

End of Life Care: Frequently Asked Questions and Frequently Questioned Answers

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A peaceful death would be at home, surrounded by near and dear ones and free from pain. Usually when a patient is about to die in a hospital, he or she is actively resuscitated and his family is asked to leave the room. Terminally ill patients have choices regarding approaching death, which must be respected. Singer, et al.,³⁰ have reported that patients and their families are very clear about what they want from the health care system at end of life situation. This situation is very difficult and trying for the family and handling the end of life situation can be very taxing and at the same time rewarding for the health care system.

In an effort to present up-to-date information regarding the EOLS, *Medline* search was done using key words - death, hospital, and end of life and organ donor. Limits were set for articles with full text and English language.

We regularly diagnose and treat people with severe illnesses that lead to death. End of life situation (EOLS) is a very unstable and high-energy environment in a hospital for the dying as well as for the family and the health care provider. Certifying a patient dead is a legal process. The emotional sadness associated with death is universal. Death has other implications too. It will mean removal of life supports and harvesting of organs for transplant donations. In the socioeconomic context assets of the deceased will be transferred, life insurance policies become collectable, marriage ends and many other legal and financial changes will be activated. We all must have sound knowledge of the existing definitions of death and the profound consequences of this medical conclusion.

Key Words: death, diagnosis, life

The WHO authorized HINARI web site was used to access the full texts. The google search engine was used to find high profile law suits regarding misdiagnoses of death and the "Right to die" cases of PVS (Permanent vegetative state patients). The information gathered was subsequently grouped into the following major headings.

- Definitions of death.
- Retrieval of organs after death.
- Care of the end of life patients.
- The currently accepted practices and guidelines are discussed.

Definitions of Death

At homes conclusion of death is a simple decision made by family members once the breathing and heart stop. In the hospital setting life support systems of the present time have made the definition of death a very complicated medical and legal term. Debate on when a patient can be certified dead will continue, as it needs consideration of evolving medical knowledge as well as personal and religious aspect of the person dying. In addition, futility and expenses involved in prolonging life support also comes into consideration. There are four major accepted definitions of death each with its own set of controversies:

- Cardiopulmonary death;
- Whole brain death;
- Higher brain death; and
- Patient determined definition of death.

Cardiopulmonary Death

Till the advent of respirators in the 1950's this was the universal definition of death. The heart lung machines and dialysis units now can maintain life for prolonged periods even for patients without any form of cure.

Whole Brain Death

Harvard Medical School in 1968⁴ was the first to formally give this definition. They also were the first to recommend withdrawal of life support once irreversible brain death was determined. The UDDA (Universal Determination of Death Act) of 1980 accepted this criteria and this is the form of death most widely accepted all over the world. To overcome indecisive circumstances most countries will require a physician not involved in the transplant effort to document brain death and another physician to confirm the findings. The most widely accepted guideline for determination of brain death is available on line at http://www.usc.edu/hsc/medicine/surgery/trauma/Trauma_Protocols/15BRAIN.html. In the presence of even minimal brain stem activity we are justified in refusing to withdraw life support in the absence of convincing proof that this is what the patient would have wanted.²²

Higher Brain Death

The concept of whole brain death was to prevent "corpses being ventilated indefinitely" and it has nearly succeeded throughout the world. This still does not answer the situation of PVS (Permanent vegetative state) where the patients can ventilate themselves but lack the higher brain function to control emotions, consciousness and cognition. Brain stem being more resistant to hypoxia will survive the insult that will kill the higher brain. It is estimated that at any given time there are in USA alone 25,000 adults and 10,000 children in this state.²³ PVS is in 'the no man's land' between life and death. Needless to say ethical and medical groups are embroiled in this discussion. Proponents of this form of death argue that without consciousness all that makes a human being is lost.^{9,28} Higher brain death cannot be ascertained to with the same degree of certainty as the whole brain death. This will mean the real danger of misdiagnosing death in patients who are temporarily unconscious. Hesitancy of the legal systems to accept this definition widely is well understood. To definitely document degeneration in the hemispheres by positron emission tomography (PET) or magnetic resonance imaging (MRI) 3-12 months are needed.²⁶ It is only then that higher brain death can be confirmed.⁸ Reports of PVS patients recovering after prolonged coma⁵ further highlights the difficulty in arriving at the concrete diagnosis of higher brain death. There are two landmark "Right to die" cases worth-mentioning here.

Case 1: K.A.Q. became permanently unconscious after receiving a drug overdose. Her father was appointed as her legal guardian. He requested withdrawal of life support. This was refused by hospital authorities. After a prolonged court battle¹⁷ the New Jersey Supreme Court held that her legal guardian could order withdrawal of life support. Her ventilator was removed. Her body continued to function for nine years with artificial hydration and nutrition.

