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SPECIAL FOCUS SECTION

# Ethical Issues at the End of Life

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**Providing good care for dying patients requires that physicians be knowledgeable of ethical issues pertinent to end-of-life care. Effective advance care planning can assure patient autonomy at the end of life even when the patient has lost decision-making capacity. Medical futility is difficult to identify in the clinical setting but may be described as an intervention that will not allow the intended goal of therapy to be achieved. Medical interventions, including artificial nutrition and hydration, can be withheld or withdrawn if this measure is consistent with the dying patient's wishes. Physicians caring for terminally ill patients receive requests for physician-assisted suicide. The physician should establish the basis for the request and work with the healthcare team to provide support and comfort for the patient. Physician-assisted suicide could negate the traditional patient-physician relationship and place vulnerable populations at risk. Physicians need to incorporate spiritual issues into the management of patients at the end of life. The integrity of the physician as a moral agent in the clinical setting needs to be recognized and honored. The physician has a moral imperative to assure good care for dying patients.**

**(Key words: end-of-life care, ethics, palliative medicine, advance care planning)**

Physicians and other healthcare professionals providing care for dying patients will confront many ethical dilemmas and challenges. Providing good care to dying patients requires physicians to be knowledgeable of potential ethical dilemmas and be aware of strategies and interventions aimed at avoiding conflict. It is important for the physician to be proactive with regard to decision making and have good communication skills. Keeping the patient central in all decision making, that is, respecting patient autonomy, is essential to ethical care for dying patients. Thus, the role of advance care planning is important in caring for patients at the end of life. The physician needs to have a good understanding of ethical principles and issues such as medical futility and the withdrawing and withholding of medical interventions as well as the legal ramifications of these ethical issues. With the growing attention on physician-assisted suicide and euthanasia, physicians need not only to be knowledgeable of the ethical, legal, and professional ramifications of these issues, but also to have a clear understanding of their own beliefs on this and other ethical issues at the end of life.

Good care for dying patients also encompasses attention to spiritual issues at the end of life. Therefore, physicians need to be comfortable with their role regarding end-of-life care and spirituality. It is important that physicians have an understanding of the ethical principles that underlie biomedical ethics and how they relate to providing care for dying patients.[1] Providing good care to dying patients is an ethical mandate inherent in the very nature of the physician's role. As indicated in the 18th Century by John Gregory, "It is as much the business of a physician to alleviate pain as to smooth the avenues of death...as to cure disease."[2]

## Ethical Principles and End-of-Life Care

An understanding of the principles that underlie biomedical ethics is important in addressing the issues that confront physicians and their patients at the end of life. The ethical principles include autonomy, beneficence, nonmaleficence, justice, and fidelity (*Figure 1*).

If one of the ethical principles could be viewed as central to ethical decision making, *autonomy* would meet that description. Autonomy calls for the patient to be the decision maker, that is, having the right to self-determination. This principle calls for physicians to preserve a patient's right to self-determination even when the patient has lost decision-making capacity. This preservation can be achieved through the appropriate use of advance directives. Because of the difficulty physicians and patients have in discussing end-of-life issues, physicians frequently resort to caregivers to make decisions in lieu of the patient. This action may be a violation of the principle of autonomy if the patient still has decisional capacity and has not authorized a surrogate decisionmaker, or if the patient no longer has decisional capacity and the decision maker was not designated by the patient or is unaware of the patient's wishes.[3]

The ethical principle of *beneficence* calls for the physician to advocate for what is good or beneficial for the patient. Fre-

