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PERSPECTIVE

End-of-Life Decisions about Withholding or Withdrawing Therapy: Medical, Ethical, and Religio-Cultural Considerations

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Abstract: Towards the end of life, physicians face dilemmas of discontinuing life-sustaining treatments or interventions. In some circumstances, these treatments are no longer of benefit, while in others the patient or family no longer want them. The physician plays an essential role in clarifying the goals of medical treatment, defining the care plan, initiating discussions about life-sustaining therapy, educating patients and families, helping them deliberate, making recommendations, and implementing the treatment plan. Communication is key. It should be clarified that when inevitable death is imminent, it is legitimate to refuse or limit forms of treatment that would only secure a precarious and burdensome prolongation of life, for as long as basic humane, compassionate care is not interrupted. Agreement to DNR status does not preclude supportive measures that keep patients free from pain and suffering as possible. Acceptable clinical practice on withdrawing or withholding treatment is based on an understanding of the medical, ethical, cultural, and religious issues. There is a need to individualize care option discussions to illness status, and patient and family preferences, beliefs, values, and cultures. The process of shared decision making between the patient, the family, and the clinicians should continue as goals evolve and change over time.

Keywords: withholding or withdrawing life-sustaining treatment, DNR, CPR, euthanasia

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Introduction

Most hospitals have patients who receive treatments or interventions that keep them alive; these interventions include mechanical ventilation for acute or chronic respiratory failure and dialysis for acute or chronic renal failure. Eventually, the patient's physician will have to face the dilemma of whether or not to continue these treatments. In some circumstances, treatment is no longer beneficial to the patient, while in other cases, the patient or families no longer want treatment to continue.¹

According to the Education for Physicians on Endof-life Care (EPEC) curriculum,2 physicians play an essential role both in defining and implementing the medical care plan and in providing continuity of care as goals evolve and change over time. Physicians often take the lead in initiating discussions about lifesustaining treatment, educating patients and families, helping families deliberate, and making recommendations about treatment plans. As part of this role, the physician is responsible for ensuring that the patient's wishes, and/or the parents' wishes if the patient is a child, are documented and supported by the appropriate medical orders. One major study demonstrated that the majority of patients in intensive care unit settings die without attention to issues of life-sustaining treatment. Many of these patients have undergone some form of invasive medical treatment against their previously stated wishes.³ All too often, patients are transferred to the acute-care setting where life-sustaining measures are administered because the appropriate treatment plan and physician's orders have not been completed and placed in the patient's chart.⁴ This scenario is repeated to this day and I have personally encountered such patients, who were referred to palliative care only in the last few hours or days of life.

In her 1987 article 'Must We Always Use CPR?', Blackhall tackled the appropriate use of cardiopulmonary resuscitation (CPR).^{5,6} The withholding and withdrawing of life-sustaining therapies is ethical and medically appropriate in some circumstances, such as when the treatment no longer fulfills any of the goals of medicine. In general, these goals are to cure (if possible), palliate symptoms, prevent disease or disease complications, and improve functional status. For example, patients with massive intracranial bleeding from a stroke or severe head trauma, and judged to have no chance for recovery of brain function, can no

longer benefit from being on a mechanical ventilator; it achieves only the maintenance of the biological function. In such a case, it would be justifiable to withdraw mechanical ventilation.¹

On the other hand, there is the question of whether it would also be justifiable to withdraw mechanical ventilation in patients with chronic obstructive pulmonary disease (COPD), in whom the presence of acute or chronic respiratory failure is often seen as a terminal phase of the disease. A great variability in end-of-life practice is observed in these patients, mainly because physicians are not always able to correctly predict survival. There is a need for a clear discussion about decision making in stages earlier than when acute respiratory failure ensues. Indeed, a perceived poor quality of life does not necessarily correlate with a clear willingness to refuse invasive or noninvasive mechanical ventilation. Therefore, the decision to commence or terminate mechanical ventilation in end-stage COPD needs the active participation of the patient. Physicians and educators should target patients with COPD to improve patients' education about diagnosis and the disease process, together with the explanation of the treatments, prognosis, what dying might be like, and advance care planning.7

