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HOLDING OUT HOPE OR PERMITTING SUFFERING?

A Case of Medical Ethics

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“If you can, help others, if you cannot do that, at least do not harm them.”

— Dalai Lama XIV

THE CASE OF E.C.*

E.C. was a 26-year-old Black female with a past medical history of lupus. She previously required a 13-month hospital stay for infection with parechovirus necessitating a tracheostomy and PEG tube placement. Having recovered from that set of circumstances, she presented to Lancaster General Hospital in January 2022, 15 days after testing positive for SARS-CoV-2. Her COVID-19 symptoms were worsening upon presentation and included fever, cough, and respiratory distress. Her condition quickly deteriorated, and she soon required ventilator support and venovenous extracorporeal membrane oxygenation (VV ECMO).

The patient did not have advanced care planning documents, and according to PA Act 169,¹ the patient's father was her health care representative; thus, consent for each of these measures was obtained from her father. What followed was a protracted hospitalization, lasting 97 days (see Fig. 1). During her stay, numerous health care professionals were involved in E.C.'s care.

Although her care team soon realized that her condition was not survivable, E.C.'s father continued to choose for the health care team to pursue all life-preserving measures. During this time, her father appeared emotionally unable to hear any negative news regarding her prognosis. He did not visit her in person. As a result, several ethical dilemmas became evident in her care, and the Penn Medicine Lancaster General Health Ethics Committee was consulted to help provide assistance to all involved.

ETHICAL QUESTIONS AND CONSIDERATIONS

The following are some of the ethical considerations surrounding E.C.'s care. The Ethics Committee members, in their consultation, weighed these factors,

among many, as they formulated their recommendations regarding E.C.'s case.

Who is the appropriate decision-maker? E.C. did not have an advanced directive and did not have capacity to make decisions after she had been sedated, intubated, and started on ECMO. According to PA Act 169,¹ her father would be her health care representative. A health care representative has the responsibility to use substituted judgment to act as the patient would if they had decision-making capacity. When a patient is unconscious or in an end-stage condition, a health care representative may make decisions involving withdrawal of life-sustaining care.

When does care become potentially inappropriate? “Potentially inappropriate treatment [or] non-beneficial treatment [references a] medical effort to provide a benefit to a patient when reason and experience suggest it is highly likely to fail and whose rare exceptions cannot be systemically produced.”² ECMO, for example, is designed as a bridge to recovery or transplant. When both outcomes became exceedingly unlikely, one could argue that continuing ECMO became inappropriate.

The term “futile” has fallen out of favor. “Futile” does not take into account that all decisions regarding medical interventions are made based on weighing the probabilities of particular outcomes.

What principles of biomedical ethics are involved? In this case, all four principles are involved, namely autonomy, beneficence, non-maleficence, and justice. These principles must be weighed and balanced against one another.

- **Autonomy:** Patients have the right to make their own informed decisions about their care, provided they have the cognitive ability to weigh the risks and benefits of treatment decisions. Autonomy as an ethical principle holds enormous weight in

*Names changed out of respect for privacy rights of individuals involved.

Western biomedical ethics. This right extends to the health care agent/representative acting on a patient's behalf.

In this case, however, the patient's representative was not present with the patient in the hospital for extended periods of time and repeatedly declined to receive bad news surrounding her prognosis. Thus, the Ethics team had concerns about the representative's informed, cognitive ability to make decisions. Nevertheless, the team tried to provide a complete picture of the situation while attempting to reduce undue psychological stress on E.C.'s father.

- **Beneficence:** Health care providers must act in the best interests of their patients. ECMO is a life-sustaining treatment, and withdrawal of ECMO in this case would lead to death. In previous hospitalizations, E.C.'s father had seen her make miraculous recoveries despite her care team delivering poor prognoses. As such, he was wary of prognostication. On the flip side, in the absence of potential meaningful recovery, ECMO could lead to unnecessary prolongation of patient suffering.
- **Non-maleficence:** Harms to patients must be minimized when providing care. E.C., especially toward the end of her hospital course, was showing signs of suffering and possible iatrogenic harm. For example, it was documented thoroughly in the record that she was experiencing body decompensation with pressure ulcers and critical limb ischemia. Her body started to go through the process of auto-mummification. She would frequently cry with repositioning. The care team witnessing this experienced significant distress. There was increasing mention in the medical record over time of the patient's tears, and concern that the level of care being provided was prolonging E.C.'s suffering.
- **Justice:** In recognition of limited resources, care must be provided equitably. This includes ECMO, ICU rooms, ventilators, staff, and blood products, all of which were utilized in the care of E.C. In addition, E.C. continued to test positive for SARS-CoV-2 during her hospitalization. Thus, there was additional concern for the safety of the staff involved in her care.

