38th Annual WVNEC Symposium

# When Values Collide: A Framework and Strategies for Contemporary Ethics Consultation

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WEST VIRGINIA NETWORK OF ETHICS COMMITTEES

# Speakers

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# Objectives

**At the conclusion of this activity, participants will be able to:**

- Implement a systematic framework and process for conducting ethics consultations.
- Formulate clear, well-justified ethics recommendations and communicate them effectively.
- Examine when and how clinicians should override treatment refusals of patients with limited capacity.
- Apply relevant West Virginia health care law to cases in which there are issues regarding decision-making capacity, informed consent, advance directive implementation, and respecting medical orders.

# Disclaimer

The contents of this symposium are intended for general informational purposes only and should not be construed as legal advice or legal opinion.  For legal advice, please consult your organization's attorney.

# WVNEC 7-Step Process of Ethical Decision-Making in Patient Care

1. What are the ethical questions?
2. What are the clinically relevant facts?
3. What are the values at stake?
4. List options. What could you do?
5. What should you do? Choose the best option from the ethical point of view.
6. Justify your choice.
   - Refer back to the values and give reasons why some values are more important in this case than others.
7. How could this ethical issue have been prevented?
   - Would any policies/guidelines/practices be useful in changing any problems with the system?

# Demystifying Medical Abbreviations in Today's Symposium



- CAR-T is Chimeric Antigen Receptor (CAR) T-cell therapy, an immunotherapy that genetically engineers a patient's own T cells to recognize and attack cancer cells
- ENT is an ear, nose, and throat doctor. AKA otolaryngologist!
- MVA is a motor vehicle accident
- OSF is an outside facility (usually a hospital)
- ICU is an intensive care unit
- MPOA is a medical power of attorney, an advance directive
- IV is an intravenous catheter to administer fluids and medication
- BiPAP is Bilevel Positive Airway Pressure, a noninvasive ventilation machine
- DMC is decision-making capacity

# Case 1: Mrs. M Wants to Die: How Should Her Physician Respond?



- Mrs. M, a 71 y.o. woman with progressive mantle cell lymphoma despite CAR-T, required a tracheostomy early on because of tumor burden.
- Her course was complicated by severe distal tracheal stenosis requiring multiple tracheostomy tube exchanges.
- Recently she was admitted with repetitive irritating coughing. ENT found her to have tracheal stenosis down to her carina.
- In the last six months, Mrs. M, who was living independently and running a farm, has experienced marked anxiety with daily panic attacks.
- In the month before her present admission, she had messaged her ENT physician that she felt miserable, was in pain, and wished to die.

# Case 1: Mrs. M Wants to Die: How Should Her Physician Respond?

- In the hospital after a tracheostomy exchange, Mrs. M asked her ENT physician to remove her tracheostomy and allow her to die. She said she was tired of living with continuous symptoms of coughing, pain, and anxiety.

- She told him she can no longer do the things that she enjoys. She is tired of being sick. She wants her tracheostomy removed and to be allowed to die.

- Her ENT physician requested an ethics consult. He did not think it would be ethical (or legal in West Virginia) to remove her tracheostomy because she would die from hypoxia from airway obstruction within minutes.

What should be done?

# Euthanasia vs. Withdrawing/Withholding Care



- *Euthanasia* refers to the practice of intentionally ending a patient's life via an active intervention (e.g., injection of a lethal dose).
- This stands in contrast to cases of *withholding or withdrawing* life-sustaining treatment (e.g., not inserting/removing a tracheostomy).
- These may correspond to a moral distinction between *killing* and *letting die*.
  - It is sometimes argued that, while euthanasia involves a physician intentionally killing a patient, withdrawing or withholding life-sustaining treatment involves letting the patient die from other causes.
- Another way of drawing a distinction: in cases of euthanasia, the physician *originates* or *initiates* the sequence of events (e.g., injecting KCl) that results in the patient's death.

