Introduction

Although Hippocrates typically gets the credit, it does not belong to him. The axiom, “first do no harm” was first written both in English and Latin (not Greek), in an English publication in 1860 and is attributed to the British physician, Thomas Sydenham. It translates into "above all, do no harm" (Smith, 2015). In the area of end-of-life treatment and care, the adage, along with tremendous advances in medical treatment, can present ethical dilemmas for the health care professional.

Traditional codes of medical ethics and perceptions of what physicians should do, tell us that all human life has worth, and their job is to save and preserve life. However, when balanced with quality of life concerns, should life be preserved no matter the cost? General ethical arguments have been developed to address this question. First, a distinction must be drawn between refraining from treatment that may save an individual’s life and actively causing someone’s death. Withholding life-sustaining treatment (LST) may be permissible when the patient’s quality of life is so poor, and the treatment options will create a great burden. The patient’s best interests would be better serve if LST was withheld. On the other hand, it is not permissible to lethally inject a patient with medication to end his/her life.
Third, autonomy is paramount. The patient has a right to have control over his or her life including how that life should be lived up until the time of death. From a physician’s perspective, issues arise when the patient or surrogate representing the patient’s interest demands that futile treatment is performed, or requests assistance in ending the patient’s life. Since the physician has both the duty to act in the patient’s best interest (beneficence) and also has a duty not to harm (nonmaleficence), always knowing how to advise a patient or surrogate on treatment decisions can be difficult (Ethical Issues-End of Life Decisions, 2015).

Moreover, practical considerations come into play. Until very recently, Medicare did not reimburse physicians for detailed stand-alone conversations with patients or their surrogates on advance care planning when the patient nears the end-of-life. Prior efforts to require Medicare to provide this reimbursement ran into road blocks when a vocal group argued such reimbursement would lead to “death panels” (Wolf, Berlinger & Jennings, 2015, p. 680).

The following offers guidelines on how to deal with these ethical issues and new information on reimbursement efforts, both of which should encourage physicians to competently and actively engage in end-of-life care discussions with their patients more often, resulting in better quality of care and life for their patients nearing death.

**Concrete Ethical Guidelines for The End-of-Life Care Discussion**

In 2013, the Hastings Center published revised guidelines for decisions on life-sustaining treatment and care near the end-of-life. The first time the Hastings Center had published such guidelines was in 1987. The Center revised the guidelines to “reflect the subsequent twenty-five years of empirical research, clinical innovation, legal and policy developments, and evolution of professional consensus concerning the practices and systems that can support ethically sound treatment decision-making and the delivery of safe, effective, and compassionate care near the end of life” (Berlinger, Jennings & Wolf, 2013, p. xiii). This monograph covers the guidelines as they relate to decision-making. Before discussing those guidelines, an overview of advance care planning (Advance Directives) is necessary.
Advance Care Planning in General

“A primary goal of advance care planning is to ensure that treatments are consistent with patient preferences near the end of life” (Hickman, Nelson, Moss, Tolle, Perrin & Hammes, 2011, p.1). The more thorough and informed the advance care planning, the easier it will be to formulate and implement final decisions about life-sustaining treatment and other end-of-life treatment.

Advance care planning is not only for those “facing decisions about life-sustaining treatment and those nearing the end of life but also the broader population of patients planning ahead about life-sustaining treatment and end of life care” (Berlinger et al., 2013, p. 35). The patient’s right to plan end-of-life care in advance has been a topic of discussion in the medical and legal profession for forty years. However, the 1990 Supreme Court case of Nancy Cruzan helped to fuel efforts to promote Advance Directives (Wolf et al., 2015, p. 679).

The case revolved around a dispute between Nancy Cruzan’s family and the state of Missouri. Miss Cruzan was involved in a car accident after which she was found face down in a ditch. While paramedics re-started her heart, she had apparently stopped breathing for about 15 minutes and suffered serious brain damage.

“For almost eight years, her body was rigid, and her feet and hands contracted and bent. She had occasional seizures and vomited, and while her eyes sometimes opened and moved, she showed no sign of recognizing her family. A month after the accident, a feeding tube was implanted in Miss Cruzan’s stomach to allow her to receive nourishment. She would breathe without assistance from a ventilator” (Lewin, 1990, para. 15).

