

ETHICAL CONSIDERATIONS IN END-OF-LIFE CARE: A PHYSICIAN'S PERSPECTIVE

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ABSTRACT

This article discusses ethical issues during end-of-life care in hospitals. The commonly used medical-ethics framework for ethical reasoning comprising of autonomy, beneficence, non-maleficence and justice is somewhat limited in guiding healthcare decisions. The continuing advancement in medical technology, current medico-legal environment, longer life-expectancies and increasing contextual awareness are some of the reasons why this ethical framework is limited. In addition to this, the high costs involved in end-of-life care make limit-setting decisions necessary. In order to be well received, these decisions need to meet the four conditions of accountability for reasonableness namely – publicity, relevancy, revision and appeal, and regulation. There are many stakeholders in decisions pertaining to end-of-life care besides the patient, with their own unique perspectives that complicate the situation. The article provides examples of ethical conflicts, the relevant stakeholders, factors that influence these unique perspectives and the potential for politicization of issues. The author touches on the subject of physician-aid-in-dying and concludes with a few recommendations for healthcare organizations to effectively deal with ethical issues during end-of-life care.

KEYWORDS

Ethics, End-of-life, Healthcare,
Medical decisions, Patient,
Physician

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Introduction

End-of-life care refers to all the health care provided to someone in the days or years before death, whether the cause of death is sudden or a result of a terminal illness that runs a much longer course. Caring for patients at the end of life is a challenging task that requires not only the consideration of the patient as a whole, but also an understanding of the family, social, legal, economic, and institutional circumstances that surround patient care. The most common framework for ethical reasoning here involves four guiding principles of medical ethics:

1. *Autonomy* – Applies to the patient where an informed patient is enabled to participate in medical decision making and direct his or her own care. A patient's authorized surrogate decision-maker can also participate in the decision-making, if it can be reasonably established that the surrogate decision-maker truly represents the patient's previously established preferences, even if extrapolated from values or proximate wishes that the patient previously held.
2. *Beneficence* – Mandates clinicians to always act in the best interest of their patients.
3. *Non-maleficence* – Applies to physicians: first, do no harm.
4. *Justice* – Applies to all stakeholders, addressing the need to be treated well and fairly. It also touches on the equitable use of health resources.

Issues

Approximately 2.5 million Americans die each year in the United States (Meisel, 2008). Most adults (90%) say they would prefer to receive end-of-life care in their home if they were terminally ill, yet data shows that only about one-third of Medicare beneficiaries (age 65 and older) died at home (Teno, et al., 2013). Only 15–20% of Americans have written advance directives such as living wills (Meisel, 2008). Even when there are advance directives in place, their usefulness is questionable as they tend to be either too general or too specific in relation to issues at hand. Medicare spends about

a quarter of its budget for services provided to its beneficiaries in their last year of life – a proportion that has remained steady for decades (Rile & Lubitz, 2010; Hogan, Lunney, Gabel & Lynn, 2001).

This presents a challenge for administrators and clinical leadership within a healthcare organization who want to facilitate provision of compassionate end-of-life care, while avoiding costly interventions that do not add real value. The four guiding principles of bioethics are indispensable, but often prove insufficient to guide healthcare decisions, especially in the end-of-life care setting due to multiple factors including (Lorenzl, 2013):

- Rapid advancement in medical technology.
- An increasingly scrutinized and punitive medico-legal environment.
- Increase in life expectancies despite significant medical and functional impairment
- Increase in overall cultural, ethnic, economic and religious awareness

The relevant stakeholders in case of end-of-life care issues include the following:

Patient. He or she is central to all the related issues. A patient's perspectives can be influenced by multiple factors including personal values, family values, ethnicity, religion, cultural background, educational status, socio-economic status, previous experiences and overall outlook on life to name a few. A patient may feel pressured to satisfy other stakeholders and end up making decisions that do not reflect his or her actual wishes.

Family members. The same factors that can influence the patient's perspective can also affect the family member's assessment of the situation. They usually have the best interest of the patient at heart but may end up making decisions biased by above factors that may not reflect patient's actual wishes. In addition to the above factors, there are intrapsychic, interpersonal, and family history factors that frequently and significantly color family members' representations of the dying person's preferences. Often it is difficult, without some form of counseling or introspection, for family members

to distinguish their own preferences, whether based on guilt, unfinished personal or business agendas, displaced fear or other emotions, from their terminal family member's.

Provider. Physicians, in their role as an agent, need to recommend what is best for their patient. They are the ones who are usually caught in the middle of most ethical conflicts. Their perspectives can be influenced by their training, past experiences and an increasingly polarized and scrutinized medico-legal environment surrounding healthcare. Due to the above factors, physicians may feel obligated to provide care even if it is medically futile

Hospital administrators. They do not commonly have any direct patient contact and hence their perspective is usually influenced by organizational policy and managerial resource assessment tools. Their perspective is shaped more by organizational pressures and ethical issues, including budget and staffing related concerns rather than clinical ethics.