# Case #1 Takeaways

- Patients with capacity can refuse or seek to have discontinued any treatment even if the outcome is death—this is what it means to be self-determining. Clinicians need to ensure the decision is fully informed and if so, respect it.
- There is a distinction in the intention underpinning the act of discontinuing, a burdensome, unwanted intervention vs intending to hasten someone's death.
- It is not “normal” to want to die. When a patient asks to die, inquire about
  - the accuracy of their understanding of their prognosis,
  - the reason for the request,
  - the stability of their request, and
  - whether there are unaddressed reversible (treatable) factors.
- Often a request to have life-sustaining treatment withdrawn is because patients are experiencing unbearable suffering.
- This case illustrates how addressing the suffering can lead the patient to change her mind and wish to continue living.

# Case 2: Who's in Charge: The Patient or His Son?

- Mr. N, a 64 YO male with quadriplegia secondary to a MVA, stage IV decubitus ulcer with osteomyelitis and obstructive uropathy with an enterovesical fistula and bilateral nephrostomy tubes was transferred from an OSF for a dislodged nephrostomy tube.
- He underwent cystoscopy/nephrostomy tube replacement but required mechanical ventilation.
- He had a respiratory arrest from hypoxia from mucous plugging in the setting of respiratory depression from anesthesia and underlying neuromuscular weakness from quadriplegia.
- Mr. N was admitted to the ICU. His son Jim, who was his MPOA representative, made medical decisions for him while he was intubated and sedated. After several days, Mr. N was extubated, but he had persistent problems with secretions and hypoxia.
- Mr. N was ordered qhs BiPAP, deep suctioning prn, and a vibrating pulmonary vest, all of which he did not like and at times would refuse. However, he was willing to be reintubated for respiratory failure. This willingness distressed the treating team including the nurses because it seemed illogical.

# Case 2: Who's in Charge: The Patient or His Son?



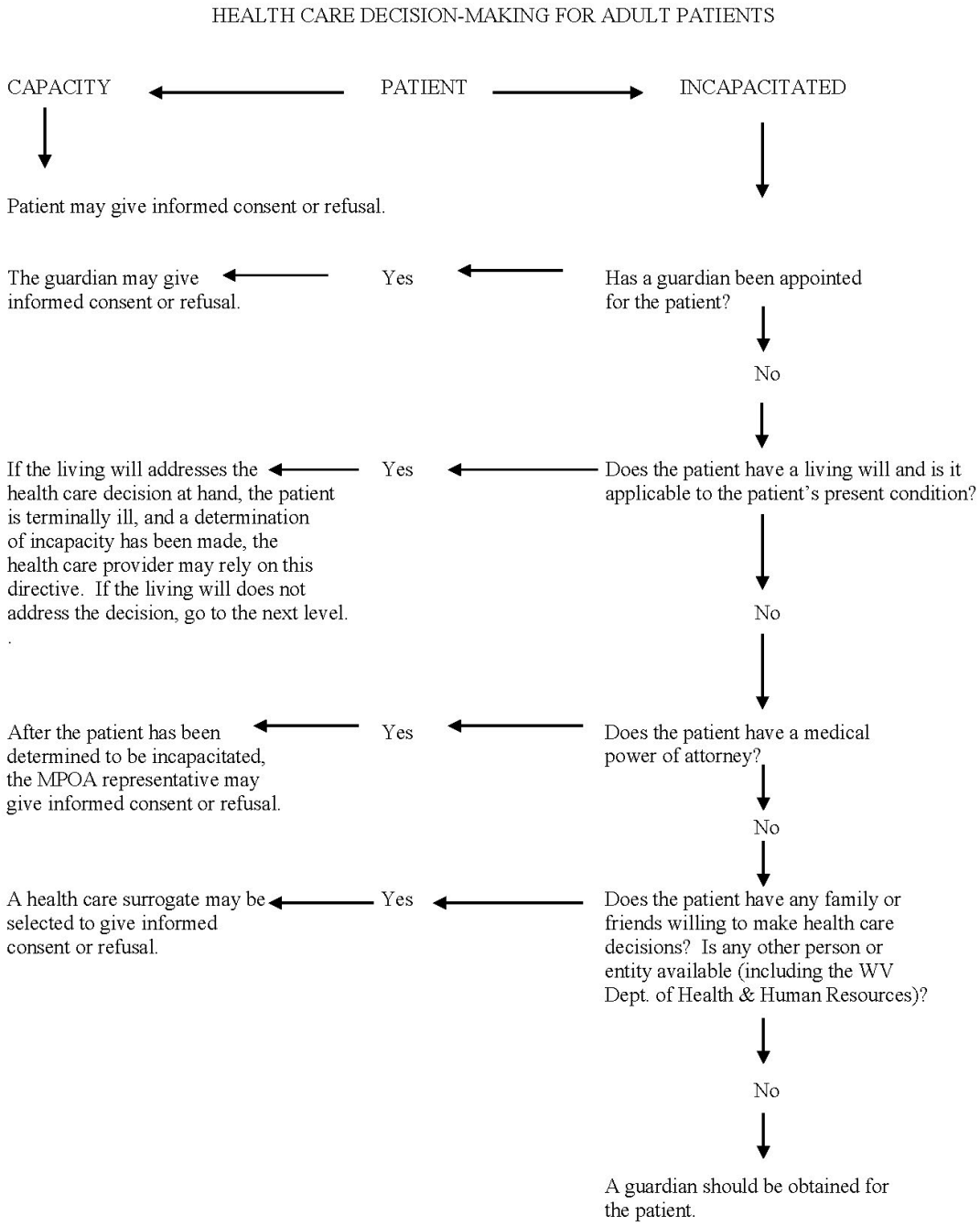
- Jim raised questions about his father's DMC, and Mr. N's physician thought he did not have it because he was refusing treatment to get him better. Mr. N had previously always wanted full code and full aggressive treatment—"everything possible."
- Jim thought he was deciding as his father would if he was in his right mind.
- A psychiatry consultant deemed that the Mr. N did have DMC and that he understood that his respiratory status might get worse without the suctioning, vest, and BiPAP. Mr. N was refusing treatments periodically because they were just too uncomfortable.
- The ethics committee met to discuss Jim's insistence on deep suctioning, the vibrating vest, and BiPAP against his father's wishes. They thought that Mr. N had a right to bodily integrity and that he should be allowed to autonomously refuse pulmonary treatments unless Jim can convince him otherwise.
- Jim contested the ethics committee's recommendation based on his father's prior expressed wishes and best interests. How should the ethics committee respond to Jim?

