Futility a Fancy Trigger

Chapter 8

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It should be no surprise that I encountered many situations beyond the healthcare team's control during my wards $(\bullet_-\bullet)_\Gamma$. However, even if I *knew* that it was virtually impossible to save, cure, heal everyone...the frustration still seeped in $(\smile_-\smile)$. Come forth *futility*, a term I heard often. A term that seemed to bring some sort of comfort to all the members of the team when reaching a dead end $(\smile_-\smile)\setminus(\smile_-\smile)$. But was "*futility*" really "futility"? $(\sim_-\sim)$

An elderly woman (around her 80s) with history of advanced Alzheimer and cardiopulmonary complications, was admitted due to a painful acute skin detachment. It simulated Toxic Epidermal Necrolysis (TEN), but there was no clinical indication for Steven Johnson Syndrome (SJS) nor TEN. During her stay, she could not move or eat. She could not open her eyes. Her only interaction with the team was mumbling and heart wrecking screams every time we needed to move her...even placing the stethoscope caused her great amount of pain.

As a third medical student, my responsibilities were to "pre-round" with my residents and then "round" with my residents + attending. During pre-rounds, we asked the patients how their night was, how did they feel at the moment, and then proceeded to make a focus exam. The Heart-Lung exam was a must for every patient (^0-). Later, during rounds, patients were re-asked again the same questions and the exam was re-done either by residents, fellows or the attending. The term futility started to slip into my thoughts. Was it really necessary that we kept doing the

physicals exams? I caught myself (•_•). Of course, it was necessary! \(\c)_<)/ Just because someone is old, has Alzheimer, and a very painful skin condition does not mean that the benefits of a physical exam should be waived(>\co). Yes, it was awful seeing our patient cry, but it would be worse to have our patient with a developing pneumonia, or any other condition that would drown her slowly during her stay at the hospital... *Exactly, Bingo!* (•.•) I could waive my pre-round insight.

Let's pause for a second, even if the following will hit my 3rd-year student self-ego very hard (७-७) (and the rest 3rd-year med student for eternity), a third-year medical student is practically in pull-ups (","). We think that we are big enough ((")), we have our "own patients" (() (), you have your [short (¬,¬)] white coat\ (•••) /, and can even walk in epic slow motion (¬, and can even walk in epic slow motion (¬, and students have the books, question banks and medical material tattooed in our brains (¬, this is practically the equivalent of being equipped with a butter knife and thrown in the most dangerous Indiana Jones -Tomb Raider Adventure you can think off \(\)(\(\)\)(\(\)\)\.

In other words, making our patients endure my pre-round test would bring no benefit because I was at the training stage where I hear all weird chest sound (Yeah like the heartbeat and normal breathing? $(\neg \circ \neg)$) or when there is something really going on (sounds like a Metallica concert inside the patient's chest $(\neg \neg)$) but you hear "normal" chest sound (\neg) . However, I was sure of one thing, I would bring her an extra-

round of pain by placing the stethoscope and trying to move her to the side in order to have access to her lungs. I spoke my concerns to my residents; I would have more than plenty of chances to learn Lung and Heart sounds in healthy and ill patients [(. • _ •)], but I felt that I was just causing harm because my competency level was not yet par to par to make any clinical diagnosis (¬¬). And even if I had the full competency, either them or the attending would need to confirm my findings. The residents agreed to waive the patient from the pre-round, in fact, the residents decided that due to the circumstances, they would make one physical examination with the attending and minimize the physical checkup once a day, unless her clinical condition required more assessment. Our attending agreed with the plan (• • • •).

It would be a Happy Ending if I stopped the story here and claimed that the futility concept was solved (~o~). That I just shielded myself with the futility term and waived my pre-round in this pre-text, when in fact what I did was a balancing of harm and benefit principles. Nonetheless, futility was just in the corner waiting to ambush us again(~___).

