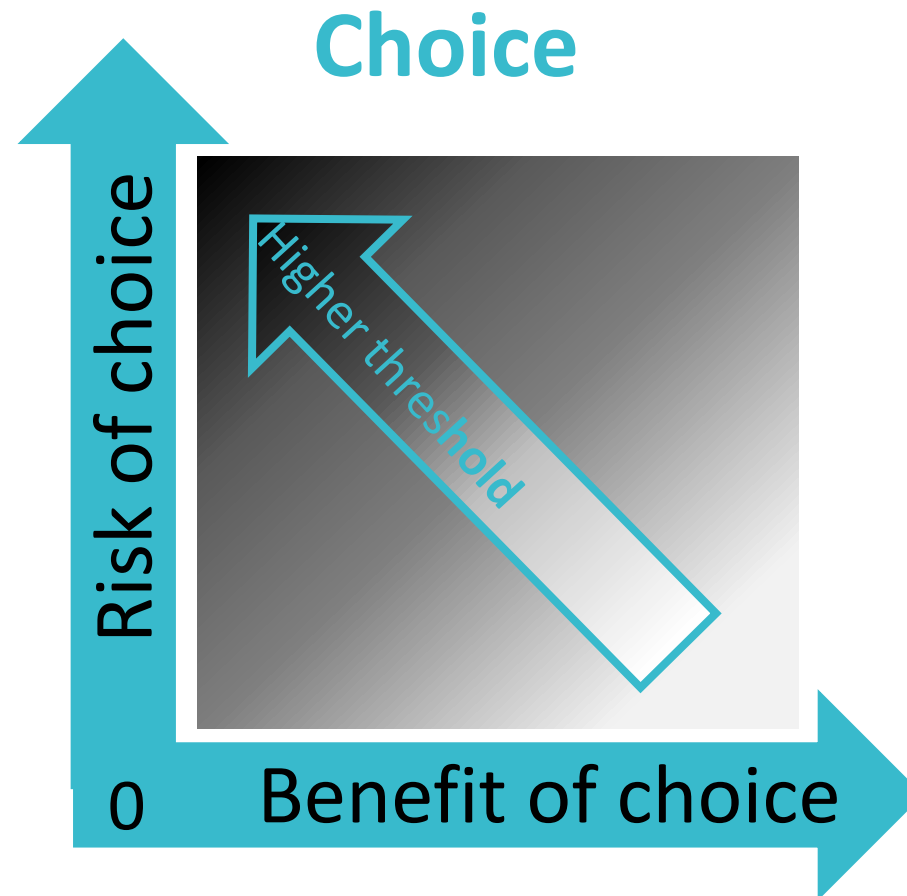
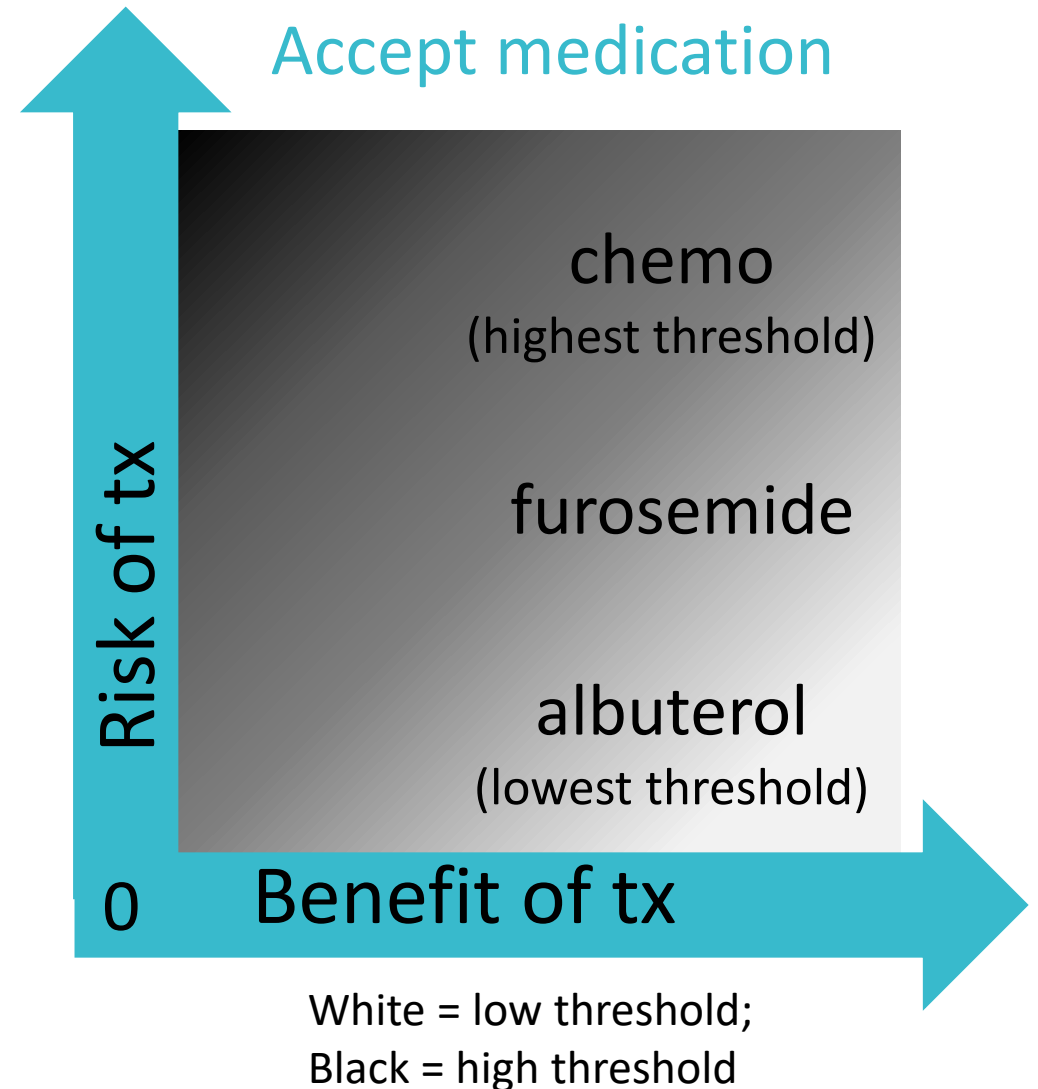White = low threshold; Black = high threshold