Family members wanted the feeding tube removed even though their opponents accused them of wanting to starve their daughter to death. For the first time, the Supreme Court ruled an individual has a right to refuse life-sustaining treatment. However, the Court stated Missouri could require the family to establish that this was Miss Cruzan’s desire only with clear and convincing evidence (Cruzan by Cruzan, 1990). It was not until after the Supreme Court’s decision that the family was able to present this evidence. Miss Cruzan died on December 26, 1990, at the age of 33 with her family at her bedside, twelve days after the feeding tube was removed (Lewin, 1990, para. 1).
The *Cruzan* decision pointed out that at that time, in 1990, “Few individuals provide explicit oral or written instructions regarding their intent to refuse medical treatment should they become incompetent” (*Cruzan by Cruzan*, 1990, p. 289). That began to change after the decision was rendered. In the month after the ruling, the Society for the Right to Die answered nearly 300,000 requests for advance-directive forms. In response to *Cruzan*, Congress enacted federal legislation to require health care providers that received Medicare or Medicaid funding to educate patients about Advance Directives (Lewin, 1990, para. 10).

As physicians, it is not necessary to know the details of a particular legal case or statute. However, as the persons on the front line of end-of-care discussions, physicians should have some appreciation of the law surrounding this issue.

In a nutshell, Advance Directives can be documented in a Living Will, portable medical orders, an appointment of a surrogate in a Medical Power of Attorney or all of the above. Through these directives, any adult person is permitted to make decisions in advance of death regarding the withholding or withdrawal of life-sustaining procedures in the event such person should have a terminal and irreversible condition (Berlinger, 2013, pp. 3, 4 & 39). If the Living Will clearly shows a decision to withhold life-sustaining treatment, or a surrogate makes that decision, withholding such treatment is not automatic. The conditions set forth in the Living Will need to exist, and a physician will need to sign a Do Not Resuscitate Order (DNR) or other orders regarding withdrawal of care consistent with the Living Will.

While traditional Advance Directives like Living Wills and Medical Powers of Attorney have been utilized for decades now, portable medical orders have emerged in more recent years. These orders have their genesis in the Physician Orders for Life-Sustaining Treatment (POLST) paradigm.

A POLST or similar document is an order that travels with the patient and expresses the patient’s wishes in specific areas of medical care.

- Cardiopulmonary resuscitation (CPR)
- Medical interventions such as intubation, advanced airway interventions, and mechanical ventilation
- Antibiotics
- Artificially administered fluids and nutrition

(Hickman et al., 2011, pp. 1-2) Many POLST forms will directly address DNR order status. Because a POLST is signed by a physician, an additional order such as a DNR is not needed.
Hastings Center’s Guidelines for the Decision Making Process

While ideally, a patient close to death has previously documented his or her every wish covering every possible scenario that arises at the end-of-life. However, idealism is not reality. Fortunately, the Hastings Center has set forth Guidelines to assist physicians and other health care providers in the decision-making process at the end of a patient’s life.

1. Evaluating the Patient

Foremost, having one professional take on the role as the primary evaluator is critical. Adding to the confusion of a loved one’s decline is when professionals do not appear to be providing consistent information, leaving the family wondering who is really in charge (Berlinger et al., 2013, p. 44).

Imagine a hospital patient with pulmonary fibrosis and COPD, who is not doing well. There have been multiple room changes, equipment failures and like most patients, he is begging to be discharged. The family is asked to consider Hospice. The Hospice team tells the family that when he goes home, he will receive the same level of oxygen that he received in the hospital. The pulmonologist’s nurse practitioner disagrees but says the morphine will make him comfortable. The family is confused but agrees to Hospice primarily because their father has had such a difficult time in the hospital. Although, his death may have been inevitable, the fact that the professionals were not on the same page, added to the family’s anxiety and ongoing uncertainty as to whether they made the right decision.
To avoid this type of situation, a physician or possibly a physician and a nurse combination should be designated as being the responsible health care professional and thus have primary responsibility for a patient’s care. Once the responsible health care professional is identified, he or she should perform an evaluation that examines the following:

1. **The patient’s current concerns**
2. **The patient’s diagnosis**
3. **The patient’s prognosis**
4. **The treatment options (benefits and burdens) and professional’s recommendations**
5. **The patient’s capacity to understand the current diagnosis, prognosis, & treatment options**

The health care professional with primary responsibility should use loved ones and other healthcare professionals caring for the patient as resources to address these issues (Berlinger et al., 2013, pp. 44-46).