A few days passed, and our patient started to deteriorate. She was on IV and topical antibiotic but was not responding. She continued to slough her skin, the sheets needed to be constantly changed due to blood and pus stains shed day and night. Her folded skin emitted a putrid odor...I felt she was decaying while alive. No capacity, no advanced directive, no designated health proxy. Oxygen saturations levels reaching

dangerous levels, her physical examinations were not improving either...our patient was crashing. In a matter of days or hours she would be in cardiac arrest(——).

"The team believes that doing CPR is futile" -explained the senior resident of the team, to two out of the three offsprings.

"You are giving up."- accused the youngest. He looked at each of the members of the team. "She is my mom!" he exclaimed.

"We know that this is difficult."

"No, you don't"- interrupted the youngest, but the older of the two, placed a hand on his shoulder. The room fell quiet. My residents had a serious, neutral expression, the one that we are trained to wear...The sons, they were mortified; however, the eldest was the one with more control, his face unreadable.

"What is the plan?" – the eldest asked, his voiced calm and soft.

"We don't think CPR, resuscitation, would be beneficial for your mother... We will keep her in comfort, but if her heart stops, we are not going to do anything."

I remember the long pause that followed that sentence. Neither of the siblings uttered a word. The youngest had a fierce gaze, the eldest was prompting the team to go on with the plan...that was the plan.

"We need you to sign the DNR (Do not resuscitate)-"

"No."- interrupted the eldest.

The resident remained quiet.

"We will not sign; you will do everything possible to save our mother. We will speak this with our eldest sister. In the meantime, keep our mother alive."

We were in a deadlock. Our attending wanted the DNR paper signed, the team firmly believed that performing CPR would be causing more harm than good, and 2 out of 3 siblings were vehemently refusing DNR...no advanced directive, no health proxy and a deteriorating patient.

Eventually our patient crashed (, and the full code was activated. The code was successful... I think...almost two years later, I still remember the conflicting emotions I felt after witnessing the code (, _ .). Our patient end up on a ventilator and high sedative, the skin on her chest was completely destroyed... CPR is a very rough intervention, it is not the fancy and chic TV version were almost everyone survives, or spontaneously wakes up to confess their undying love to their savior (¬¬¬)....this is real life CPR.

Dr. Jennings gave an *Ethics for Lunch Seminar* at Bayview regarding this misperception. During the lecture, I learned that CPR was labelled by Safar in 1975 as an intervention "To challenge death anywhere", and since then the notion has taken root. I also learned that in 1968, Dr. W. Symmers emphasized the "Not allowed to die" concept...Which delivered us to the question "Should we always try to defeat death?" What about futility? If it is medically futile it would not make any sense. Nonetheless, the problem is when we try to measure probabilistic futility.

Another term that comes into play is *futility*. If the concept of CPR was mindblowing, futility is just crazy (@_@). First there is debate in the definition, and then there is even more debate in the proper application to each case (>>.<<). Brauch Brody and Amir Halevy makes three categories of futility: physiological, brain-dead patient as paradigmatic case of futility, and qualitative futility²³. Based on Brody and Halevy, Clark and Mikus expanded from these categories into the four new ethical analysis; which are Physiological, Imminent-Demise, Lethal-Condition, and Qualitative Futility ²⁴. Physiological is defined as "an intervention that fails to achieve their intended physiological effect"24. Meanwhile, Imminent-Demise is defined as "treatments carried out despite that the patient will die in the near future"24. Lethal-Condition is "a treatment given to a patient with an underlying lethal condition, and said treatment cannot affect the results"24. Lastly, Qualitative is defined as "a treatment that fails to lead to an acceptable quality of life for the patient"24.

From the four definitions, physiological futility is the one that would be understandable to deny right away, just like it is justified denying medical intervention that would not address the disease (i.e. breaking a bone to focus the pain in the leg, and thus, alleviating migraine (u,u)). However, this works in theory but during practice it is challenging (@o@). First, in most of the cases, medicine faces uncertainty...seldom in cases can clinicians be sure that they have reached an end. Furthermore, the other "futility" comes into play. For example, would the two minutes in between CPR be

important for the patient, if they have a chance to wait and say goodbye for a loved one? It all depends in the circumstance of each case ().