Capacity Threshold - example

Let's look at capacity to take medications:
- Albuterol for asthma
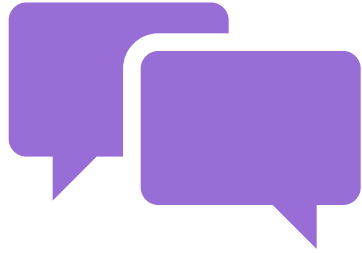- Furosemide for heart failure
- Chemo for chemo-responsive cancer

Even though they all are highly beneficial for their prescribed conditions, they have different levels of risk. Furosemide needs to be carefully dosed and has risk of AKI. Chemo, depending on which agent, can have significant risks and impacts on quality of life, such as nausea, hair loss, bone marrow suppression, neuropathy, etc. Thus, agreeing to take chemo requires a more robust level of capacity than agreeing to take albuterol, even though they are all beneficial, life-saving medications for the underlying condition.

Accept medication

Risk of tx

chemo
(highest threshold)

furosemide

albuterol
(lowest threshold)

0 Benefit of tx

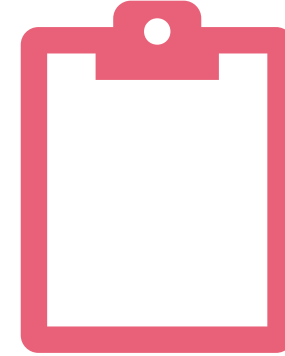White = low threshold;
Black = high threshold

Four Elements of Capacity
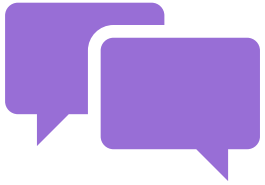
Communicate a choice

Understand the information

Appreciate the situation & consequences

Reason about treatment options

Four Elements of Capacity

Communicate a choice:
can convey decision and decision-making process and express a stable choice
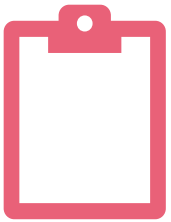
Understand the information:
can convey information about medical situation, risks/benefits of the chosen intervention, risks/benefits of alternative options

Appreciate the situation & consequences:
can apply their understanding of the information to their own life. This requires insight having the illness and the ability to anticipate how their life would be impacted by their condition and their choice. This is where patients' life experiences, values, and preferences come into play.

Reason about treatment options:
can explain how they reached their decision

Decision-making capacity caveats

There is no diagnosis that dictates whether a patient has capacity or lacks capacity.

Some diagnoses (like major neurocognitive disorders, TBIs, and certain types of mental illness) place patients at a high risk of losing capacity, but patients are assumed to have decision-making ability until proven otherwise

Remember, the assessment of capacity depends not on their diagnosis but on whether they meet the capacity threshold for each of the elements of capacity for a specific medical decision.

Decision-making capacity caveats

Patients are allowed to make choices that doctors disagree with as long as their decision-making process stands up to scrutiny. This is why knowing the capacity thresholds and the four functional components is helpful. If the patient demonstrates all four components to the degree warranted by the risk/benefit analysis (i.e. the capacity threshold), then the physician must respect patient autonomy. If the patient does not sufficiently demonstrate all four functional components given the risk/benefit ratio, then the physician concludes the patient is not of "sound mind" for this decision and, acting out of beneficence, appoints a surrogate or attempts to help restore a patient's decision-making capacity.

References

- Appelbaum, P.S. (2007) 'Assessment of Patients' Competence to Consent to Treatment', *The New England Journal of Medicine*, 357(18), p1834-40.

- Appelbaum, P.S. and Grisso, T. (1988) 'Assessing Patients' Capacities to Consent to Treatment', *The New England Journal of Medicine*, 319(25): p1635-1638

- Beauchamp, T.L. and Childress, J.F. (2013) *Principles of Biomedical Ethics.* 7th ed. Oxford, UK: Oxford University Press.