Case 2: N. C.'s father struggled to have her artificial hydration and nutrition removed after it was clear that she would not regain consciousness. The court ruled that this was impossible¹⁰ as she was not legally dead. It was only after Justice Stevens dissent¹¹ stating that "N. C.'s life might have expired the moment her biological existence ceased serving her own interests" that her hydration and nutrition was terminated. The 'court controversy' revolved around the issue based on the patient's right to refuse treatment.²⁴ Courts overall will conclude that not every life is worth sustaining medically. They will generally allow removal of life sustaining support according to the patient and family wishes for the PVS state. In case the family seeks to continue support for the PVS patient in spite of contrary medical advice then nothing can be done but to maintain support.²

Patient Determined Definition Of Death

As if there were not enough problems some courts have introduced an additional factor in determination of death: The moral and religious beliefs of the patients.¹³ This leads to a quaint situation where the patient's concept of death may override the physician's medical determination of death and may force a determination of death by cardiopulmonary status only. This problem was given high profile coverage in the Mariah case.³ M.H. a five-month-old baby was declared brain dead. Her parents petitioned to prevent the declaration of death based on religious freedom law and wanted to take drastic measures to keep the baby alive. This led the author to comment "Maintaining a corpse in an ICU for a few days maybe reasonable as a matter of sensitivity to religious and moral beliefs, but treating a dead body as if it were alive for a long period is bizarre and arguably a violation of basic human dignity." Here we see a clear clash between religious beliefs which usually support aggressive life saving measures and medical prudence which always balances the effectiveness of treatment and likelihood of recovery.³² In a free society, unless there is a compelling state interest, the government is obliged to uphold the religious belief of any individual. The same will hold for a patient to refuse treatment.³¹ The major problem that one faces with this freedom is that if non-medical (religious/moral) criteria are permitted to diagnose death and active measures are taken to terminate bodily functions, this could be in direct conflict with the existing homicide laws.

Organ Retrieval for Transplantation after Death

In 1987, Loma Linda hospital created worldwide controversy by initiating a protocol to keep anencephalic infants on cardiovascular support to maintain their organs for transplantation,²⁹ until they could be legally declared brain dead. The debate centered on the ethical issue of initiating life support just for the purpose of harvesting organs. This protocol reported that only one of the six infants kept alive met the criteria for brain death after one week and the conclusion was, "It is not usually feasible with the restrictions of current law to produce solid organs for transplantation from anencephalic infants."²⁵ An anencephalic infant is a major source of solid organs.

Waiting for the infant to be legally dead under UDDA reduces the chances of the organ being viable for transplantation.⁶ The American Medical Association (AMA) allowed organs to be harvested before brain death if

- Parent's initiative was present.
- Two physicians with special expertise and who were not in the transplant effort diagnosed anencephaly.
- Council guidelines for transplantation of organs were followed.

This led to severe controversy and finally the AMA had to reverse its stance.¹⁴ In Europe anencephalic infants are classified as "brain absent". This nullifies application of brain death rule. Organs are immediately harvested for transplantation.¹⁶ The UAGA (Uniform Anatomical Gift Act) of 1968 mandates that the patient be brain dead before organs can be retrieved. It permits individuals above 18 to decide if they wish to be donors. It also allows the relative to allow donation if prior decision was not made. At any given time in the US alone there will be 38,000 patients awaiting transplantation, but only 4000 donors each year.²¹ In spite of all this multiple failures at all levels contribute to the great shortage of organs.²²

- Potential donors have not signed written consents.
- Existing donor cards could not be located.
- Medical personnel do not harvest organs based solely on written directives.
- Hospital does not approach families to request donation.
- Family consent not obtained.
- Medical examiners do not release bodies for organ harvest in time.
- Two major proposals are being investigated to overcome these shortcomings;⁷
- Mandated choice in which individuals are required to state if they wish to be donors at regular intervals e.g.; license renewal, income tax payments etc.
- Change of system from voluntarism to presumed consent where physicians will be allowed to remove organs for transplantation without consent unless expressly objected to by patient and family.

The Pittsburgh protocol¹ permits retrieval of organs from terminally ill and obviously hopeless patients who do not fit the whole brain death criteria. They remove life support and after 2 minutes of cardio respiratory nonfunctioning, harvest the organs. They use the fact that UDDA considers cardio respiratory and whole brain deaths as equivalent.

End of the Life Situation

Technological advances have enhanced our ability to prolong life. Without attempting to cure we can sustain bodily functions for near indefinite times. Debates are ongoing focusing on the rights of terminally ill patients to make decisions with respect to their treatment and the times and manner of deaths.