POTENTIAL BIASES AND PRECEDENT

We also note potential biases in this case. Racism permeates the structural underpinnings of American health care and has direct negative implications for

Fig. 1. Hospitalization Overview

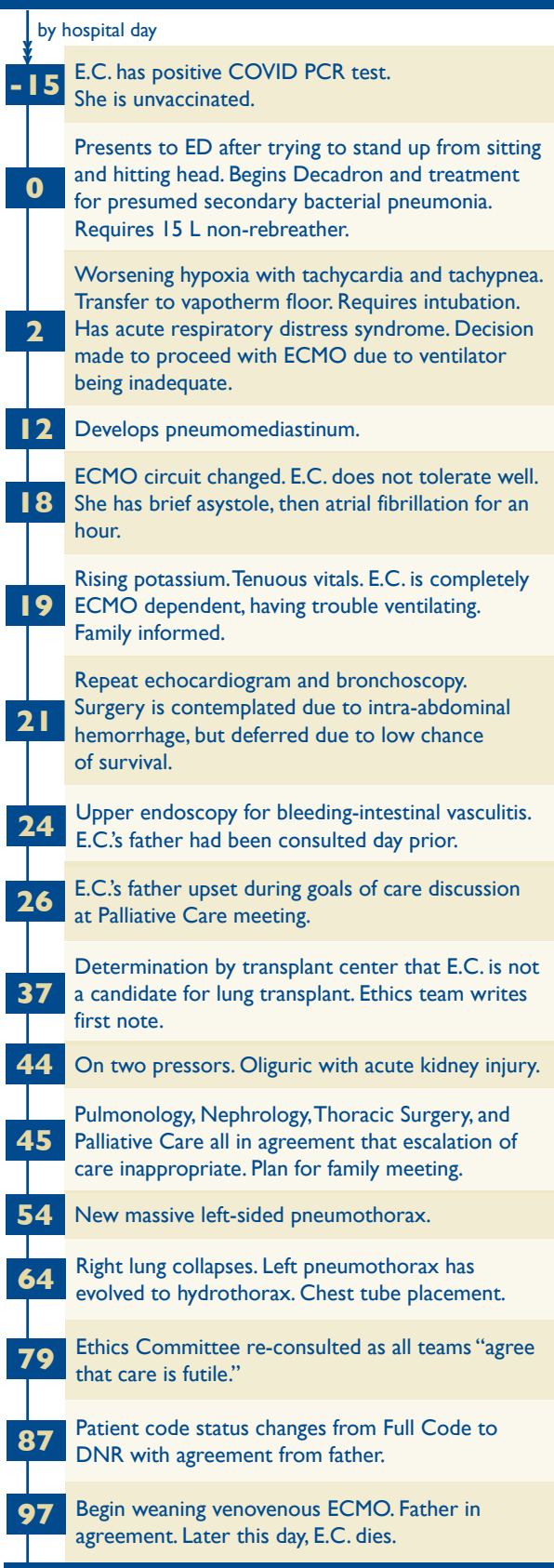


Fig. 2. Resources Available to Support Care Teams

- LG Health Critical Response Team
- Free counseling services through EAP and Penn Cobalt
- Nurse Leadership: nurse managers, nursing professional development practitioners, clinical nurse specialists
- Palliative Care Team
- Chaplain Department

Additionally, the LG Health Ethics Committee can be consulted by any member of a patient's care team for any patient in the LG Health system as these questions arise. Please reach out if you feel that a patient, family, or the care team could benefit from an Ethics Committee consult. The committee thanks you for your care of patients and your care of one another.

clinical outcomes for Black patients. Mistrust of the health care system may have stemmed in part from this reality. Further, bias related to age may have impacted her care. Had E.C. been elderly, the family and care team may have perceived the appropriateness of her care differently.

The above considerations are contextualized by policy and precedent. Navigating cases where the care team and family cannot come to an agreement regarding the appropriateness of care can be challenging. The LG Health policy on medically inappropriate care focuses on the care team clearly explaining prognosis and discussing the patient's goals of care. If there is disagreement between the care team and the patient and family, the care team may call upon other entities. These include the Biomedical Ethics Committee consult team, hospital chaplain, hospice workers, social workers, patient care representatives, nurses, legal staff, community clergy, and physicians offering a second opinion. Further, the Biomedical Ethics Committee members may meet to facilitate discussions and come to a common understanding with the patient/family.