# Priority Order for Decision Making

- Real-time decisions with a patient who has DMC

For a patient who lacks DMC

- Prior expressed wishes verbally or in advance directive
- Living will
- Medical power of attorney
- Health care surrogate
- Patient best interests



# West Virginia Health Care Decisions Act

**§16-30-5. Applicability and resolving actual conflict between advance directives.**

- (a) The provisions of this article which directly conflict with the written directives contained in a living will, medical power of attorney, or combined medical power of attorney and living will executed prior to the effective date of this statute may not apply. An expressed directive contained in a living will, medical power of attorney, or combined medical power of attorney and living will or by any other means the health care provider determines to be reliable shall be followed.
- (b) If there is a conflict between the person's expressed directives, the portable orders for scope of treatment form, and the decisions of the medical power of attorney representative or surrogate, the person's expressed directives shall be followed.

# The capacity to make health care decisions requires that the patient have the following abilities:



- The ability to understand one's condition;
- The ability to appreciate the consequences of the options including non-treatment;
- The ability to judge the relationship between the treatment options and one's values, preferences;
- The ability to reason and deliberate about options;
- The ability to communicate one's decisions in a meaningful manner;
- The ability to make decisions that are based on reality and free of delusional thinking; and
- The ability to implement essential tasks to protect oneself and not compromise health and safety, i.e., to possess the capacity for self-care and self-protection.

# Questions to Determine Decision-Making Capacity

- Can the patient understand what is wrong with her and what are the proposed procedures or treatment?
- Can the patient understand the benefits and risks of the proposed procedure or treatment and the benefits and risks of the alternative procedures or treatments including non-treatment?
- Is the patient able to reason and make a decision using the medical information which has been disclosed to her and to incorporate her personal values and wishes into the decision?
- Is the patient able to **explain** why she made the health care decision that she did, and is the explanation consistent with her stated values and wishes into the decision?
- Is the patient able to make a decision that is not substantially based on delusions or depression, and which would not result in self-neglect?