Advance Directives

This would be a written document prepared by the patient expressing his or her preferences regarding life sustaining care and who should make decisions on his or her behalf if he or she becomes unconscious. We should have a working knowledge of advance directives as we may be requested to assist prepare one or required to implement one. The idea of patient autonomy, which is the right of a competent adult to determine what, shall be done to his or her body must always be upheld. The logical corollary of the doctrine of informed consent is that the patient has the right "not to consent" i.e. refuse treatment.^{10,11} This will have a legal support in nearly all countries even if the refusal to get treated leads to death. Expanding on this theme most courts are of the position that rights of patients in making decisions regarding their care is not lost simply because they are incapacitated.^{11,15,19} This is where advance directives are most useful. Even oral statements made by the patient before being ill may be used to assess what the patient would have wanted in the particular disease and illness circumstances. Most patients will not have advance directives thus legal systems will usually enact a "surrogate consent" or "family consent". This does provide an important alternative but cannot substitute for a carefully prepared advance directive.

Discussing End Of Life Care

Patients surprisingly welcome such discussions.^{13,20} The most important contribution of this discussion is that it indicates to the patient that his physician can be relied upon as life nears its end. It is also reported that inpatients will want to discuss these situations than outpatients.¹³ **Table 1** will be useful guide to such a situation.

Do Not Resuscitate (DNR) Order

Overall, survival to discharge for hospitalized patients who received cardio-pulmonary resuscitation (CPR) is relatively low. The typical 'end of life patient (EOLP)' will be the one with multi-system organ failure, metastatic cancer, or chronic pulmonary airway disease, etc. Such patients will have survival after CPR of <1%.²⁰ We should always be neutral and accurate when dealing with EOLP as our description of an intervention can easily sway the patient's decision. It must be made clear to the patient that CPR is not a single event intervention. It should be a statement about how and in what circumstance the patient might die.

Discussing Prognosis

Most people say that they would live their life differently if they knew their life span was significantly limited. This is the most compelling reason to discuss the prognosis with the patient. Patients will usually understand explanations of statistical probability and will appreciate the limits of accuracy. EOLP are generally too ill to communicate and we will have to rely on families to make decisions.¹² We must make special arrangements to discuss with the family and document the conclusions. We must take special care of the family of the dying. They are in severe form of

Technique	Description	Example
Listen	Sit silently allowing the patient to his/her opening statement uninterrupted.	Focus on the patient and sit quietly.
Avoid jargon	Use simple words or phrases that the patient and family understand.	The medicines we are using to make sure your father's blood pressure is high enough are no longer working, telling me he is getting sicker.
Elicit values and goals of care.	Ask patients what they fear most as they face the future, or what they hope will happen.	When you think of getting sicker what worries you most?
Make emphatic statements.	Listen for and respond to emotionally laden terms, phrases or comments.	Sounds like you are really worried about being a burden to your family.

Table 1. Communicating about End of Life Care.

emotional stress and at the same time will be required to make very difficult treatment decisions. Feeding has a great cultural significance. Refusal to eat at EOLS is a normal part of dying and not the cause of death. Families will usually agree to artificial nutrition and hydration in the mistaken belief that this will prolong life and promote comfort.

Imminent Death

This would be the last 24-48 hours of life. Changes in this period, though normal to the treating physician, can be very distressing to the families because of, Cheyenne Stokes breathing; death rattle; unresponsiveness and groaning; refusal to eat etc. Straightforward explanation that this is a normal part of dying ameliorates anxiety and fear. It is very comforting for the family that the physician has anticipated and is aware of the very uncomfortable looking changes in their loved one. Grief at EOLS has been described by Elizabeth²⁷ to have five stages: 1) Denial; 2) Anger; 3) Bargaining; 4) Depression; and 5) Acceptance. There is also a universal fear among the dying that their physician may abandon them.¹⁸ Our presence itself though less technologically intensive will do lot to relieve the suffering of the patient. Physicians usually pull away from the dying patient to lessen their own sense of grief and loss.

Self Care of the Physician after Death

Care of EOLP taxes the physician. The loss experienced sometimes equals that of the family. Physicians must take adequate aftercare of themselves to cope up with such stresses regularly. The ultimate reward in caring for the EOLP is the sense of clarity about personal priorities that is derived from helping the dying. This always enriches us in many ways.

Conclusions

Clarity about the legal definitions of death is indispensable to anyone dealing with EOLS regularly. Expansion of the definition of death will continue because of ever-increasing demand to increase the organ pool and to reduce unnecessary treatments and costs. Medical

technology will continue to advance and will offer hope to critically ill, potential donors and transplant recipients. Definition of death will continue to be debated. Caring for the EOLP is taxing but also extremely rewarding. Patients will want to be more informed even in the dying period. All efforts must be made to be with the patient at the time of death.

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