2. **Determining Decision-Making Capacity**

A surrogate should not make the decisions regarding the care of a patient unless the patient lacks decision-making capacity. A legal presumption that an individual has the capacity to make treatment decisions exists. Keep in mind, simply because the patient lacks the capacity to handle finances or personal affairs does not mean he or she lacks the capacity to make medical decisions.

When there is a significant concern about whether the patient has the capacity to make treatment decisions, the responsible professional should attempt to resolve this concern by determining whether the patient can do the following:

1. Understand his or her condition and treatment
2. Deliberate in accordance with his or her own values and goals and make uncoerced decision among treatment options
3. Communicate (verbally or nonverbally) this decision
In the case of a patient normally with decision-making capacity but who temporarily loses that capacity in an emergency situation and lacks a surrogate, a presumption that the patient consents to life-saving treatment exists unless the person has prepared a Living Will or POLST that pre-determines refusal of such treatment. When a patient lacks legal capacity, and there is a surrogate, the patient should still be involved in the process to the extent possible because one of the primary goals of the Hastings Center Guidelines is “respect for persons” (Berlinger et al., 2013, pp. 46-48).

3. Identify the Key Decision-Maker

The health care provider should assume that the decision-maker is the patient unless he or she lacks decision-making capacity. If the patient does not have this capacity, the surrogate is the decision maker (Berlinger et al., 2013, p. 48).

4. Surrogate Decision-Making

The health care professional with primary responsibility should identify the surrogate, who can be one of several individuals:

<table>
<thead>
<tr>
<th>Patient designated surrogate</th>
<th>Court-appointed surrogate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surrogate by default (family)</td>
<td>Multiple potential surrogates</td>
</tr>
</tbody>
</table>

Source: Adapted from Berlinger et al., 2013, pp. 48-49.

Issues may arise when the surrogate is someone who has been uninvolved in the patient’s care and does not know his or her preferences. The responsible professional may need to work with this surrogate to make decisions that are consistent with the patient’s explicit preferences or if these are not known, the patient’s inferred values and preferences or if none, the patient’s best interests.

What happens when the patient has no surrogate and is unable to make decisions on his or her own? These patients are often referred to as “unbefriended patients.” For these unbefriended patients that need low-risk treatments that would not require a signature consent, the provider may proceed with the treatment if: (1) it is within the broadly accepted standards of medical practice, and (2) it is based on the patient’s specific values and wishes (if known) or in the patient’s best interest.
When there is doubt, the professional should consult with either an ethics committee at the hospital or legal counsel. For treatments and procedures that require signature consent, in addition to the above, the attending physician must indicate the approval of the treatment in the progress note. For decisions to withdraw or withhold life-sustaining treatment, a curator or guardian should be appointed by the court. The health care professional with primary responsibility should not make the unilateral decision to withhold LST\(^1\) (Berlinger et al., 2013, p. 51).

To ensure clarity about the surrogate’s identity, the health care professional with primary responsibility should always document the name of that person in the medical record.

5. Making the decision at hand

This decision involves the balancing of the benefits of treatment with the burdens associated with it by considering the following:

<table>
<thead>
<tr>
<th>Benefits</th>
<th>Burdens</th>
</tr>
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<tbody>
<tr>
<td>Relief of Pain</td>
<td>Pain and suffering</td>
</tr>
<tr>
<td>Better functioning</td>
<td>The perception or prospect of loss of self, cognitive impairment or helplessness</td>
</tr>
<tr>
<td>Longer life if the quality of life is acceptable</td>
<td>Decreased ability to do meaningful things</td>
</tr>
<tr>
<td>Opportunity to do meaningful things</td>
<td>Stress including financial cost on the patient or loved ones</td>
</tr>
<tr>
<td>The possibility of specific goals being met</td>
<td></td>
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</table>

The health care professional should always tell patients or surrogates that palliative care is part of good care and can be a treatment option regardless of whether the patient or surrogate chooses to withhold LST (Berlinger et al., 2013, p. 54).