This delivers us to our second and last point of the futility-CPR discussion: What is the medical profession's role? \(\text{(\cdot _\ell)} \) \(\text{Is it tasked with preserving life, prolonging} \) life, mitigating diseases, preventing harm... all of them are loaded terms? \(\text{(\cdot \cdot \cdot \cdot \cdot)} \) Note that preventing disease and preventing harm are not the same. A fair amount of my MBE thesis is dedicated to the physician role...the *AMA* Code talks about incompatibility with healer role, but what is a healer? \(\text{(\cdot \cdot \cdot

At first, it resonates with the historical label, "shoo" death away from people (\circ, \circ) . A more epic concept is to bring people back from the death "resuscitation" $(\bullet_{-}\bullet)$. Yet, if this were to be the purpose of CPR, then it would not be permissible to stop $(o_{-}O)$. A second that we could "shoo" death away, is a second that we owe to our patient (>>,<<). Therefore, if we do not perform CPR, then we are infringing the Justice Principle and Non-maleficence by not allowing the same opportunity to have another second in life.

This is absurd! (o_o) First, because we are ignoring that the act of CPR in itself is also harmful (o_o). CPR is a strenuous and invasive intervention (o_o). This is not the two soft chest pushes, a tender mouth-to-mouth respiration, the dramatic eyelash fluttering, (•o•) three coughs with a little bit of water and then the romantic kiss between the two protagonists "Oh darling, you risk your life for me" cliché (--). The real CPR is a chaotic (yet organized) event, ribs are constantly broken, bruises are formed, potent chemicals are injected into your veins, there may be some electro-shock or there may be a tube trying to bypass the air into your lungs ...anything necessary to restart your heart (--). In sum, CPR should not be provided lightly, there is also a responsibility to not provide CPR. The harms and benefits should be weighed, and that is when futility comes into play. Furthermore, the patient's and family's values are important...the scenarios are not easy for the family nor for the healthcare team ([--)/||1|.

After the full code, the team met once again with the family, this time with the three siblings. When we entered the room, they were around her mother, talking to her ...the youngest was holding her hand, carefully not to aggravate the skin around it ——).

Our patient was deeply sedated, their only answer was the steady sound of the ventilator. The team explained that cardiac arrest would more likely occur soon. And once again, the team believed that performing the full code was causing more harm and suffering to their mother.

"We want you to do everything. We brought her *here* for you to save her, not to give up on her. She is strong" – said the eldest sibling, the middle one nodded in support, the youngest just kept glaring at the team. The DNR was not signed and the team was obligated to perform the full code when the patient crashed once again. That day was my last day on the Internal Medicine Ward Service.

For this case in particular, I think that the first CPR was ethically permissible, just like not performing it. This may be a little bit confusing at first ლ, $\int \bullet \mathfrak{D} \cdot \mathfrak{L}$. At the time of the first CPR, the prognosis was a little bit uncertain...it looked poor, but we were not certain. From a medical perspective, CPR did not seem quite efficient either. Therefore, if the family decided not to pursue CPR and provide comfort care, it would be ethically permissible. On the other hand, for the second attempt CPR may not even be ethically permissible. At that time the uncertainty level decreased, her health was quickly deteriorating, and CPR would continue to cause more harm than the possible benefit the patient may had received. Signing the DNR would also be correct, from my ethical analysis. When CPR is no longer a medical indication (i.e. performing CPR in a dead brain patient), then there is an ethical obligation to not perform CPR. The team needs to communicate the decision with the family and help them cope with the new scenario. Of course, this should not be made based in the clinician's standpoint of whether it would be "worth the shot" at life, but under an ethical approach (=_=).