On a similar note, would it be justifiable to withhold or withdraw life-sustaining treatment in patients with end-stage heart failure (HF) refractory to medical therapy? The 2005⁸ and 2009⁹ American College of Cardiology and American Heart Association guidelines state that aggressive procedures performed in the last several months of life that do not contribute to recovery or improve quality of life, including intubation and implantation of a cardiac defibrillator, are not appropriate. It is recommended that end-of-life care strategies be individualized and a specific discussion about resuscitation be held in the context of planning for overall care and for emergencies with all patients with HF.¹⁰

What is important to keep in mind is that physicians are not obligated to and should not offer or provide useless or futile treatments, ie, treatments that no longer offer benefit to the patient, even in the name of patient autonomy. Despite this, physicians still seek and obtain patient or proxy consent when CPR is not indicated before writing a Do Not Resuscitate (DNR) order; reasons for this action include



fear of legal repercussions/misconceptions, limited physician-patient relationships, time constraints, institutional culture, 11 guilt, grief, and concerns about the family's reaction. Other obstacles are insufficient legal and palliative knowledge, as well as treatment requests by patients or families. 12

Blackhall⁵ asked why physicians continued to consider CPR for patients even in scenarios where it is known to offer no benefit. Her data showed that physicians, due in part to their own discomfort with death and dying, tended to avoid end-of-life discussions, with the result that CPR and DNR conversations often didn't take place in the non-acute setting. Patients typically do not make these decisions proactively and it is the family members who are often asked to act as surrogate decision-makers and decide on the patient's behalf. Family members are then faced with the pressure of considering—on the spot—what their loved one would have wanted. After all, it is much easier and less uncomfortable to present CPR as an option than to inform a patient that she will die soon, regardless of the intervention. Blackhall also implied that physicians were, on average, rather poor at having these discussions. She also claimed that most patients lacked the medical knowledge needed to fully understand the role of CPR. Blackhall challenged the presumption that patients always have a right to CPR any more than they have a right to receive a medically nonsensical treatment.

On the other hand, doctor-patient discussions about end-of-life treatment are often framed as a choice between medical treatment versus treatment withdrawal. When framed in this manner, treatment withdrawal becomes a negative choice that often implies giving up, abandonment, or not giving the doctor a chance to do his or her job; worse, it implies not caring. Thus, this option can appear to be no option at all.¹³

In a study by Eliott and Olver,¹⁴ a common assumption underpinning patients' and families' discussions about a DNR decision is that it requires a choice between life and death. Accordingly, in making decisions about CPR, each patient and their families are implicitly required to make moral judgments about the value of the patient's life, including their relationships with significant others. This proved to be particularly problematic when patients failed to make their own DNR decisions and the decision defaulted to family members, identified as surrogate decision-makers.

Choosing to forgo CPR was construed as choosing to let the patient die, with various unpalatable moral evaluations of family or patient applicable—either the patient was not worth saving, or the family did not care enough to save them. Alternatively, the choice to opt for CPR might have sentenced their loved one to life in unacceptable circumstances.

It should be underscored that communication is key to all discussions of this nature. 15-17 Very often it is perceived that if CPR is performed, a patient will be resurrected from the dead and will be well. This view can be a barrier to decision making. DNR should be addressed in the context of a broader discussion about the patient's understanding of his or her illness and prognosis, and the goals of care. In order to make an informed decision, the patient should be made aware of the benefits and burdens of CPR. It should be clarified that a DNR order does not mean "do not treat." and that agreement to DNR status does not preclude other supportive measures. 18 Although CPR will not be given to a person who has a DNR order, maximal medical therapy that meets patient's goals, such as alleviation of suffering and of distressing symptoms, and supportive measures that maximizes the patient's comfort, will continue.19

Discussion

There are many requirements and factors that affect the decision to limit life-sustaining therapy. From the medical perspective, the first requirement is that there is at least acceptance and at best consensus among the members of the health care team to limit therapy when hope for recovery is outweighed by the burden of the treatment.^{20,21}

Treatments should not be withheld because of the mistaken fear that if begun, they cannot later be withdrawn. Instead, a time limited trial of therapy could be used to clarify the patient's prognosis. At the end of the trial, a conference should be held to review and revise the treatment plan.²²