# DMC is NOT a global determination!



- DMC is time-sensitive. Can have DMC at some times but not others-low oxygen/pneumonia, medication, low sodium, high calcium
- Can have capacity for some decisions but not others
- DMC is said to be task- or decision-specific. Need higher capacity for decisions entailing greater risk.
- There is said to be a “sliding scale” of DMC-not all or none
- Ask, “Decision-making capacity for what?”- Suzanne Messenger, Esq.

# Case #2 Takeaways

- Patients with seeming “limited” capacity are increasingly common.
- Ethics consultations often hinge on whether the patient has decision-making capacity (DMC) and is fully informed.
- Hence, ethics consultants need to understand its complexities.
- DMC is presumed and uncertainty is managed in the direction of the presumption, not the impairment—to protect the autonomy-based rights/interests of the patient
- Emotional support for surrogates/family members absent clarification about the legal and ethical obligations owed to the patient can set up a dynamic where a surrogate/family member ***thinks*** they have a say in the care plan—when they do not.
- This case illustrates the importance of a thorough evaluation of whether the patient has decision-making capacity in the present moment, especially if the patient is refusing a treatment he has previously stated he wanted.
- Even patients without DMC need some level of engagement in the treatment plan. Force, AS THE PLAN, is a nonstarter even if capacity was assessed as impaired.

# Case 3: The Right to Refuse Cancer Treatment: Should It Extend to Minors?



- C is a 15 yo with moderate intellectual disability with a development age of about ~10 years old; he has “limited” capacity. He has metastatic osteosarcoma to the lungs s/p arm disarticulation.
- He presents to the hospital for scheduled chemotherapy. C has completed 4 of the 5 infusions on this course. He was refusing the final infusion because it made him so sick. Ultimately it was decided to let C be discharged without the final infusion.
- C is scheduled for a second round of chemotherapy. Oncology reached out to the Ethics team to ask what to do if C refuses again.
- There is no new radiographic evidence of disease, so the chemo appears to be slowing down cancer progression. The oncology team estimates a prognosis of ~25% 5-year survival.
- C’s mother wants him to continue cancer treatment; father’s whereabouts are unknown.
- Unclear if the underlying reason for the ethics consultation was:
- Moral distress of giving treatment to a fairly mature pediatric patient who can articulate that he does not want it OR moral distress that they are undertaking this treatment plan with dismal prognosis but feel they must do it because he is a pediatric patient.
- What should the Ethics team recommend?

# Issues for Pediatric Patients

- Who consents for treatment?
  - General Rule – parents
  - Exceptions for venereal disease, addiction to drugs and/or controlled substances
- When is a patient under the age of 18 considered to be an adult?
  - Emancipation
  - Mature Minor

# Mature Minor Doctrine

- Recognizes that unemancipated minor patients may be mature enough and/or capable of informed consent to accept or reject health care treatment.
- Often recognized for religious or spiritual beliefs
- Recognized in at least 17 states either by statute or case law

# Rule of 7's Regarding Capacity in Minors

- Under 7 years old – presumed incapable
- 7-14 years old – presumed incapable, but rebuttable presumption
- 14 years old and older – presumed capable, but rebuttable presumption.

# *Belcher v. CAMC* conclusions 422 SE2d 837, 1992



- Recognizes the rights of mature minors in WV to make health care decisions
- If there is a conflict between parents and a mature minor, the mature minor decides
- Health care provider must exercise his/her best medical judgment as to whether patient has the capacity to appreciate the nature and risks involved in the procedure to be performed or the treatment to be administered or withheld
- Factors to consider:
  - Age
  - Experience
  - Education
  - Degree of maturity
  - Demeanor of the patient

# Case #3 Takeaways

- Adolescents, even though legally minors and under age 18, may still possess DMC.
- Ethics consultants need to be knowledgeable about the law regarding decision-making by mature or emancipated minors.
- Assessing DMC in an adolescent requires the same knowledge/skills as for an adult.
- Depending on the situation, adolescents with sufficient DMC may be able to make their own medical decisions. Such determinations need to be made on a case-by-case basis. It should not be automatically assumed they can override their parents' wishes, especially in serious, high-risk cases.
- In general, the closer children are to age 18, the greater the obligation to listen to what they are saying and to respect their decisions, i.e., parental decision making is not an "absolute."
- For an adolescent who lacks DMC, it is ethically preferable to obtain his assent.
- This case illustrates the importance for ethics consultants of knowing the clinical, ethical, and legal issues surrounding decision-making by adolescents.