- Buchanan, A.E. and Brock, D.W. (1989) *Deciding for Others: The Ethics of Surrogate Decision making.* Cambridge, UK: Cambridge University Press.

Part 2: Decision-making capacity related to COVID-19

Unique elements of SARS-CoV-2 and COVID-19
And impact on capacity assessment

Because of the highly infectious nature of the virus and the high healthcare utilization resulting from COVID-19, we have to consider the risks/benefits not just to the patient, but also to the community. This perhaps is the most difficult aspect to consider, since we normally do not practice in this way.

Furthermore, because this is a new virus, we do not have as much information as we are used to dealing with when we discuss risks/benefits.

The next slide provides more details.

Unique elements of SARS-CoV-2 and COVID-19
And impact on capacity assessment

SARS-CoV-2 is highly infectious

- Risk of COVID+ patient exposing others to COVID
  - ➤ Elevates risk of leaving AMA if COVID +/PUI because of community effect
- Risk of hospital exposing patient to COVID
  - ➤ Elevates risk of medical inpatient treatment for non-COVID+/PUI patients

COVID-19 has resulted in high healthcare utilization

- Resource shortages in some areas (hospital beds, ICU beds, ventilators, tests)
  - ➤ May need to ration care in order to maximize community benefit

High uncertainty about clinical course of COVID 19

- Unclear true rates of illness, sometimes unpredictable deterioration, and lack of established non-experimental treatments
  - ➤ Difficult to accurately estimate risks and benefits for individual patients
  - ➤ Older patients and patients with underlying medical conditions at higher risk

Example 1

- COVID+/PUI patient wants to leave hospital AMA
  - First, we will think through the risks/benefits and map them out on the capacity thresholds graph
  - Then we will discuss what information the patient needs to provide for the four functional abilities.

COVID+/PUI Patient Wants to leave AMA

Allow pt to leave

Detain pt involuntarily

Benefits to pt :
- Being more comfortable at home
- Not being detained involuntarily

Benefits to community:
- Less healthcare utilization*
    *level of benefit depends on current hospital/city situation

Risks to pt:
- Pt may deteriorate rapidly and die*
    * Depends on patient risk factors, but still unpredictable

Risks to community:
- Pt can expose/infect others if not properly quarantined or isolated

Benefits to pt:
- Ability to intervene if clinical status worsens*
    * Depends on patient risk factors, but still unpredictable

Benefits to community:
- Limits exposure/infection risk to others

Risks to pt:
- Autonomy impacted

Risks to community:
- None

Setting the threshold for leaving AMA

White = low threshold
Grey = medium threshold
Black = high threshold

Medium-high threshold

Risk of leaving hospital

Expose/infect others if careless

Clinical deterioration, including death [varies]

0

Benefit of leaving hospital

Comfort

Autonomy

Less healthcare utilization [varies]
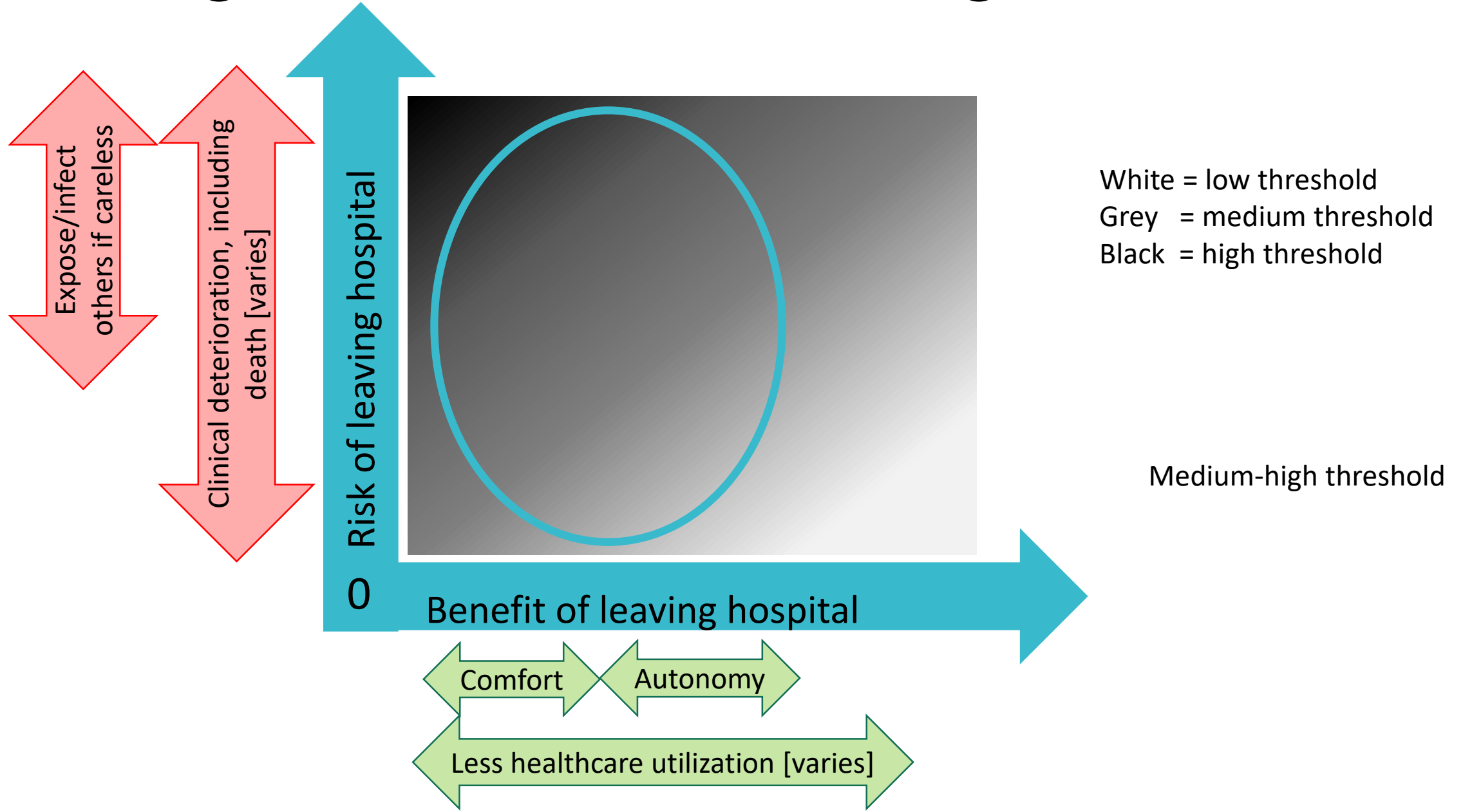
Example: Setting the threshold for leaving AMA

