Worlds Collide: Hospital Meets Patient Who "Will Not Be Moved"

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Objectives

1. Survey an extremely challenging palliative care case
2. Understand how to better communicate with and care for patients (and providers working with them) who exhibit challenging coping styles.
3. Review moral distress theory and identify issues of a case that elicit strong feelings of moral distress

Background

Duke University Hospital
Academic 900 bed acute care
Took place 7/2017 to 10/2017

- Patient's primary team consulted Palliative Care (PC) for "Goals of care".
- PC Team included Dr. Tyler Tate, a PC Fellow at the time; PC Attending Physician; PC Clinical Social Worker (Vickie) and Nurse Practitioner. (All well known to the unit).
- During the admission, patient was seen by 4 different PC consulting physicians

Case

- C.R. is a 46 yo male diagnosed with amyotrophic lateral sclerosis (ALS) in 2010 who now has a tracheostomy and Percutaneous endoscopic gastrostomy (PEG) tube and speaks using an electronic eye gaze communication tablet. His only motor function includes his eyes and, minimally, his lips. C.R. has two school-aged daughters. His wife has been his primary caregiver throughout his illness course.

- Over the past few years C.R. had become a well-known figure in the ALS and local community through his media-presence and outreach. He was extremely proud of his various activities, many which had raised awareness for ALS and generated funds for several non-profits. C.R. has maintained an active social media presence throughout his illness.

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- In the weeks before admission, C.R. has been emotionally abusive toward his wife. She states that he was having wild fluctuations in his emotions (happy, angry, mean to her) and for the few days before admission had started having erratic behavior (such as transferring money between bank accounts without her knowing). She no longer felt safe at home. She called C.R.'s outpatient neurologist who recommended bringing him to the Emergency Department to be admitted.

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- Once admitted, C.R.'s case became increasingly complex. A palliative care consult was called to assess goals of care and to help facilitate communication. It was determined that returning to home was not an option. C.R. required 24-hour care, and further inquiry revealed that C.R. had either fired, or been refused by, more home health nurses than any patient in the history of his home health company. When questioned initially, C.R. said he wanted minimal intervention. He was DNAR, declined blood draws or IVs, and stated that he "will die in here" and wanted his daughters to fall asleep next to him.

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- However shortly thereafter, C.R. began vacillating between different dates on which he wanted to die. Psychiatry was consulted and helped determine that C.R. had decision-making capacity. C.R. then requested to be transferred to hospice to die on a specific date in August.

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- When asked why he chose that date, he answered, "because it's my wife's birthday." When questioned about his motives and the trauma this could inflict on his wife and daughters, he answered "tough shit," and "don't go there." After hospice declined to accept him, he called for an ethics consult stating he was being treated unfairly by both his case manager, and by hospice who were "denying him care" due to the perception that he might change his mind about when to withdraw from the ventilator.

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Discussion

- What *makes* C.R.'s case so difficult?
- What are fair, practical approaches for dealing with "difficult" patients?

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Reflections on the case

- What Vickie thought
- What Tyler thought

From a Clinical Social Work Lens…

Setting the Stage: Premise

- Saw long standing psychopathology, based on current and collateral information
- Our patients and families are not (necessarily) asking for mental health assistance with their personality disorder
- The behaviors often seen, nonetheless, directly impact their care
- We must correctly identify these behaviors and devise strategies to ensure their coping styles don't become barriers to good care, or our empathy

Hard to Spot, often misunderstood

The Perfect Storm

The Hospital

- Structured environment
- Changing Providers
- Complex, inconsistent communication
- Little autonomy
- Little control

The Person/Patient

- Creates chaos for people who are not able to adjust to this setting easily
- Challenging for maladaptive coping styles
- Need Control
- Don't do well with ambiguity

"Hang on, I can save you!

Intense emotions and reactions

Challenges for Pt

- Pt does not have a primary caregiver anymore
- Has two children
- Wants to control when he dies
- Feels misunderstood by staff
- No discharge options

Challenges for Staff

- Sympathetic presentation
- Has positive and large social media presence
- Compelling story
- Fired several nurses and case managers
- Very abrupt communication
- Open hatred for wife (wants to die on her birthday)
- Staff is split between empathy and anger
- Arguing amongst themselves as to best disposition

What is Moral Distress?