# Case #4: A patient with “limited” capacity and a complex decision about disposition



- Kathy is an 87-year-old hospice patient with end-stage heart failure. She is bedfast, but with assistance, she can make it to the bedside commode.
- She is hard of hearing.  She does not manage her medications nor her finances.  Her cousin, Shellie, her MPOA representative, arranges for paid caregivers for Kathy.
- Kathy also has a 92-year-old sister Claire who lives with Kathy in Kathy’s house.
- Kathy will eventually run out of money for caregivers. Shellie has been contacting nursing homes and discussing Kathy’s finances with a Medicaid planner.
- The hospice social worker learned that Kathy does not want to go to a nursing home.
- The hospice nurse and social worker believe Kathy has DMC and should be included in planning.
- Shellie thinks Kathy is unrealistic about Claire’s ability to care for Claire and her.
- Claire says caregivers for Kathy and herself are “absolutely needed.”
- If up to Kathy, Shellie thinks Kathy would fire her caregivers and leave Claire and her neglected.
- What should be done?

# Nuances of Decision-Making Capacity



(1) *DMC is a set of capacities/abilities*, including:

- The ability to understand one's condition.
- The ability to appreciate the consequences (risks and benefits) of the main treatment options, including non-treatment.
- The ability to understand how treatment options (and their consequences) relate to one's values, preferences, and goals.
- The ability to reason and deliberate about one's options.
- The ability to make a decision based upon the exercise of the above abilities.
- The ability to communicate one's decisions in a meaningful manner.

(2) *DMC may be partial*: one might have some of the above abilities and not others.

(3) *DMC may come in degrees*: *each* of the above abilities can come in degrees.

***Because of (1) – (3),

(4) *DMC is task specific*: one might have requisite abilities for *certain* tasks but not others. (this may also depend upon a "sliding scale" standard for DMC).

# One Definition of Self-Neglect*

"…an adult's inability due to physical or mental impairment or diminished capacity to perform essential self-care tasks including:

- Obtaining essential food, clothing, shelter, and medical care;
- Obtaining goods and services necessary to maintain physical health, mental health, emotional well-being, and general safety;
- managing one's own financial affairs."

*Elder Justice Act, 2010, p. 785

# WVDoHS APS Definition of **Self-Neglect**

- The inability of a vulnerable adult to meet his or her own ***basic*** needs of daily living due to mental or physical condition.

# Case #4 Takeaways-1

- There are nuances to possessing DMC. Patients may have capacity to make certain decisions but lack capacity to make other more complex or risk-laden decisions.
- Often a patient's failure to have full understanding and insight into her present condition in a complex situation can lead to a determination that the patient lacks capacity for that decision. Clinicians should make every effort to ensure that the necessary information, including options, risks and benefits, is provided in a clear, understandable, and non-judgmental way to maximize the individual patient's decision-making ability.
- For patients who lack capacity because of self-neglect, the ultimate decision may conflict with the patient's wishes. However, every effort should be made to respect the patient's wishes/preferences to the maximum extent possible and include the patient in all discussions and planning.
- Consultants need to distinguish what is "unwise" from what is "unsafe." Patients with DMC retain the right to make unwise decisions that are contrary to their health-related interests and to experience the consequences. Sometimes they need to fail a few times before they can appreciate that their needs have changed.

# Case #4 Takeaways-2

- When patients are vulnerable (such as an 87-year-old on hospice) and have "limits" to their capacity, the “work” of the ethics consultant is to ensure the least restrictive option is implemented.
- In doing the “work,” consultants should ask, “Have I exhausted all available additional in-home supports for which this person qualifies? Is there a possibility of increasing CNA visits, use of volunteers, etc. or are there other home-based supports that could be added, even as a "trial" since it is unknown if she will fire more caregivers?”
- In this case and in general, time-limited trials are a way to negotiate an acceptable compromise and reduce conflict.
- This case builds on the knowledge base from the prior cases and challenges ethics consultants to be able to address an increasingly common problem in the category of “dignity of risk” and when to draw the line on allowing the patient to accept risk.