Community. The community is indirectly impacted in the context of allocation of resources. Each dollar spent on futile care is a dollar taken away from other community benefits. This is where setting limits fairly becomes necessary, given the following four conditions of accountability for reasonableness are adequately met when limit-setting decisions are made (Daniels & Sabin, 2002):

1. **Publicity:** The decisions and the grounds for making them must be made public to ensure transparency
2. **Relevancy:** The decisions must be relevant to meeting healthcare needs fairly under reasonable resource constraints:
3. **Revision and appeal:** The decisions must be subject to revision and appeal and process of doing so must meet the first two conditions
4. **Regulation:** There must be some form of regulations to ensure that the above three conditions are met

The ethical conflicts during end-of-life care present in many ways. A particularly challenging ethical situation that I faced at my work involved an 83-

year-old female, whom I had admitted for respiratory distress and altered mental status. On review of her chart, she had a DNR (Do Not Resuscitate) order entered on the last two admissions, about a year prior to the current admission. The hospital policy requires the "Code status" to be confirmed every time a patient is admitted, but due to her altered mentation and failure to reach any of her family members or a surrogate decision maker, this could not be done. After discussing this situation with the hospital administration and the ethicist, it was decided that patient should be a "full code" or in other words should receive CPR as indicated until her DNR status can be confirmed for the current encounter (or admission). Unfortunately, the patient ended up coding and received CPR the same night. In my view, we did not make the best decision for the patient despite all the policies and procedures in place. I believe a major blame goes to the current medico-legal environment, where organizations and providers faced with an ethical conflict immediately go into defensive mode and are hesitant to do the right thing for fear of litigation. Some other examples of ethical conflicts in relation to end-of-life care are as follows:

- Is it ethical to do everything possible in order to keep a patient alive on family request when there is an advanced directive on file stating "No life prolonging measures"?
- Is it ethical to give high dose pain medications, knowing that it will hasten death?
- Is it ethical to perform CPR and provide life support to a patient if the chances of survival and decent quality of life thereafter is miniscule?
- For a patient who is on life support, is it ethical to withdraw life support if chance of future survival and decent quality of life is miniscule
- Is it ethical to hide a patient's terminal diagnosis from him or her at the family's behest?
- Is it ethical to withhold a medical intervention if to do so goes against a provider's moral values?

- Is it ethical to not resuscitate a patient who does not have decision making capacity but has expressed a desire for or against resuscitation in the past when no surrogate decision maker is available?
- Is it ethical for a physician to refuse participation in physician-assisted death if requested by a terminally ill patient?

Conflicts between values of different stakeholders typically arise when patients lack decision-making capacity. This can lead to different interpretations of their preferences by loved ones and their clinical providers. Clear policies and lines of communication along with due process to address these issues can resolve some of these issues at the organizational level but not always. A conflict could arise between Winkler and Gruen's (2005) first principle of organizational ethics, "spend resources reasonably," and the bioethics principles of patient's autonomy, beneficence and family's need for justice. As we extend these conflicts and start looking at them through Potter's (1996) concentric circles of organizational and community ethics, the situation becomes more complex. Proponents on one side of the fence contend that an individual's decision to continue medical care at the end of life must be weighed against the cost-benefit ratio, and such treatment may be denied if it will provide little or no benefit, especially when the cost is borne by the society (e.g., by taxpayers through Medicare, Medicaid and other public programs). The opponents of this position claim that such "rationing" of care violates the physician's professional obligation to act solely in the patient's best interest. The physician's obligation is a balance between several factors, not the least of which is the patient's best interest, but also justice and the larger community needs. Does the common assumption that physicians should act solely in the patient's best interest need to change?

In 2016, Medicare will begin covering advance care planning—discussions that physicians and other health professionals have with their patients regarding end-of-life care and patient preferences—as a separate and billable service (Kaiser Family Foundation, 2015). When a previous, similar issue

was discussed, the phrase "death panels" was widely used to politicize this sensitive issue. The same ethical issues that sometimes seem straightforward from the lens of bioethics, become very complicated at the community and policy level. Empowering patients and families with information that can help them understand the bigger picture is one the most important ways to simplify these issues and prevent them from being politicized.

Physician aid-in-dying is a subject that warrants special mention when it comes to end-of-life care issues. Many providers, especially those in the fields of Oncology and Palliative Care are faced with request for assistance in dying by terminally ill patients. The inherent values can be contrasting on both sides. This represents a conflict between a utilitarian argument that it is justified because the patient requested it to spare him a painful death. Contrasted with this is a deontological argument that clinicians have a duty to not participate in actively ending a patient's life. No matter what the provider's ethical or moral position on this issue is and regardless of whether these practices are legally permitted or prohibited in a given jurisdiction, providers have a duty to carefully consider and decide how they will respond to these requests in accordance with the organization's policy. There is broad consensus that health professionals are not obligated to participate in care that they find morally objectionable.

Healthcare organizations deal with ethical issues on a regular basis. These issues tend to become more complicated in cases involving end-of-life care. The following recommendations can help healthcare organizations deal with these issues more effectively:

- A dedicated ethics committee that follows a multistep ethical decision-making process where the ethical conflict is identified and relevant information discerned.
- Clearly defined mission and vision statements that can guide decision-making in times of conflict.
- Clearly outlined, comprehensive policies that are directly applicable to end-of-life care decision-making.

- Entering “Code Status” for all patients in the health record at the time of admission so that there is no conflict regarding care at the time of an emergency.
- Identify and enter contact information of a surrogate decision maker as soon as able following admission to the hospital.
- Include provision for a nursing referral to palliative care, so that palliative needs of the patient can be addressed at multiple levels.

Conclusion

Healthcare expenditures in the last year of life do not provide commensurate value in terms of comfort and quality of life. End-of-life care follows the clinical ethics framework consisting of four guiding principles – autonomy, beneficence, non-maleficence and justice. The framework becomes increasingly complex as we extend these issues to the level of the organization, community and national policy. Comprehensive policies, procedures and dedicated ethical committees are essential at the clinical and organizational level to resolve the many ethical conflicts related to end-of-life care. However, beyond that, empowering the stakeholders with relevant information beforehand can play a vital role in simplifying these ethical issues and prevent them from being politicized.

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