

# Ethical Consideration in End-Of-Life Medicine

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## Citation

C Parmley. *Ethical Consideration in End-Of-Life Medicine*. The Internet Journal of Law, Healthcare and Ethics. 1999 Volume 1 Number 1.

## Abstract

### INTRODUCTION

With the advances of technology over the past decades, physicians, especially those who practice in the intensive care unit setting, are increasingly faced with patients who are not going to recover, but who are not going to die due to the application of modern treatment modalities. Development of life-sustaining technology brought about the expansion of the definition of death in the 1970s to include brain death. Some now argue that the definition of death should be further liberalized, while others deem it appropriate to restrict the definition back away from brain death. The concept of medical futility, a hot topic for ethicists, seems to be an outgrowth of our advancements in medical practice. While it is widely accepted that futile treatment should not be provided, many practitioners grapple with the potential for legal ramifications associated with the withdrawal of futile treatment when the very definition of futility seems to be somewhat amorphous.

Protection and guidance afforded by State living will statutes and natural death acts tends to apply when there is agreement between the physician and the patient or surrogate decision-maker regarding life-sustaining treatment. These statutes may not completely encompass situations where medical futility and disagreement between physician and surrogate decision-maker are involved. The decisions to withhold or withdraw treatment, which is keeping a patient alive, become even more complex when considered in terms of physician-assisted suicide and euthanasia. Physicians must maintain a clear distinction in this regard, as have the courts and most philosophers and ethicists.

Unfortunately, medical training often focuses on the sustaining of life with little or no training directed at providing appropriate care for the dying <sup>1</sup>. The following discussion is an overview of some ethical principles related to death, medical futility, treatment withdrawal and

euthanasia. It is intended to provide a very general view of the medico-legal and ethical frontier faced by the practice of modern critical care medicine. For those of us who feel we do a better job of practicing medicine than arguing ethics, it is helpful to work with a relatively simple set of principles and definitions. The four principles of biomedical ethics which tend to be the foundation of our ethical issues in the ICU setting are Beneficence—do some good; Non-maleficence—do no harm; Autonomy—an individual can decide for himself what will be done to his body; and Justice—health care should be allocated fairly to all. When we apply these principles to our challenging ethical situations our discussions will make more sense, and decisions can be reached more easily.

### DEATH

No doubt there was a time when nothing could be clearer than the definition of death; a person was either alive or dead. Based on traditional criteria, the loss of circulatory and respiratory function, death could be declared. Discussions about the stages or process of death tend to progress to a distinction between dying and death <sup>2</sup>. To this discussion is often added consideration of the definition of life, without which there is death <sup>3</sup>. Even when organs are alive and functioning, human life is not sustained in the absence of certain neurologic mechanisms which maintain at least vegetative functions. If these neurologic mechanisms are absent, and the brain is dead, so is the patient. This is true despite the fact that mechanical devices provide support in the absence of neurologic control of the person.

Work started in the late 1960s <sup>4</sup> eventually culminated in the Universal Determination of Death Act which incorporates brain death with death determined by traditional criteria. “An individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain,

including the brain stem, is dead. A determination of death must be made in accordance with accepted medical standards”<sup>5</sup>. The concept of brain death is widely accepted, and forms the foundation for organ retrieval for transplantation. Some believe that societal interests in improving health by organ transplantation are sufficient to further expand the concept and definition of brain death <sup>6,7</sup>.

Brain death is recognized as the loss of whole brain function, including the brainstem. Philosophical arguments based on the unique aspects of human existence would accept a definition of brain death if higher cortical functions are lost despite ongoing brainstem function <sup>8</sup>. Confusion over seemingly optional definitions of death, circulatory death or brain death, has led to the belief that the newer, brain death, definition could be further refined to encompass the permanent cessation of the critical functions of the organism as a whole. Those functions being

1. vital functions of breathing and neurologic control of circulation,
2. integrating functions of physiologic mechanisms that maintain homeostasis, and
3. consciousness, as necessary for a person to maintain hydration, nutrition and protection <sup>9</sup>.

Interestingly, such a definition of death would include individuals existing in a persistent vegetative state (PVS)<sup>10</sup>; the most vulnerable of our society, the protection of whom is a significant governmental interest. An evolutionary expansion of brain death, while of ongoing philosophical interest, is not likely to occur in the near future<sup>11</sup>.

### MEDICAL FUTILITY

In 1994 the Council on Ethical and Judicial Affairs of the American Medical Association (AMA) issued an opinion pertaining to the ethics of futile care. “Physicians are not ethically obligated to deliver care that, in their best professional judgment, will not have a reasonable chance of benefiting their patients. Patients should not be given treatments simply because they demand them. Denial of treatment should be justified by reliance on openly stated ethical principles and acceptable standards of care . . . not on the concept of “futility,” which cannot be meaningfully defined”<sup>12</sup>. Acceptable standards of care relate to the allocation of limited medical resources, and should consider the likelihood of benefit, urgency of need, change in quality of life, duration of benefit, and, in some cases, the amount of

resources required for successful treatment. Also included in acceptable standards should be consideration of the physician’s duty to provide adequate health care for society<sup>13</sup>.