\(^1\)The process is described in Veterans Health Administration, VHA Handbook 1004.01, Informed Consent for Clinical Treatments and Procedure, paragraph 14c (1a-3d), effective August 17, 2009. This process is supported by VHA Handbook 1004.2 and VHA Handbook 1004.3, which include the VHA’s guidelines for the implementation of a decision to withhold or withdraw life-sustaining treatment. These Handbooks are available at [http://www.va.gov/vhapublications/](http://www.va.gov/vhapublications/) accessed October 31, 2015.
What happens when a patient requests treatment that has no possibility of physiological benefit or a family member asks that everything is done for their loved one regardless of the prognosis? No ethical obligation to comply with such requests when it is not in the best interest of the patient exists. In fact, providing such treatment could be a deviation in the standard of care and could constitute medical malpractice. The professional needs to be forthcoming with the patient and family about the burdens versus benefits of therapy. The longing for a cure may be based on a lack of information. Effective communication could itself resolve the ethical problem. For example, if the professional thoroughly explains the results of the treatment requested, the patient or surrogate may decline once informed. Ultimately, it may be possible to fulfill the needs or wishes of the patient through psychological or palliative modalities with input from specialists (Berlinger et al., 2013, pp. 57-58). When the conflict does not resolve, the professional should seek an ethics consultation.

Physician-assisted suicide (PAS) was first recognized in Oregon and Washington; it is now legal in five states to prescribe patient self-administered drugs to hasten death. Physician administered lethal medication may be prescribed in five countries outside the U.S., including Canada (Quill et al., 2016, p.245).

However, PAS is strongly opposed by some, including the American Medical Association and the World Medical Association. The AMA argues that it undermines the physician’s healing role. “Physician assisted suicide is fundamentally inconsistent with the physician’s professional role” (AMA Policy statement). Instead of PAS, the AMA recommends more medical education in advanced pain relief and the use of hospice care. The World Medical Association says that, “Physician-assisted suicide, like euthanasia, is unethical and must be condemned by the medical profession.” (WMA Statement on Physician-Assisted Suicide, 2015).
6. Documenting the Decision

Accurately documenting the decision to withhold LST is imperative. This not only ensures that the patient’s wishes are honored but protects everyone involved to show an adequate process was followed (Berlinger et al., 2013, p. 59). Since portable orders, like POLST, travel with the patient, accessibility when these orders are used should be automatic. The Hastings Center Guidelines recommend the use of POLST orders (Berlinger et al., 2013, pp. 62, 121).

7. Implementing the Decision

The Hastings Center Guidelines recommend that before making a final decision to withhold LST, a professional may wish to implement a time-limited trial of treatment if it is consistent with the patient’s goal of care and there is potential for benefit. The intervention can be withdrawn if it fails and the patient or the surrogate has the right to decline such a trial (Berlinger et al., 2013, pp. 55, 62).

8. Changing Treatment Decisions

The professional should inform patients or their surrogates that they can reverse their decision to withhold or withdraw LST. The professional should also be willing and prepared to discuss possible changes in the decision and should document them in the chart. If a patient or loved one informally discusses changing the decision with members of the health care team, they need to alert the responsible professional (Berlinger et al., 2013, p. 63).