Example: 55 year old male with COPD, heart failure presents with anosmia, fever, and acute-on-chronic dyspnea, wants to leave AMA, states the hospital is too hectic, and wants to be at home. He states he will use nebulizer and Tylenol. He does not want to use a mask. He lives with his 77-year old mother.

Needs a high threshold!

Risk is very high due to patient's clinical presentation concerning for COVID, underlying patient-specific risk factors for poor outcomes from COVID, and risk of infecting his elderly mother if not properly isolated

Risk of leaving hospital

0   Benefit of leaving hospital

Comfort of home is a low-level of benefit. I placed the benefit of leaving hospital in moderate range to account for the fact that if he left home, he would have his freedom, whereas if he was kept in the hospital against his will, he would temporarily lose that freedom
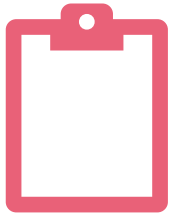
Capacity Elements to leave AMA

Communicate a choice:

Patient wants to leave AMA

Understand the information:

Can report contagious nature and airborne transmissibility of virus

Can report signs/symptoms of clinical deterioration and mortality risk

Can describe rules for isolation and for how long

Can list risk factors (older age, comorbidities, immunocompromise)

Appreciate the situation & consequences:

Acknowledge having or being at risk of having the virus AND risk of infecting others

Accurately assess current symptoms and clinical status (including own risk factors)

Describe with details plan for isolation (length of time, acquisition of food, other people in household, communication with doctor, when to call 911)

Reason about treatment options:

Needs to explain why they want to go home

Check cognitive status
R/o suicidality and psychosis

Next steps

- Has capacity (meets the threshold for all 4 elements): patient can leave
- Does not have capacity (does not meet the threshold for all 4 elements):
  - If there is a psychiatric illness affecting their reasoning (for example, depression with suicidality or mania or psychosis), may meet criteria for psychiatric hold
  - If altered mental status (encephalopathy), sign medical incapacity & seek surrogate
  - If severely cognitively impaired, sign medical incapacity & seek surrogate
  - No psychiatric illness, AMS, or cognitive impairment:
    - Educate patient or enlist family/friends; that may change patient's decision
    - Place a "medical hold" or "medical detention." However, most states do not have a legal basis and security/police may refuse to enforce. Check your hospital policy
    - Call local public health department.

Example 2

- Patient (not PUI or COVID+) refuses clinic or hospital-based treatment because afraid of catching virus
  - We will discuss risks/benefits and then map them onto the capacity thresholds graph. However, this is highly depending on the specific patient factors
  - We will discuss what elements to consider for the four functional components
  - We will discuss next steps

Patient (not PUI or COVID+) refuses clinic or hospital-based treatment because afraid of catching virus

Stay at home

Come to clinic

Benefits to pt :
- Avoid potential virus exposure to self
- Avoids potential virus exposure to family

Benefits to community:
- Less healthcare utilization*
    - *level of benefit depends on current hospital/city situation
- Patient minimal risk of spreading if isolated

Risks to pt:
- Primary illness progresses, leading to increased morbidity/mortality

