

Accepting End of Life Care Realities - When the Choices are Limited

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Abstract

As a nursing instructor, I was rounding with my students in the Intensive Care Unit [ICU] when my junior colleagues expressed discomfort about the management of a 25 years old man, admitted after head injury in a road traffic accident. The gentleman in question was being ventilated for the last ten days although declared brain dead. However, despite effective communication, family refused to give consent to disconnect the ventilator. They were not ready to accept the brain death, as the patient's heart rhythm was visible on cardiac monitor. There was no evidence of patient's own wishes about his end of life care.

Keywords: End of Life Care Realities; Dilemma; HCW

Dilemma

Brain death criterion is internationally accepted for diagnosing death. A study conducted by 'American Academy of Neurology' reports that, amongst 80 countries, 70 use brain death criterion in their hospitals [1]. In Pakistan, brain death criterion is commonly used for declaring a patient's death. Although, a valid and extensively practiced criterion for diagnosing death, the brain death criterion is not well comprehended by patient's family. One reason that families are reluctant to accept death is visible heartbeat on cardiac monitors, obvious breathing, and normal skin color, all due to mechanical ventilation [2,3]. On the other hand, this denial by the families becomes a challenge for Health Care Workers [HCWs], who believe that further treatment is futile. As a result crucial dilemma arises; whether to respect the family's wish and continue with routine care of a brain dead patient or to respect the decisions of HCWs and stop a waste of precious resources [4].

Distributive Justice

Health care resources, like all other commodities are limited. Principle of distributive justice mandates fair allocation and prioritization of these limited resources. Ventilated ICU beds are a precious health care resource especially in developing countries like Pakistan. This principal is questioned when a brain dead patient occupies a ventilated bed that could be used for a salvageable patient. In addition, treating a brain dead patient is wastage of HCWs energies that can be utilized for patients with better chances of recovery [5,6].

Conflict between Values of HCWs and Families

The respect of HCWs decision is neglected when they have to provide aggressive care and treatment to brain dead patients according to hospital protocols. Dinsmore and Garner [3] write that HCWs have no disagreement on brain death criterion for diagnosing a patient as dead therefore still continuing care is a potential violation of the value of their decision. HCWs are aware of the irreversibility of brain death and being a nurse it is experienced that providing futile treatment results in dissatisfaction to HCWs. Furthermore, Ersoy and Akpinar [7] inferred that protecting patients from suffering of futile treatments is one of the important duties of a nurse working in ICU.

On the other hand, despite scarcity of ventilated ICU beds, the patients' best interests cannot be ignored. Nurses must identify the patients' wishes about her end of life care and should incorporate them in the plan of care [7]. Secondly, if the HCWs consider the patient as dead, then on the basis of risk benefit ratio they should continue care till the patients' family members are willing, as there is no harm of an intervention to an already dead patient.

Thirdly, the family members of a dying patient should be given a chance to get to the acceptance phase from denial phase. Literature supports HCWs' responsibility of providing care to the grieving family members after patients' death is established and considers it a part of caring process of a dying patient [8]. Lastly, it is more valued to let the natural death process occur itself instead of removing a brain dead patient from the ventilator.

Religious Tenets

The patient was of Muslim beliefs and his religion did not disagree with the concept of brain death. Most of Islamic jurists have accepted the brain death criterion's validity for diagnosing death in their meeting at Jordan in 1986 [9]. Although, continuing treatment of a brain dead patient may not give apparent harm to the patient but it is believed that continuing care is nothing more than prolonging the patients' dying process [3].

Is there a Solution?

In the light of available literature and practical examples, it can be claimed, with reasonable certainty that a brain dead patient should not be continued with ventilator support once his brain death is confirmed and announced. Wastage of precious resources like HCWs energies and ventilated ICU beds for a futile treatment cannot be justified by mere emotional non-acceptance. Grieving process of the families is a normal response and a short delay in discontinuation is acceptable for family's emotional care but it must not be taken as continuation of the futile treatment. It is recommended that if there is prolongation of the futile treatment beyond a short period and family expresses the wish to still continue, then the HCWs must say no to it [5].

This might lead to family's mistrust in HCWs with a compromise in their emotional support and care but another life can be saved through better utilization of ventilated beds. In addition, the HCWs decision of brain death will be valued if it will be practically exercised

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and the patient will be removed from the ventilator, leading to better work output by them. This line of action will also shorten the family's grieving process by eliminating the false hope that patients' condition is revivable. Furthermore, unnecessary prolongation of the patients' dying process will prevent the financial drain, this being significantly important in developing countries where most of the health care expenditure is out-of-patient pocket.

For countries like Pakistan with low literacy rates, a focus on increasing public awareness about the concept of brain death is mandatory. Family's presence during performance of brain stem tests is encouraged as it can help in strengthening the concept of brain death [2,6]. Involvement of family physicians while communicating with the families has been seen to help them understand the situation better [6].

- A clear policy should be formulated to deal with the conflicting situations relevant to brain death. Formation of clear guidelines for dealing with a brain dead patient on ventilator will be the most important future plan. For establishing new protocol for brain dead patients on ventilator the concept of "Accountability for reasonableness" presented by Daniels and Sabin can be utilized [10]. In *publicity* condition, the family members must be informed at the time of patient's admission to ICU that a brain dead patient will not be continued with ventilator support for treatment purpose; however, the family will be given some time for their grieving process. The information must be accessible to all family members at the time of admission and should also be disseminated to all HCWs in the institution. ICU managers, head nurses, supervisors, and consultants should be well-versed with the policy. In *Relevance* condition, the policy will be justified with appropriate reasons that are acceptable for all fair-minded people. The head nurses, supervisors and ICU consultants should be part of the group that would handle the *Revisions* and *Appeals* conditions. The head nurse of ICU should keep a check on *Regulative* condition to make sure that the policy is practiced effectively. In addition, there must be a clearly defined process of policy review after an identified time period.

Conclusion

Ventilator is a support for life in certain life threatening situations but once this treatment is deemed futile, it becomes merely a reason for prolonging the process of death and the suffering of the family. Moreover, it leads to wastage of precious resources besides being a cause for injustice to other salvageable patients. There should be clear guidelines for handling such crucial situations to maintain justice in treatment of all those requiring this limited resource.

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