If an understanding is still not reached, little precedent or guidance is available for how to proceed.³ AMA policy on Medically Ineffective Interventions follows a similar theme of first attempting all routes to get family and the care team in agreement. This policy addresses limiting inappropriate interventions but does not address withdrawing care already in place.⁴

Pennsylvania state law is equally ambiguous regarding this situation. Physicians, it states, are not subject to criminal or civil liability for "refusing to comply with a direction or decision of an individual based on a good faith belief that compliance with the direction or decision would be unethical or, to a reasonable degree of medical certainty, would result in medical care having no medical basis in addressing any medical need or condition of the individual."⁵

However, this act does not provide a definition of "unethical" or what is meant by "having no medical basis" in patient care. Importantly, regarding this case, it also does not address the withdrawal of treatment. Overall, if the patient, their

family, and the care team cannot come to an agreement concerning appropriate treatment, there is very little to guide the next steps.

LESSONS LEARNED

Providers can learn many lessons from this difficult case, along with considerations for future cases like this one. The first is the importance of advanced directives. E.C. was a medically complex patient with a history of a prolonged hospital stay. Having advanced care planning documents would have been helpful to the care team. This case serves as an important reminder about the importance of advanced care planning with patients who have a high likelihood of hospital admission, regardless of age.

Another important lesson to consider is the responsibility of health care representatives to act in the best interest of the patient, rather than acting on what they want for the patient. One could argue that, in purposefully avoiding "bad news" about E.C. and shielding himself from the reality of her prognosis, her father did not have the information to act in her best interest.

When looking at this case from a legal perspective, it becomes clear that there is very little precedent to guide providers who believe that continuing care is inappropriate without patient/family agreement. In some cases, seeking guardianship would be another avenue to explore, but this would require evidence that the family was not acting in the best interest of the

patient.⁶ This is difficult to prove legally and is further complicated by the emotional distress that was contributing to E.C.'s father's decision-making. Hospital policy, the AMA, and Pennsylvania state law all stress the importance of coming to an agreement or transferring the patient if an agreement cannot be reached.

But what happens when neither is possible? With the growing complexity of health care decision-making, there is a need for more guidance in cases such as these.

In the meantime, considering timed trials-of-interventions (e.g., an early discussion of a two-week ECMO trial) could help providers set expectations with families and help them better understand the limits of these interventions before they reach the point of being inappropriate. Conversations should begin early and be revisited often regarding the potential risks and benefits of each treatment avenue. All appropriate treatment paths should be given a reasonable chance. It is the health care team's responsibility, *prior* to the initiation of complex intervention, to define what is considered an appropriate trial-of-intervention duration.

The final important lesson from this case is the need for care team support. Nurses, patient care assistants, providers, social workers, and many others were involved in this distressing case and were ethically conflicted about the care they were providing to E.C. Cases such as these contribute to burnout and bring to light the need for resources to support members of the care team as they process their own response to them (see Fig. 2). The care team's effort in communi-

cating with family, caring for E.C., and advocating for her best interest is commendable, but the personal toll of providing such care must also be acknowledged.

CONCLUSION

This case eventually reached its conclusion following multiple meetings and conversations between the care team and E.C.'s family. As a result of consistent and open communication between the family and the care team, E.C.'s father agreed to the withdrawal of life-sustaining measures and a palliative approach to her care. E.C. passed away shortly thereafter surrounded by her family.

We offer special thanks to everyone who participated in the care of E.C. While her name was changed to protect patient privacy, we know that many will recognize her story. E.C. was far more than her illness. A note from the palliative care team detailed how E.C. was very close to her sister and that her nephews were her world. She was learning to cook, and despite all her medical challenges, remained hopeful. She was always looking for a way to help others.

Health care providers desire to help others, too, and cases like that of E.C. can be particularly distressing as teams struggle to ask themselves, "Are we doing the right thing?"

ACKNOWLEDGEMENTS

The authors offer special thanks to the members of the Ethics Committee who helped in the development of this article, including Kari Oftedal Moreno, MD; Keith Espenshade, MDiv; Katie Weinrich, JD; and Eric Piasecki, MSN, RN.

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