Risks to community:
- Potentially worsens future healthcare utilization

Benefits to pt:
- Treat primary illness
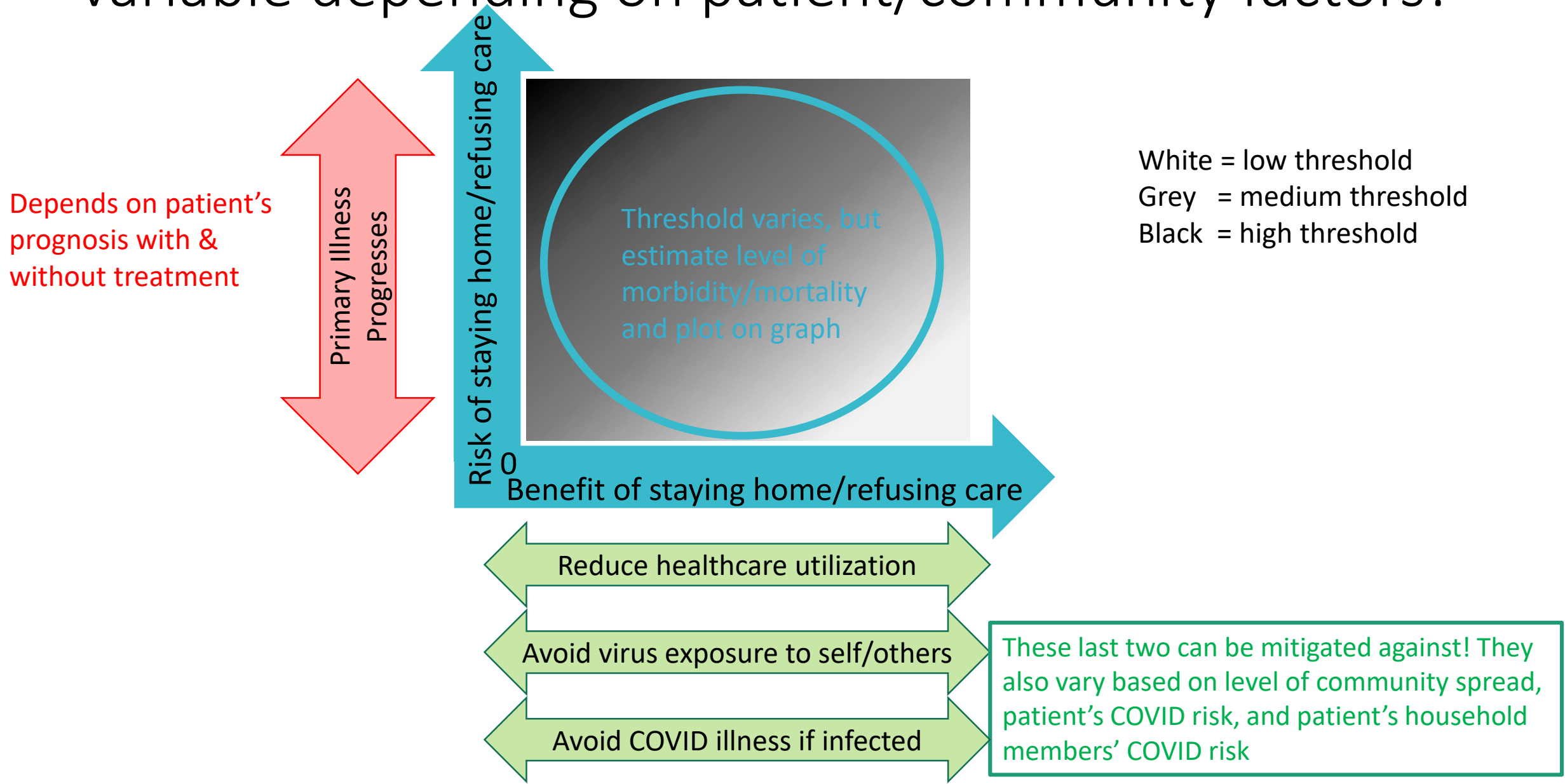
Benefits to community:

Risks to pt:
- Potential viral exposure to self*
    - *level of risk depends on patient factors; lower risk if younger or healthier
- Potential viral exposure to household members