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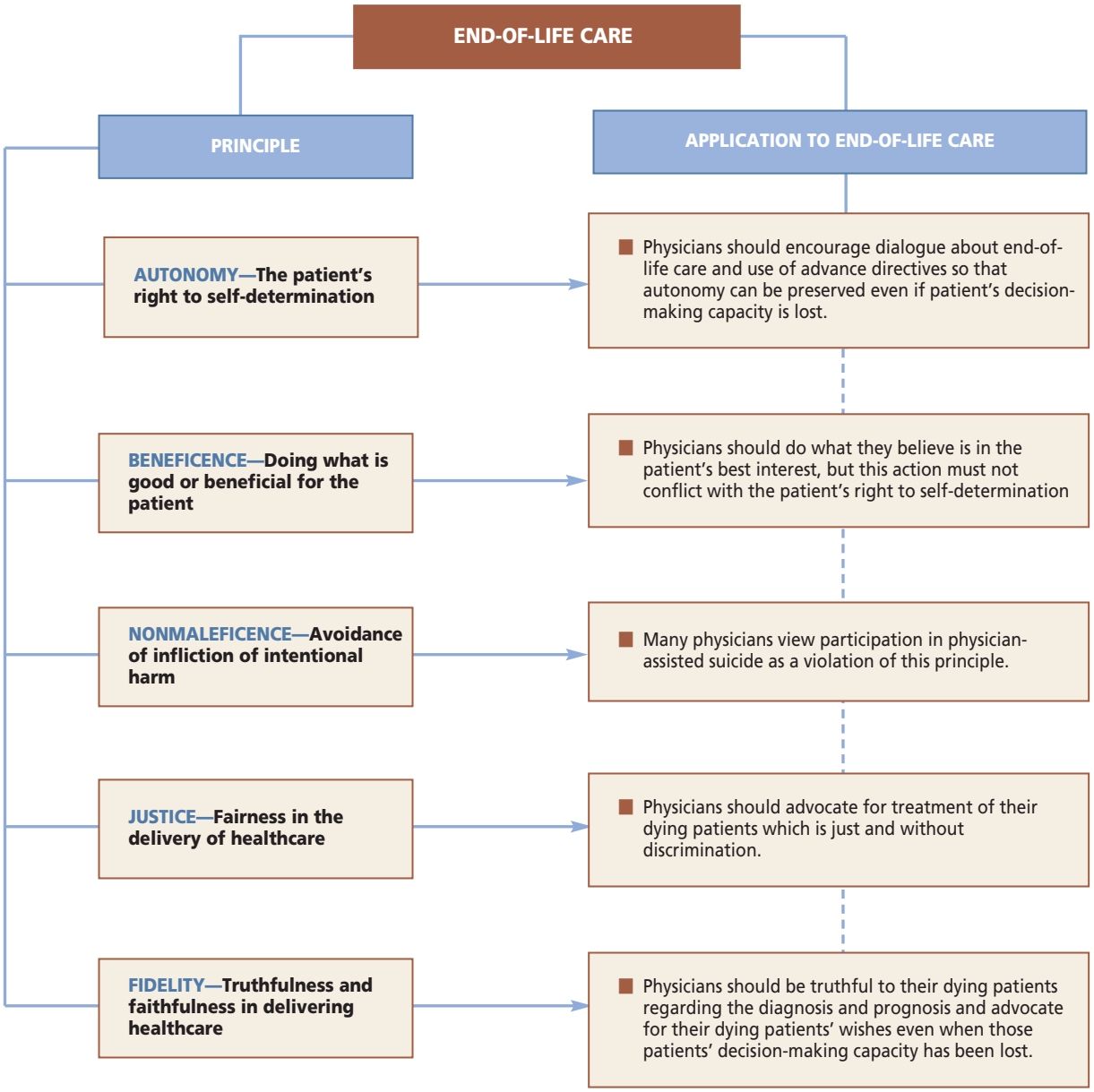


**Figure 1.**

quently, patients' choices regarding end-of-life decisions have not been expressed through advance care planning and caregivers who are knowledgeable of the patient's wishes may be absent. In this case, the physician's role for the dying patient must always be to advocate for approaches that promote good care for the patient at the end of life. The physician needs to be careful that patient autonomy must not be violated in an attempt to do what the physician views is in the patient's best interest. The patient's desire to choose an option should be respected even if the physician views the option as not in the patient's best interest. Thus, patient autonomy should prevail over paternalism.[1]

The principle of *nonmaleficence* calls for the physician not to inflict harm intentionally. This principle relates to a basic maxim in good medical care, *Primum non nocere* ("above all, do no harm"[1]). Many physicians view participation in physi-

cian-assisted-suicide as a violation of this principle.[4,5] This position is reflected in the Osteopathic Oath required of all graduates of colleges of osteopathic medicine, which states "I will give no drug for deadly purposes to any person though it may be asked of me."

The ethical principle of *justice* demands fairness in the delivery of healthcare. It may apply on a societal level by assuring a just distribution of healthcare resources, or it may apply to an individual patient by assuring fair treatment to that patient at the end of life. In either case, physicians have an ethical obligation to advocate for fair and appropriate treatment of patients at the end of life.