- "Painful feelings and/or psychological disequilibrium that occurs when nurses are conscious of the morally appropriate action a situation requires but cannot carry out that action because of institutionalized obstacles"

Jameton, A. Nursing practice: the ethical issues. Englewood Cliffs, NJ: Prentice Hall. 1984

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Top reasons for moral distress*

1. Following a family's wishes for life-sustaining therapies when it is not felt to benefit the patient
2. Observing physicians being untruthful about a patient's prognosis
3. Participating in a code when you believe it merely prolongs death
4. Having your opinion about patient care dismissed by the health-care team.

Epstein, E. et.al. (2019). Enhancing Understanding of Moral Distress: The Measure of Moral Distress for Health Care Professionals. AJOB Empirical Bioethics. 10:2. 113-124.

Moral Distress

- Cases like C.R. can cause healthcare providers significant moral distress. What is the role of palliative care in cases involving moral distress?

Moral Distress Map: What can we do about it?

	Emotions	*Source(s)*	*Constraints*	*Conflicting Responsibilities*	*Possible Actions*	*Final Action*
Case						

Instructions: The facilitator invites clinicians to discuss a case that caused them moral distress. Participants answer the questions below. They can answer privately and then discuss as a group or the entire process can be done together in a large group. Encourage everyone to respectfully express differences of opinions. The facilitator probes the group for more specific responses and guides the group in examining the ethical issues underlying moral distress.

Emotions: *What emotions are you experience?*
E.g. sadness, frustration, anger

Source: *What precisely is the source of the moral distress?*
E.g. inadequate staffing leading to suboptimal patient care

Constraints: *Name the internal and external constraints to taking action.*
E.g. fear my concerns will be ignored; patient does not qualify for services she needs

Conflicting Responsibilities: *Fill in X and Y*
Value/obligation/responsibility **X** conflicts with value/obligation/responsibility **Y**.

Possible Actions: *What actions could you take?*
To improve outcomes for the patient in the case
To cope with your own moral distress

Final Action: *What action should you take?*

Dudzinski D. Navigating moral distress using the moral distress map. J Med Ethics 2016;42:321–324.

Principle of Protecting the Vulnerable (PPV):

- We have an *obligation* to act so as to prevent harms to, or protect the interests of, those who are especially vulnerable to our actions and choices.

Goodin, Robert. 1985. *Protecting the vulnerable*. Chicago: University of Chicago Press.

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Our personal obligation

- Easy to get "sucked into" pathology
- Take time to notice when our reactions are not "the usual"
- Help colleagues to recognize our reactions, especially if not helpful
- Separate our personal feelings from person
- Set appropriate expectations
- Educate the staff about why we are having difficulty
- Use non-judgmental language when possible – this helps to take blame away from pt, thus engender empathy.
- Character pathologies are different than personalities we simply don't like.

Case ending

- Lots of anger among staff (including us!)
- Too many teams got involved including ethics (called by patient directly) – another reflection of the personality disorder
- On floor: Set boundary with patient (called his "bluff")
- Reduced palliative care involvement except for support to providers
- Able to transfer to inpatient hospice unit (IPU)
- Able to visit with wife and children
- About 2 weeks after getting to IPU, turned off vent and died at IPU
- Was the subject of two case debriefings at hospital (one in ethics)…the drama continues.

"Care more particularly for the individual patient than for the special features of the disease…. Dealing as we do with poor suffering humanity, we see the man unmasked, exposed to all the frailties and weaknesses, and you have to keep your heart soft and tender lest you have too great a contempt for your fellow creatures. The best way is to keep a looking-glass in your own heart, and the more carefully you scan your own frailties the more tender you are for those of your fellow creatures."

- William Osler

Cushing H. *The Life of Sir William Osler*. New York, NY: Oxford University Press; 1940:489, quoted in: Gunderman RB and Gunderman PR. Forty Years since "Taking Care of the Hateful Patient. *AMA J Ethics*. 2017;19(4):369-373

References

- Epstein, E. et.al. (2019). Enhancing Understanding of Moral Distress: The Measure of Moral Distress for Health Care Professionals. AJOB Empirical Bioethics. 10:2. 113-124.
- Feely, MD, et.al. "Management of end of life care and of difficult behaviors associated with borderline personality disorder." J. of Pain and Sympt. Management. 45:5. 2013
- Sansone, R. & Sansone, L. "Borderline Personality in the Medical Setting." Prim Care Companion CNS Disord. 2015, 17:3

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