During the MBE we were introduced to multiple ethical analytical tools. One of them is the four-box quadrant method which was adapted from Jonsen AR, Siegler M, Winslade WJ. *Clinical Ethics: A Practical Approach to Ethical* ²⁵. This method helps to lay down all the important facts necessary for an ethical analysis. Johns Hopkins has a unique approach that combines the 4-box with a series of questions:

STEPWISE APPROACH FOR ADDRESSING ETHICAL ISSUES [Prior the first CPR]

- 1. What is your concern? Why does this case bother you?

 Should the team withhold CPR against family wishes? My worries are patient's interest and autonomy, inflicting harm and futility.
- 2. Is this ethics: does this concern arise from conflict between moral obligation or other important values?

Although the case may have legal implications, there is an ethical concern.

a. What are the moral obligations?

The moral obligations are [1] inflict no harm to the patient, [2] provide effective medical intervention, [3] respect patient's values and autonomy.

b. Are there competing moral obligations?

Patient's values are unknown, and patient lacks capacity. Next to kin desires to continue aggressive intervention such as CPR. The medical team believes that performing CPR or other aggressive intervention is causing harm and no benefit to the patient.

- 3. What are the facts of the case? (SEE 4-BOX APPROACH) Do we need additional information?
 - a. Who are the moral agents or stakeholders?

 Healthcare team, patient, patient's family, hospital, country (due to state of emergency and limiting resources).
 - b. Who gets to participate in identifying and defining the relevant values, principles, duties and moral facts?

Healthcare team and patient's family (due that patient does not has capacity). In case patient recover capacity, it would be the patient.

c. What do you, as the provider, bring to the table?

Medical expertise, comfort care, diagnostic explanation.

4. Are there other sources of information that can provide guidance or help resolve issue?

- a. Paradigm case: More helpful c/d
- b. Case law or professional guidelines: More helpful c/d
- c. Helpful literature on this ethics issuess

Schneiderman, Lawrence J., Nancy S. Jecker, and Albert R. Jonsen. "Medical futility: its meaning and ethical implications." *Annals of internal medicine* 112.12 (1990): 949-954.

Persad, G., Wertheimer, A., & Emanuel, E. J. (2009). Principles for allocation of scarce medical interventions. *The Lancet*, 373(9661), 423-431

d. Other ethics framework besides the four principles (i.e. virtue theory)

Social Justice, Principles for allocation of scarce medical

intervention (due to state of emergency).

5. What actions will be taken?

a. What choices are *possible?*

Provide CPR, not provide CPR, Discharge and transfer.

i. What are the advantages and/or disadvantages of each?

Discharge/Transfer: Patient is not medically optimized for discharge nor transfer.

Provide CPR: Family wishes are met, death is delayed | Patient's wishes unknown, inflicting harm, may not be medically indicated.

Don't Provide CPR: Do not inflict damage, do not perform intervention that may not be medically indicated | Family wishes are not met, patient's wishes unknown.

b. What should be done?

 $\ensuremath{\mathsf{CPR}}$ should not be provided if there is no medical benefit to the patient.

i. Is there a choice that is preferable and is that what should be done?

Not providing CPR is preferable because this action does not inflict harm. However, the team should provide CPR at least at this current point. The team should educate the family and continue to re-evaluate the patient to determine whether CPR continues to be medically indicated.

c. What can we do?

Not provide CPR + provide comfort of care and education Provide CPR + provide comfort of care and education

i. Take into account impediments to choices in "should"

Regardless of the CPR choice, comfort care and education to family about prognosis should be done.

d. What will we do?

Provide CPR and continue to re-evaluate patient, if health deteriorates to the point that CPR is not medically recommended, the team should not perform CPR. The team should continue to educate the patient's caretaker regarding the prognosis, benefit, and risk of CPR. Continue comfort care and adequate pain management. Explore other emotional/spiritual support (i.e. chaplaincy service).

THE 4-TOPIC METHOD TO APPROACHING AND ANALYZING ETHICS CASE

Medical Indications

(Principles: Promote welfare, avoid harm)

Consider

1. What is the patient's medical problem? History? Diagnosis? Prognosis?

Severe total body skin sloughing; skin infection complication. Alzheimer, cardiovascular disease. Poor prognosis.