The AMA’s 1994 ethical opinion regarding futile care is of particular interest in that it seems to be founded on the ethical principles of beneficence and justice, and that it indicates the difficulty in clearly defining futility. In fact, most individuals who choose to discuss medical futility acknowledge the problems in developing a truly accurate and functional definition <sup>14</sup>. Wide definitions include references to the amount of time a life may be saved, the quality of life, the probability of the treatment failing, the costs, and the nonvalidation of treatment not yet proven effective. Narrowly defined, futility can be construed as treatment which is implausible on a physiologic basis <sup>15,16</sup>.

In general, medical futility can be considered care that serves no useful purpose and provides no immediate or long-term benefit, or treatment which even though having physiologic effects, is non-beneficial to the patient as a person. Always surrounding questions of medical futility is the debate over undue physician paternalism and patient autonomy. The potential for imbalance in this area is especially present with the wider definitions of futility, which provide opportunity for the physician’s values to essentially override those of the patient <sup>17</sup>.

The issue of cost in the determination of medical futility is also problematic. Traditionally discussions regarding the ethical issue of patient care have avoided the matter of a patient’s ability to pay for treatment. Certainly a limit must be applied at some point <sup>18</sup>. While the cost of sustaining an single patient may be absorbed by a particular institution, the cost of providing such care for multitudes of such patients would be overwhelming to society. We are challenged to consider whether the use of resources to sustain a seemingly hopeless patient is at the expense of other patients who may receive greater benefit if limited resources were allocated differently. While physicians should participate in development of institutional policies controlling scarce resources, they must remain patient advocates and not make allocation decisions in specific cases. And patients should be informed of the reasoning behind decisions which limit or deny access to resources which are scarce <sup>19</sup>.

In some areas institutional policies have been developed to assist physicians and other health care providers in situations where medical care has become futile. Such policies must be

constructed to protect the patient, the institution and the individuals caring for the patient. The ultimate outcome of implementation of a futility policy would likely be withdrawal of treatment deemed to be futile; this over the objection of the patient or more often the patient's family. Many physicians are understandably concerned about such involvement. The withholding or withdrawing of treatment has traditionally been under cover of State living will statutes or natural death acts which presume an agreement between the patient or surrogate and the physician. These statutes fall short of the specific needs brought into play when medical futility is at issue.

### LIVING WILL STATUTES AND NATURAL DEATH ACTS

Although lagging behind the needs of imposed by ethical issues in modern medicine, living will statutes and natural death acts have been enacted in essentially all States. The Karen Quinlan case in 1976<sup>20</sup> was a catalyst for development of state laws which would allow patients to formally set forth desires not to be kept alive in the event of terminal illness or permanent unconsciousness. Following the Nancy Cruzan case in 1990<sup>21</sup>, the Federal government enacted the Patient Self-Determination Act<sup>22</sup> which requires all hospital that accept Federal funds i.e. Medicare, to provide patients with information regarding their rights to refuse treatment.

While virtually all states have enacted either living will statutes or natural death acts, these statutes vary widely from state to state, being shaped by input from interest groups including the right to die and right to life lobbies. Some allow for very powerful documents and others seem to be little more than window dressing without any substantive value<sup>23</sup>. In general these statutes set forth procedures for limitation of treatment, including withholding and withdrawing life-sustaining measures when a patient is terminally ill or suffers an irreversible condition. From a legal perspective, their foundation is the doctrine of informed consent; from an ethical perspective, autonomy.

Natural death acts and living will statutes set forth documentation legally sufficient to establish what is recognized as clear and convincing evidence of what an individual wishes to be done in the even of specified health situation; a living will or advance directive. The statutes also usually provide for the designation of a surrogate decision-maker. This may be through written documents known as health care power of attorney or durable power of attorney

for health care<sup>24</sup>, or if no such document has been executed, according to kinship as set forth in the statute.

A surrogate can convey the patient's express wishes, if they are known, but if not, decisions to withhold or withdraw life-sustaining treatment are still allowed in some states if such a decision would be consistent with the patient's values as expressed by the surrogate.

The surrogate decision-maker acts on behalf of the incompetent patient under the principle of substituted judgment. The decisions made are to be those that the incompetent patient would make for himself if her were capable of making the decision<sup>25</sup>. In legal terms, this is considered to be a subjective standard. The alternative, objective standard, is applied when decisions are made in what is considered to be the patient's best interest; applying terms such as "reasonable medical judgment," or "what a reasonable person would prefer." The objective and subjective standards differ largely in that the former allows for decisions to be made independent of what the patient's desires and personal values; a challenge to the individual's autonomy. Courts find that the constitutional right of privacy, which allows an individual to choose what will be done to his or her body, exists for both competent and incompetent patients, the subjective standard is consistently applied<sup>26</sup>.