9. Conflicts and Challenges Related to Treatment Decision-Making

The most problematic ethical and practical issues that arise in the end-of-life care and treatment of a patient often occur when there are conflicts in whether the decision being made is the right decision for the patient. What if the surrogate determines the patient’s life is no longer worth living, but another family member or the responsible professional believes the patient’s wishes are contrary to this position? What if there are two surrogates with equal powers in a POA, and they cannot agree on whether the patient should have surgery? The responsible professional needs to recognize and manage conflicts that arise when treatment decisions are being made.
While not every conflict can be resolved, steps can be taken to preempt conflicts from occurring or to mitigate them:

<table>
<thead>
<tr>
<th>Better communication with the patient/surrogate/family</th>
<th>Definitive clinical information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health care team being on same page</td>
<td>The responsible professional should be open-minded to concerns raised by others in the team</td>
</tr>
</tbody>
</table>

Source: Adapted from Berlinger et al., 2013, pp. 63-65

Institutions should offer resources such as ethics committees and legal counsel to help resolve unresolvable conflicts. When in doubt, the responsible professional should keep in mind that his or her first obligation is always to the patient (Berlinger et al., 2013, p. 135).

**Medicare Reimbursement**

The preceding Guidelines provide a framework that should make the physician's consultation with patients on end-of-life decision-making less difficult and ethically manageable (to the extent that it can be). Also, the Centers for Medicare and Medicaid Services (CMS) have recently taken steps to ensure that physicians are not discouraged from having these discussions due to lack of reimbursement.

“Medicare is the largest insurer of health care provided during the last year of life” (The Henry J. Kaiser Family Foundation [HKFF], 2015, para. 1). Previously, Medicare did not reimburse providers for having advance care discussions with patients if it was the sole purpose of the visit. Efforts were made to include a provision in the Affordable Care Act (ACA) to reimburse physicians for having conversations with their patients about Advance Directives. However, these efforts were side-railed by concerns that same would lead to “death panels.”

With the “death panel” controversy seemingly dormant, CMS released a proposed rule in July 2015 that includes reimbursement for “advance care planning.” Under the rule, starting January 1, 2016, Medicare will pay for annual discussions about end-of-life plans, which can lead to Advance Directives for the patient. The discussions between the physician and the patient would be voluntary. Recently introduced Federal legislation that encourages Advance Directives and end-of-life care discussions has bipartisan support.
and is, therefore, likely to pass (HKFF, 2015, paras. 8 & 9). The CMS rule and federal legislation are “monumental in signaling a new federal willingness to intervene in a historically divisive health care arena” (Halpern, 2015, para. 3).

Recommendations

In conclusion, the foregoing should encourage physicians to do the following in treating patients nearing the end of their lives:

— Physicians should have a general understanding of advance care planning tools available to their patients. Living wills, Medical Powers of Attorney, and portable medical orders (or POLST) document the patient’s wishes but operate differently. The Hastings Center recommends portable medical orders that transfer with the patient, typically document more specifics regarding desired treatment, and eliminate the need to review a Living Will or contact the surrogate to determine what orders should be written to match the patient’s desires. A POLST is already a physician’s order.

— If they are not doing it already, physicians should start having annual stand-alone discussions with their interested patients who are nearing the end-of-life. Such discussions, reimbursable by Medicare starting on January 1, 2016, will hopefully lead to advance directives that ward off the uncertainties of the patient’s treatment wishes as they approach death. When possible, surrogates and family members should be involved in these discussions to ensure they are aware of the patient’s desires.

— Communication with the patient and his/her surrogate should not end with the stand-alone discussions. Dying is a process that can be short or long. Decisions can be changed along the way. Unless the patient and/or surrogate remains fully informed about the benefits and burdens of treatment at the precise time the decisions need to be made, uncertainties may trigger uninformed decisions adverse the patient’s best interest, create conflicts that may otherwise not exist, and/or ultimately add stress to an already taxing situation.

— Often a patient who is seriously ill and nearing death will be treated by multiple specialties. However, one physician or a physician and nurse combination should be designated as the responsible health care professional and have primary responsibility for the patient’s care near the end-of-life. The responsible health care professional should keep other members of the health care team informed and be receptive to input from those team members.
Bibliography: Withholding Life Sustaining Treatment, an Ethical Paradox?

Note: Web links can change over time. If link no longer works, web-search the article by title.

Additional Resources

- JAMA for the week of January 19, 2016 titled Death, Dying, and End of Life is entirely dedicated to end of life and physician assisted suicide issues.

Reference List