Risks to community:
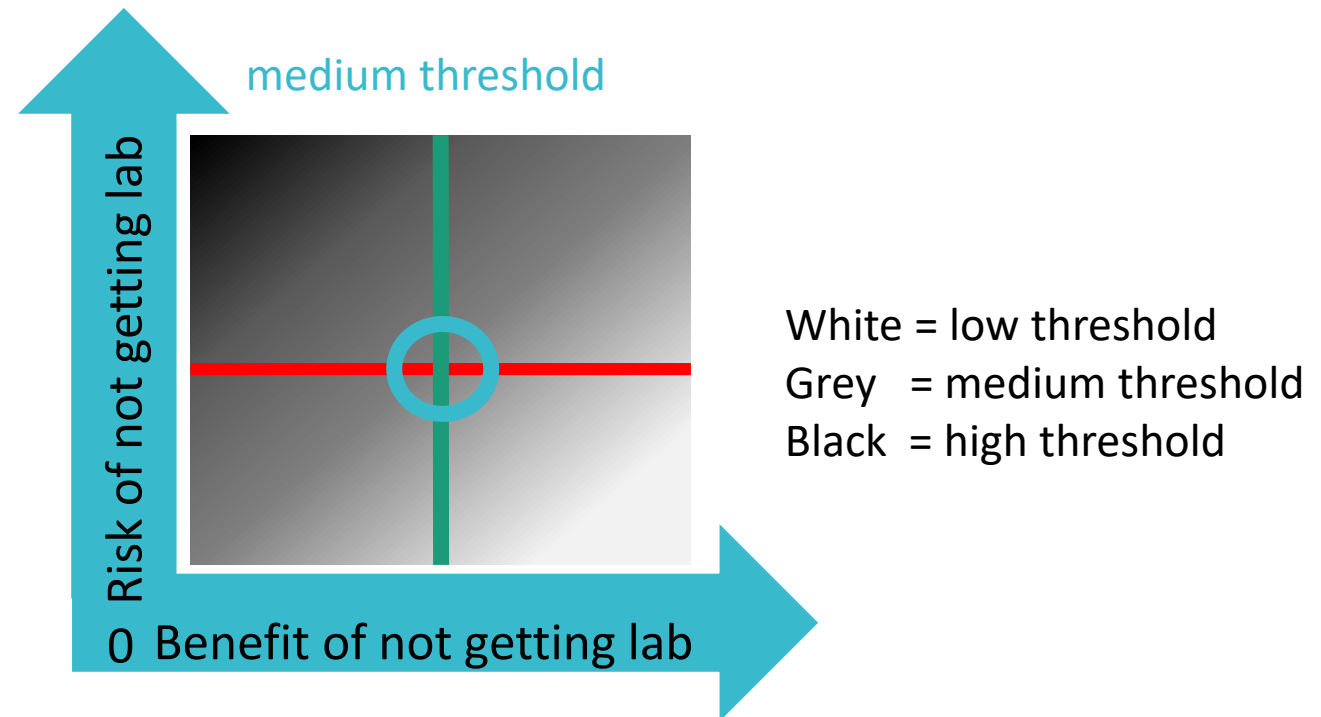- Potential spread if exposed/infected

Setting the threshold for refusing care: highly variable depending on patient/community factors!

Depends on patient's prognosis with & without treatment

Primary Illness Progresses

Risk of staying home/refusing care

Threshold varies, but estimate level of morbidity/mortality and plot on graph

White = low threshold
Grey = medium threshold
Black = high threshold

0

Benefit of staying home/refusing care

Reduce healthcare utilization

Avoid virus exposure to self/others

Avoid COVID illness if infected

These last two can be mitigated against! They also vary based on level of community spread, patient's COVID risk, and patient's household members' COVID risk

Example: Setting the threshold for refusing care

Example: 48 year old male with dilated cardiomyopathy, heart failure, and ventricular storm s/p LVAD placement as bridge to transplant. He is on warfarin for anticoagulation, but had GI bleeds on this, so digoxin was added and his therapeutic window for INR was adjusted to 1.8-2.5. He normally gets his labs checked every 1-2 weeks. His last INR was a month ago, prior to coronavirus outbreak, and was supratherapeutic at 3.8. He has not gotten labs checked since the outbreak. He reports he is feeling well and has not had any signs of bleeding. He does not want to go to the laboratory because he is afraid of getting COVID. The city has had rising number of COVID-19 cases, but the hospital system is not overwhelmed and city itself is not considered a hotspot.

Getting his INR and digoxin level checked cannot be postponed indefinitely. These are urgent, as warfarin and digoxin have narrow therapeutic windows. Although it is likely the patient is stable, there is a risk of emerging GI bleed or digoxin toxicity which would then require hospitalization. This risk is augmented by the fact that he already has a history of GI bleed and his last INR was supratherapeutic. Because there is some risk of morbidity, but not to the point of accelerating his underlying condition or death, the risk is moderate.

medium threshold

Risk of not getting lab

0 Benefit of not getting lab

White = low threshold
Grey = medium threshold
Black = high threshold

The benefit of not getting his labs and staying at home is that he can completely avoid exposure. He is certainly in a high-risk category for COVID illness, which means the benefit is more than low, but there are ways to mitigate against viral exposure (as discussed on a later slide), so this benefit is not super high either.

Capacity Elements to leave AMA

Communicate a choice:
Patient does not want to come into clinic or hospital for treatment
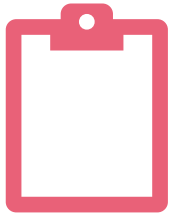
Understand the information:
Knows about COVID transmission and illness progression
Knows about ways to prevent COVID transmission
Know current medical condition and prognosis with and without treatment

Appreciate the situation & consequences:
Acknowledges own appropriate risk for COVID infection
Acknowledges own appropriate risk for medical condition
The patient may be overvaluing COVID risk and undervaluing current condition risk!

