

# When Patients Refuse: What's A Good Clinician to Do?

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# Disclosures



# Objectives



Appreciate the ethical complexity associated with honoring patient refusals and implications for clinicians and health care facilities



Describe the concept of Dignity of Risk and its potential to help reconcile clinician discomfort with unwise patient choices



Identify strategies for responding to patient refusals



# Case Scenario

- 64 y.o. male found down by his truck, presented to OSH with GCS of 8, intubated, assessed with large volume SAH, external bruising to his head and multiple SDH
- Transferred to tertiary care hospital for higher level of care, admitted to SICU on aSAH protocol
- Prior hx notable for head/neck cancer, with lymph node removal and radiation in 2021
- Patient improves in ICU and is transferred to the floor for further recovery
- Functional status back to near baseline with minimal physical limitations, remains globally aphasic
- Cannot eat or drink by mouth due to dysphagia & aspiration risk; family consented to PEG tube when patient was in ICU
- Out on floor and increasingly agitated, aggressive, elopement attempts, persistent picking and pulling at his PEG tube and at times not allowing nursing to access for med administration, feeding, etc.
- Multiple “Code 8’s” have been called with escalating uses of force (chemical & physical) for safety
- Psychiatry consulted for capacity assessment and for recommendations re: agitation and behaviors

## What To Do?



# More About Our Case...



- Patient is a resident of a border state, has involved and supportive spouse and family
- No health care agent or advance directive
- During prior cancer treatment, spouse states pt adamantly refused PEG tube. Spouse tells SICU team after placement that he will be angry when he realizes he has one.
- Patient refusing access to tube for medications, feedings and hydration
- Psychiatry assesses as lacking capacity to refuse recommended treatment and to leave AMA.
- Psychiatry recommends involuntary tx if patient refuses and to detain if attempts to elope; spouse consents to plan
- Medical team discomfort with escalating Code 8's and worried about risk of death if patient continues to refuse nutrition and hydration

## Ethical Considerations and Questions



Capacity assessment in presence  
of aphasia



Surrogate decision-making and  
consent for treatment over  
objection



Involuntary Treatment



Involuntary Medical Hold

# VT Involuntary Treatment Framework

Vermont statute prohibits **treatment over refusal in the medical context** in all but the following circumstances [18 V.S.A. § 9707(g)]:

- When the patient's advance directive contains a properly executed provision (i.e. Ulysses Clause) permitting the agent to authorize treatment over objection in the event the patient lacks capacity, and the agent authorizes treatment;

OR

- When the patient **lacks capacity** and **“will suffer serious and irreversible bodily injury or death if the health care cannot be provided within 24 hours”** and:
  - The patient does not have an agent or applicable provision in an advance directive, or the agent is not reasonably available; or
  - The agent or advance directive authorizes providing the treatment.

# NO Legal Framework for MEDICAL HOLD

In most states, there is no legal authority permitting a physician to issue temporary hold orders in the absence of mental illness; thus, physicians are left to navigate legally and ethically fraught situations with little guidance and no guardrails. Many physicians look to hospital counsel and ethics committees for assistance in these circumstances, but time is often of the essence, and without clear authority on how to proceed, patients with medical incapacity are at risk of being discharged “against medical advice” (AMA), even when the treating physician has determined that they are incapable of understanding the risks involved in refusing treatment.

Wendi Campbell Rogaliner & Elicia Grilley Green, *Medical Incapacity Without Mental Illness: A Legal and Ethical Dilemma for Physicians*, 18 J. Health Law and Life Sci L. 3 (2023).  
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# Permissible Situations & Approach

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When patients **lack capacity and it is emergent** – provide standard of treatment to stabilize (rescue). Once stable, seek assent (or at least lack of refusal) to continue treatment.

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For safety of patient, staff or others. Limited timeframe due to infringement on freedom/liberties. Uses of force CAN NOT be the care plan.

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Patient dignity and personal hygiene—attention to this need is NOT equivalent to medical treatment. Still obligated to least restrictive and minimally burdensome principles.

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Remember: Consider proportionality (i.e. potential for benefit/risk of harm) of any forced treatment and ensure least restrictive/least burdensome approaches and shortest time frame.

# The Dignity of Risk

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*“There can be such a thing a dignity in risk, and there can be dehumanizing indignity in safety!”*

*Robert Perske*

*“To understand patients as true individuals is to understand that we cannot treat our patients as separate from the risks they have taken, and the risk they are willing to take.”*

*Adira Hulkower*

# Dignity of Risk: Considerations & Application

- Risk assessment focused exclusively on medical considerations (no matter how appropriate from a beneficence/nonmaleficence standpoint) subordinates the full range of factors that patients generally consider when making decisions about their lives.
- Reframing:
  - Have we considered the risks of remaining hospitalized
  - How best can we minimize risks rather than avoid them entirely to create opportunity to individuals to live as autonomous a life as possible
  - Consider risk as a spectrum; possible time-limited trial
- Applying Dignity of Risk to patient refusals can:
  - Allow for a fuller consideration of the whole person and their rights surrounding medical decision-making
  - Promote more creative thinking about treatment plans, discharge plans, etc.
  - Afford opportunities to preserve trust and maintain a therapeutic alliance with patients who will need us in the future.

# Take Aways for Patient Refusals

- Be curious. Consider *Dignity of Risk* principles to expand consideration of options.
- Negotiate, compromise, etc. Can we make an unwise plan “safe enough”?
- For incapacitated patients – *seek assent* or at least lack of refusal; encourage, redirect, compromise, etc. Cannot use force to operationalize a care plan.
- If force is necessary to maintain safety -- minimize burden/harm, think least restrictive and shortest amount of time necessary.
- Involuntary hold only applicable for psychiatric indications. (EE process in VT)
- Guardianship with ongoing permissions to TOO or hold (where permissible) should be viewed as the option of last resort.

# Food for Thought...

- *A Place of His Own: Applying Dignity of Risk to Bioethics Consultation.* Adira Hulkower. *Perspectives in Biology and Medicine*, Volume 65, Number 2, Spring (2022); pp. 232-241.
- *Clinical Ethics Consultation and the Reframing of Risk.* Andy Kondrat. *Perspectives in Biology and Medicine*, Volume 65, Number 2, Spring (2022); pp.207-212.
- *The Medical Incapacity Hold: A policy on Involuntary Medical Hospitalization of Patients Who Lack Decisional Capacity.* Erik H. Cheung, MD, et.al. *Psychosomatics*, [Volume 59, Issue 2](#), March–April 2018, Pages 169-176
- *The doctor as jailer: medical detention of non-psychiatric patients.* Charles Kersten, MD, JD. *Journal of Law and the Biosciences*, Volume 6, Issue 1, October 2019, Pages 31 - 316, <https://doi.org/10.1093/jlb/lasz008>
- *Medical Detention of Incapacitated Patients.* Mark W. Newman MD and Carolyn S. Keller, MD, MHA. *J Gen Intern Med* 39(16):3330–2; 2024. DOI: 10.1007/s11606-024-09010-3
- *Medical Incapacity Without Mental Illness: A Legal and Ethical Dilemma for Physicians.* Wendi Campbell Rogaliner & Elicia Grilley Green, 18 *J. Health Law and Life Sci L.* 3 (2023)