2. Is the problem acute? Chronic? Critical? Emergent? Reversible?

Skin: Acute | Critical | Maybe Reversible Alzheimer: Chronic | Nor reversible Cardiovascular: Chronic | Not reversible

3. What are the goals of treatment?

Skin: Continue antibiotic; discover reason of skin sloughing, stop skin sloughing.

Alzheimer: Comfort

Cardiovascular: Continue medication.

4. What are the probabilities of success?

Skin: Medium-Low. CPR: Low; deteriorating prognosis.

5. What are the therapeutic failures?

CPR when not medically indicated.

6. In sum, how can this patient be benefited by medical and nursing care, and how can harm be avoided?

The patient may benefit from comfort care, harm can be avoided by not performing unnecessary intervention.

Quality of Life* Patient's Perspective

(Principles: Beneficence, Non-maleficence, Respect for Autonomy)

Consider

1. What are the prospects, with or without treatment, for a return to normal life?

If skin condition is treated, patient can potentially return to her basal status. Without CPR, patient will die; with CPR patient may delay death.

2. What physical, mental, and social deficit is the patient likely to experience if treatment succeeds?

Patient has advanced Alzheimer; however, poor oxygenation period may worsen mental condition. Patient may have skin scarring due to skin condition.

3. Is the patient's present or future condition such that his or her continued life might be judged undesirable?

There is a high probability that the patient's health continues deteriorating, needing multiples full codes without health improvement.

4. Is there any plan and rationale to forgo treatment?

Yes. CPR intervention is too aggressive, causing the patient harm and little to no benefit. Patient's medical prognosis is very poor.

Are there plans for comfort and palliative care? Yes.

Patient Preference

(Principles: Respect for Autonomy)

Consider

 Does the patient have decision making capacity? If so, identify preferences.

2. If without capacity, who is the appropriate surrogate? Is the surrogate using appropriate standards for decision making? Unknown, but it seems that the next to kin are using their own values as reference.

3. Has the patient/surrogate been informed of benefits and risk, indicated understanding and given consent?
Yes, surrogate have been informed of benefits and risks. They indicated understanding and gave explicit consent to perform a full code.

4. Has the patient made advance care plans or named a health care agent?

5. In sum is the patient's right to choose being respected to the extent possible in ethics and law?

Unknown. Patient did not have capacity since the point of admission. Currently, family's wishes are being respected to provide full code.

Contextual Features

(Principles: Justice; Values: Loyalty & Fairness)

Consider

- 1. Are there issues that might influence treatment decisions?
 - a. Family: Perceive healthcare team as "giving up". They want everything for their mother.
 - Provider: Moral distress by inflicting harm to the patient. External pressure due to Hurricane María.
 - c. Cultural/Religion: Unknown to influence.
 - d. Financial: Not an issue in this case.
- 2. Are there limits on confidentiality?

Not on this case. Patient has no capacity, next to kin are making decision.

3. Are there problems of resource allocation?

Although not affecting this case specifically. Overall, there were resources shortages due to Hurricane María.

4. How does the law affect treatment decisions?

Healthcare team is also worried about legal consequences if CPR is not provided.

5. Is clinical research or teaching involved?

Not research. Teaching is involved because medical students and residents are in the team, but this is not a teaching case.

6. Is there any conflict of interest on the part of the providers or the institution?

No (that I am aware of).

References

23. Brody BA, Halevy A. Is futility a futile concept? *J Med Philos*. 1995;20(2):123. http://search.ebscohost.com/login.aspx?direct=true&db=cmedm&AN=7636419&site=ehost-live&scope=site.

- 24. MIKUS CM. Time for a formalized medical futility policy. *HEALTH PROGRESS*. 2000;2:5.
- 25. Jonsen AR, Siegler M, Winslade WJ. *Clinical ethics : A practical approach to ethical decisions in clinical medicine*. Eighth ed. New York: McGraw-Hill; 2015. http://accessmedicine.mhmedical.com/book.aspx?bookid=1521.