Reason about treatment options:
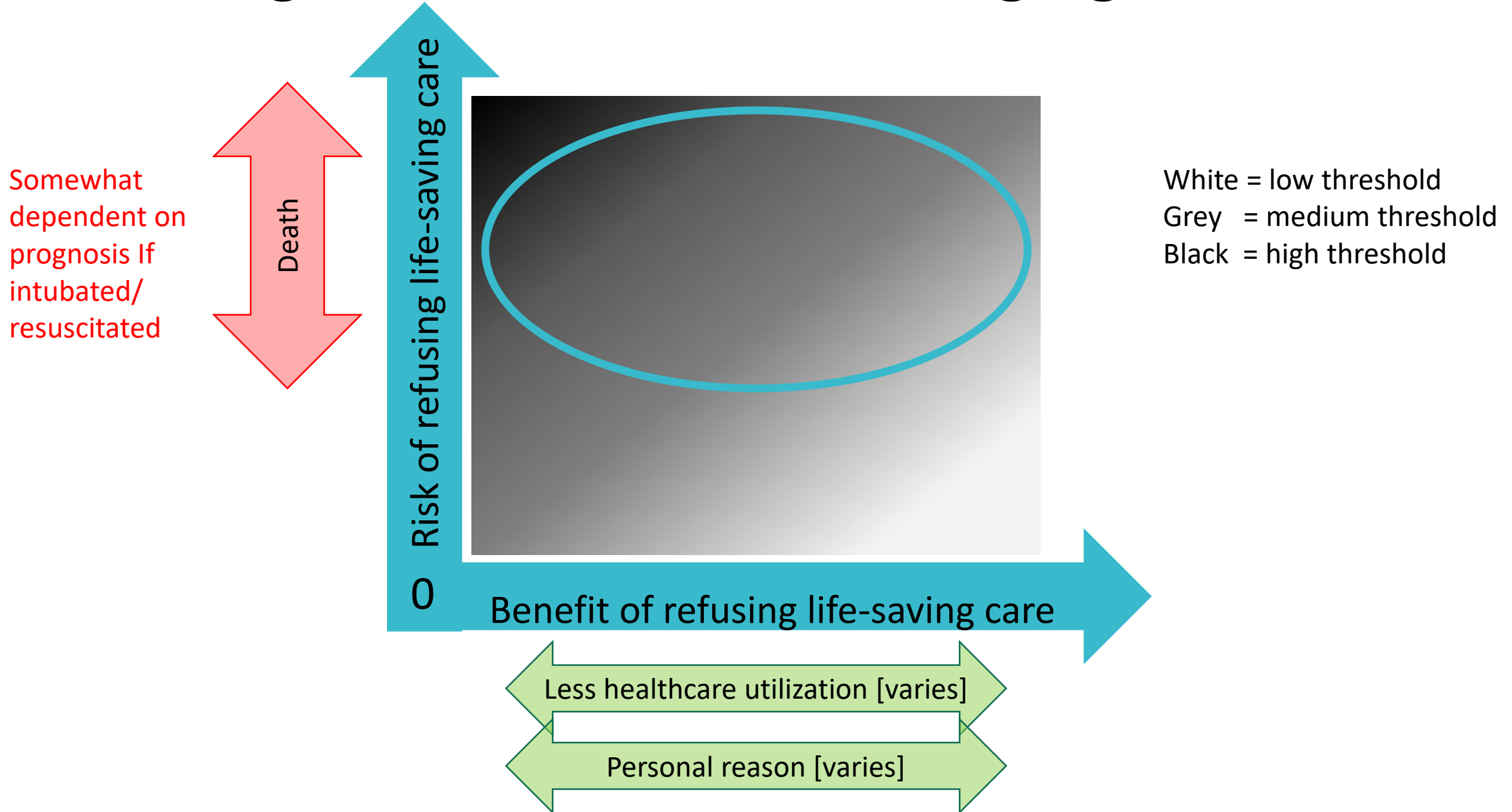Explain why they choose to stay home instead of coming to clinic/hospital

Next steps if refusing care

- No real legal resource to force patient into treatment*
  - *unless active psychiatric illness leading to imminent risk of harm to self or others OR unless person has guardian of the person
- Help patient accurately assess risks/benefits:
  - Of their medical condition: for example, risk of cancer progressing without chemotherapy, etc.
  - Of community spread in your area
- Help patient brainstorm ways to minimize virus exposure if that is the main cause of refusal. Level of viral exposure is likely a factor in terms of clinical outcomes.
  - Patient can wear a cloth mask or if your clinic provides mask
  - Providers/staff should be wearing masks if resources allow
  - Hand sanitizer available
  - Reduced number of people in the clinic
  - Infectivity based on "viral load"
  - If worried about transmitting to household members, can discuss precautions to take at home
- Enlist the help of family/friends

Example 3

- Patient who was previously full code changes code status to DNR/DNI in order to preserve resources for others

Setting the threshold for changing to DNR/DNI

Somewhat dependent on prognosis If intubated/ resuscitated

Death

Risk of refusing life-saving care

0

Benefit of refusing life-saving care

White = low threshold
Grey = medium threshold
Black = high threshold

Less healthcare utilization [varies]

Personal reason [varies]

Example: Setting the threshold for changing to DNR/DNI

A 55 year old woman with metastatic breast cancer is admitted for hypercalcemia. She is on an experimental agent that has been successful in reducing the size of the metastases and she has been able to spend time with family, go on walks, and work a little bit on her art. Whenever she is admitted to the hospital, she has always been full code. This time, however, she states that she would like to be DNR/DNI in order to conserve hospital resources. The city itself is in the middle of a surge of COVID patients, and ICUs are near max capacity. She has been upset by the news of the outbreak and specifically the toll that healthcare workers are under. She is very grateful to the doctors at this hospital system for extending her life. Though she was looking forward to living as long as possible, she knows her months or years are limited anyway and she doesn't want to further burden the healthcare system if she were to code.