Patients' and families' religious-cultural backgrounds profoundly influence preferences and needs regarding decision-making, death, and the discussion of bad news in general.²³ Hence, these factors should be considered in decisions regarding life-sustaining therapy, now more than ever as societies become increasingly multicultural, multiracial, and diverse in terms of religious beliefs. Recognizing this pluralism



is fundamental to the provision of high quality endof-life care.7 Studies have shown that non-white patients are less likely than white patients to agree to DNR orders, less likely to withhold or withdraw care, and less likely to have advance care directives.²⁴ Additionally, African-American physicians patients are more likely than Caucasians to request artificial feeding, mechanical ventilation, or cardiopulmonary resuscitation if the patient is in a persistent vegetative state or is terminally ill.²⁵ Conversely, a do-not-resuscitate order is consistent with the tenets of Islam.26 In Asian cultures, making a decision to withhold or withdraw life support from a parent may be seen as unfilial.²⁷ If the integrity of the family as a whole is valued more than the wishes of an individual family member, the patient may expect the family to do everything possible to prolong their life, even if they do not want to be on life support because to do otherwise would bring dishonor on the family.

Similarly, different cultures and religions may have differing views on the role of suffering. Some view suffering as redemptive and something to be endured as a test of faith rather than a burden to be avoided. The idea that only God, not doctors, knows when it is time to die may also affect how patients view the use of life-sustaining therapies.²⁸

In certain cultures, such as the Philippines, measures such as removing the ventilator and giving opioids could be perceived as tantamount to killing the patient; indeed, it may be equated with mercy-killing. As euthanasia is unacceptable in a country where the majority is Christian, this misperception can be a barrier to decisions to limit life-sustaining therapy in a dying patient; the result may include preventable negative consequences such as family caregiver strain and financial difficulties brought about by high hospital bills. In such cases, it should be clarified that in accordance with the Vatican Declaration on Euthanasia,²⁹ when inevitable death is imminent, it is permitted, with the patient's consent, to refuse forms of treatment that would only secure a precarious and burdensome prolongation of life, and to interrupt means provided by the most advanced medical techniques where the results fall short of expectations. It should be made clear that withholding or withdrawing lifesustaining therapies that are disproportionate to the expected outcome is not equivalent to euthanasia; it is in fact considered ethical and medically appropriate,

as long as basic humane, compassionate care is not interrupted.

Even so, some family members may be reluctant to withdraw treatments, even in cases where there is a belief that continued treatment would not be the patient's wishes. The physician should try to resolve these situations by addressing the families' feelings of guilt, fear, and concern that their ill relative may suffer once life support is withdrawn. The physician should also ensure that all appropriate measures to relieve distress are used; they should also explain their ethical obligation as a physician to follow the patient's wishes.²²

Withholding and withdrawing therapy requires attending physicians to be excellent communicators, both with patients and patients' families.2 Jox et al proposed an algorithm that focuses primarily on goals of treatment and secondarily on treatment measures. It intertwines the two principal ethical grounds of treatment decisions: patient autonomy and patient wellbeing. The model reflects a process of shared decision making between the patient, the patient's family, and clinicians. 12 The Institute for Clinical Systems Improvement (ICSI) Palliative Care Guideline also recommends the use of shared decision-making and reframing the discussion from "medical futility", or non-beneficial/low-yield therapy, to a clarification of goals of care. Note that this does not preclude the clinician making a strong treatment recommendation based on clinical knowledge and experience.30

Conclusion

Facilitating decision making and implementing decisions about life-sustaining treatments are essential skills for physicians. It should be emphasized that each case is unique and there is no single overarching principle that guides end-of-life decisions. No one doctor can claim to have all the answers, and patients and their families appreciate truthfulness and sincerity in this regard. Communication is key to these types of discussion. Acceptable clinical practice on withdrawing or withholding treatment is based on an understanding of the medical, ethical, cultural, and religious issues. There is a need to individualize care option discussions to illness status, and the preferences, beliefs, values, and cultures of both the patient and their family. Shared decision making on



treatment preferences should be periodically revisited as goals evolve and change over time.

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