The last ethical principle, *fidelity*, requires the physician to be faithful and truthful to the dying patient. The physician should provide ongoing information about the patient's condition when appropriate. Also, the physician needs to be truthful in issues such as diagnosis and prognosis and be faithful in defending the choices and decisions of the patient even when the patient can no longer speak for himself or herself. This defense, of course assumes that the patient's request not violate the physician's own moral code or values.[1]

## Advance Care Planning

Effective advance care planning is important in providing good care at the end of life because it enhances a discussion of end-of-life issues between the patient, physician, and caregivers. Perhaps even more important, it provides the mechanism to honor the patient's wishes even at a time when the patient may lack decision-making capacity. Therefore, effective advance care planning can promote patient autonomy.[3]

The Patient Self Determination Act passed by the US Congress in 1990 has had a significant impact in bringing attention to advance care planning through the use of advance directives. As part of the Omnibus Budget Reconciliation Act, this act requires institutions receiving Medicare and Medicaid reimbursement to inform patients about the use of advance directives. Whether the Patient Self-Determination Act has been successful in promoting advance care planning is a question that is still uncertain; however, it clearly has introduced this important subject regarding end-of-life care. Many believe that advance care planning can be most effective when not linked to an institutional setting but when it is part of the important dialogue between patients and their primary care physicians in the community setting.[6]

Discussions regarding the patient's wishes for care at the end of life are critical for advance care planning. Advance care planning can prevent confusion and conflict when end-of-life decisions need to be made. Without effective advance care planning, the physician is at risk of providing interventions that the patient may not have wanted. Alternatively, the physician may end up in the middle of conflict between the patient's caregivers. Advance care planning can be achieved through appropriate use of advance directives. Advance directives may be in the form of oral statements by the patient, through a living will, or by the identification of a surrogate proxy decision maker. Oral statements regarding end-of-life care consist of an expression of the patient's wishes for care at the end-of-life. It is important that oral statements be carefully documented in the patient's medical record. The living will, or instruction directive, is a written document that identifies the patient's wishes for end-of-life care. Both oral statements and the living will may include and address issues such as pain management, location for end-of-life care, acceptance or rejection of life-sustaining interventions, or even issues related to organ transplantation. One of the pitfalls to written communication of end-of-life care is the challenge of appropriate interpretation of the patient's wishes. The identification of a surrogate or proxy decision maker calls for the patient to identify someone who can make decisions when the patient has lost decision-making capacity. This is referred to as the proxy directive. It is important for the proxy decision maker to be aware of the patient's wishes regarding end-of-life care. Therefore, effective communication on end-of-life issues between patients and their proxy decision makers must be encouraged.[7]

Variations exist among states regarding laws related to the requirements for advance directives. Physicians must therefore be aware of local legislation to assure the legal status of an advance directive. Physicians and their patients should review advance directives regularly, particularly as the end of life approaches. The discussion should also include proxy decision makers. It is generally recommended that advance care planning include all three forms of advance directives. Advance care planning will enable the patient's values and goals to be identified and documented; it can build trust between the patient, physician, and caregiver; it will aid in preventing confusion and conflict in the future; and it can provide peace of mind for the patient. Many standardized advance care planning and advance directives are available to aid in effective planning. Standardized forms may emanate from state agencies, healthcare organizations, and advocacy or religious groups. Research is under way to identify the most effective format for advance care planning.[8]

Effective advance care planning should include both patient and proxy education. The physician has a key role in carefully explaining the benefits and burdens of interventions near the end of life so that patients can make informed decisions regarding refusal or acceptance of these interventions. Common pitfalls related to advance care planning frequently result from the patient's preferences being unclear; the proxy decision maker not being informed or educated regarding the patient's preferences; and the failure of the advance care

planning discussions to include a broad array of issues frequently confronted at the end of life. Thus, conflicts may arise between the physician, other healthcare professionals, the proxy decision maker, and the family regarding the patient's care at the end of life. This conflict often occurs after the patient has lost decision-making capacity and frequently involves the proxy decision maker. Ethics committees are often helpful in resolving disagreements. Effective advance care planning will often avoid such conflict.[9]

In addition to the role of advance care planning in clarifying healthcare issues at the end-of-life, advance care planning may also include issues such as financial and legal affairs, final gifts, and issues such as spirituality, autopsy, burial, memorial services, and guardianship. Effective advance care planning should involve input from other professionals such as social workers, attorneys, and the clergy. Advance care planning for patients at the end of life will not only uphold and support patient autonomy, but it also will promote the ethical principles of fidelity and beneficence by enabling the physician and proxy decision maker to honor and support the patient's wishes and values at the end of life.[1,9]

## Ethical Issues in End-of-Life Care

The management of patients at the end-of-life will involve several issues that can be challenging ethical dilemmas. These may include issues such as withdrawing and withholding of interventions, medical futility, and physician-assisted suicide.