Patients with metastatic cancer have very low rates of surviving CPR which means that the risk of refusing DNR/DNI is moderate (because they would likely die with CPR anyways). For someone with a good chance of surviving CPR, the risk of refusing DNR would be high.

In this case, I put the red line slightly higher than moderate because although the patient has metastatic cancer, she has no other health conditions and has some physical functioning, which affords her a higher chance of survival and resuscitation than other patients with metastatic cancer

White = low threshold
Grey = medium threshold
Black = high threshold
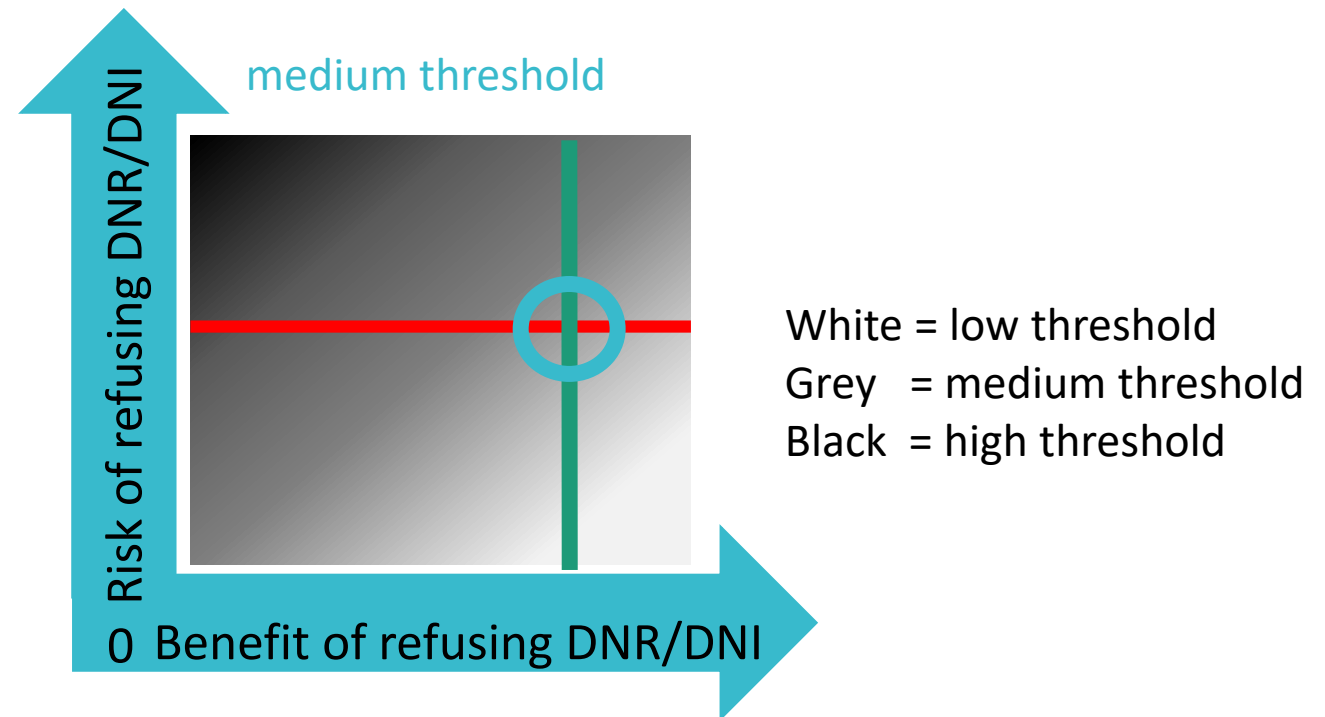
Given that the hospital and city are currently near capacity amidst a growing surge of COVID-19 patients, the benefit of refusing DNR/DNI and freeing up an ICU bed +/- ventilator is high. However, there are no other benefits to the patient (apart from psychological benefit of helping during this crisis) which is why the line ends up closer to medium-high.

Capacity elements to change to DNR/DNI

Communicate a choice:
Change DNR/DNI status
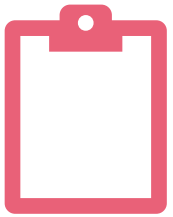
Understand the information:
Understand own risk of illness progression, of recovery, of death
Accurate assessment of healthcare burden

Appreciate the situation & consequences:
Own preferences about dying

Reason about treatment options:
Explain why they want to change in light of COVID pandemic

Ensure patient is not depressed, demoralized, and/or suicidal.
May need collateral from family to ensure this is not the case.

Next steps

- If patient meets the threshold for each of the elements, then change their status to DNR/DNI.

- If patient does not meet the threshold for each of the elements, then do not change their status and consult surrogate decision-maker