Exactly what the incompetent patient would choose at time may be evident through statements made or written directives. State living will statutes and natural death acts, which set forth procedures for withholding and/or withdrawing life sustaining treatments, vary in the quality of evidence required for surrogate decision making. In the Cruzan case, the state of Missouri's requirement for clear and convincing evidence of a patient's desires was upheld by The U.S. Supreme Court<sup>27</sup>. This high evidentiary standard is not found in most State statutes.

Several problems occur with current natural death acts and living will statutes. When an individual executes an advance directive and designates a surrogate through a durable power of attorney for health care, conflicts may arise. The advance directive may clearly indicate the patient's desire not to be sustained in the event of certain irreversible conditions, yet the surrogate's decisions can be inconsistent with this expressed intent. Problems have also occurred when advance directives and documents designating surrogate decision-makers contains specific limitations in precise detail which may ultimately preclude their activation<sup>28</sup>.

Perhaps even more perplexing is the failure of living will statutes and natural death acts to apply in situations of medical futility. Frequently families will insist on continuation of life-sustaining treatment in a hopeless situation. These statutes fail because they rely on the principle of consent for a treatment decision to withhold and/or withdraw life-sustaining treatment, and the family will not agree with such a decision. With interests in promoting ethical interests of beneficence, non-maleficence and justice, many institutions have sought to develop policies to guide physicians faced with situations where futile treatment is demanded <sup>29</sup>.

### WITHHOLDING, WITHDRAWING & PHYSICIAN-ASSISTED DEATH

Although uniformity is lacking in States' living will statutes and natural death acts, there is a common general theme; withholding and/or withdrawing treatment which delays natural death is permissible. Some physicians find greater concern in withdrawing than in withholding specific treatments. Essentially though, the same reasons that justify not instituting a treatment also justify stopping it. The fear that treatment cannot be stopped once it is started may even prevent the use of potentially beneficial treatment. Court and most ethicists find no legal or ethical difference between withholding and withdrawing treatment <sup>30</sup>. This is also the position of the American Medical Association <sup>31</sup>.

Consideration of euthanasia likely is the basis of physician concern over withdrawing treatment and allowing a patient to die naturally. Physician aid in dying has become a major interest in ethicist circles <sup>32,33</sup>. Those whose arguments support an increasing physician role in assisting with the dying process, seek to eliminate the distinction between allowing a patient to die and actually killing <sup>34</sup>. Many, however recognize a clear distinction. Likewise, courts delineate a different line of individual rights and interests when considering a patient's right to die as opposed to the autonomous decision to have treatments withheld and/or withdrawn.

Courts identify a fundamental privacy right which, constitutionally protects an individual's decisions about what will be done to his body, encompassing the right to refuse treatment which will sustain life. In cases which have addressed the issue of physician-assisted suicide, Courts have relied on a lesser, liberty interest, in the recognition of an individual's right to control the time and manner of death <sup>35</sup>. Presumably this rationale will be applied in the cases

expected to flow from Oregon's 1997 Death With Dignity Act, as increasing physician assistance in patient death is seen <sup>36</sup>.

Physician-assisted suicide is very near active euthanasia, the significant difference being whether a lethal dose of medication is administered by the patient himself, or by the physician <sup>37</sup>. In consideration of euthanasia, a physician's withdrawal or withholding of life-sustaining medical treatment in accordance with a patient's wishes falls within the definition of voluntary passive euthanasia <sup>38</sup>. It is permissible to administer comfort medications to such patients, even if the medication may also compromise vital functions, which could ultimately hasten death (double effect). By contrast if the same medication is administered specifically to hasten the patient's death, the process becomes active euthanasia.

Understandably the entire patient-assisted suicide issue is seen by many as a slippery slope. Without sufficient regulation the risk to vulnerable members of society may be great, and clearly not all physicians will choose to participate in this aspect of medical practice. Concerns on this frontier however, should not impair the capability to provide medical care at the end of life in a non-maleficent way, with due recognition of patient autonomy.

### CONCLUSION

The capability of modern medicine and technology to keep patients alive has pressed physicians into an era where the very goals of medicine must be reviewed and perhaps revised <sup>39</sup>. Patients who clearly would have died in prior decades now can survive; some but not all of whom being fully restored to normal functional existence. American society adapts to and accepts many of those with less than full recovery; buildings are modified with ramps, special parking spaces and rest rooms. At some level however, survival is not associated with function recovery, or ultimately survival itself without the assistance of artificial means cannot be expected. American society and medical practitioners must focus on this area, anticipating and shaping the changes that will occur.

Medical practice which has progressed so well in answering the question of "How can we keep patients alive?" must now better answer the question "How should we allow patients to die and properly care for them?" In doing this we must remember our ethical duty to offer and provide only that care which is of benefit, not harmful, allowing patient's to retain their decision-making right, while remaining mindful of our

societal responsibility to maintain a level of care which can be available for all.

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