### *Withdrawing and Withholding Interventions*

The withdrawing and withholding of life-sustaining treatment in the management of patients at the end of life may be appropriate both medically and ethically. First, certain interventions may simply be medically futile, in which case there are no ethical, legal, or medical requirements to administer care that offers no benefit. Second, it is appropriate to withdraw and withhold treatment that is not wanted by the patient or the patient's proxy decision maker. Physicians often have difficulty withdrawing interventions that have already been initiated. However, if an intervention can no longer achieve its intended goal or the patient no longer wants this specific intervention, the intervention should be withdrawn. Thus, from an ethical perspective, withholding and withdrawing treatment are moral equivalents.[7,9]

Although end-of-life care involves a team approach, the physician is the only member of the healthcare team who is authorized to write orders identifying interventions that are to be withheld or withdrawn. Therefore, it is important that physicians are knowledgeable about the principles of withdrawing and withholding interventions in caring for patients near the end-of-life. Unfortunately, a recent study demonstrated that the majority of patients in the intensive care unit setting die without attention to their wishes regarding life-sustaining treatment. Often, invasive medical interventions are administered against the previously stated wishes of these patients.[6]

The decision to withdraw or withhold cardiopulmonary resuscitation, elective intubation and mechanical ventilation, and artificial nutrition and hydration are issues frequently encountered in the management of patients near the end of life. However, other interventions that may be withdrawn or withheld could include surgery, dialysis, antibiotics, diagnostic tests, medications, or admissions to acute care facilities. A decision to withhold or withdraw a specific medical intervention is based on whether that intervention is able to achieve a goal established by the physician, the patient, and the proxy decision maker. From a medical perspective, the goal must be reasonably achievable and realistic. It is acceptable to agree to a specific intervention that is time limited and withdraw that intervention if the goal has not been achieved within the time specifications. For example, a time-limited use of mechanical ventilation may be appropriate if its benefits could not be achieved in a specified time.[9]

The decision to withdraw ventilator care may be challenging for the physician, the patient, and the proxy decision maker. Once the goal for artificial ventilation can no longer be achieved, it is ethically acceptable to withdraw ventilator care as long as this is consistent with the patient's wishes. Methods for immediate extubation or terminal weaning have been described, and management of symptoms with narcotic analgesics and anxyiolitics are important for patient comfort post-extubation. Establishing the do-not-resuscitate (DNR) status of the patient at the end of life is important to avoid unnecessary and unwarranted cardiopulmonary resuscitation. However, it is important to assure the patient and the caregivers that all other interventions aimed at providing care and comfort at the end of life will continue.[9]

Withdrawing and withholding of artificial nutrition and hydration require special consideration. For many years, physicians and other healthcare professionals have viewed the provision of nutrition and hydration, even for the dying patient, as standard, obligatory care. However, both from an ethical and a legal perspective, artificial nutrition and hydration are viewed as any other medical intervention. The decision to withdraw or withhold them can be burdensome, particularly for families, as the provision of nutrition and hydration has traditionally been a symbol of caring. When artificial nutrition and hydration no longer can achieve the overall goals of care, they can be withheld or withdrawn based on the decision of the patient or proxy decision maker. It is important for the physician to reassure, counsel, and educate the patient and the patient's proxy decision maker when confronted with this dilemma. Families need to understand that

signs and symptoms such as dry mouth can be effectively managed and that often the administration of fluids may actually exacerbate other symptoms at the end of life, such as shortness of breath or pain caused by edema.[1,7,9]

## Medical Futility

The issue of medical futility is a clinical situation in medical ethics that may pose challenges in providing care at the end of life. Reference to an intervention as being medically futile is a common description; however, clear definitions of medical futility are still lacking and few clinical scenarios exist in which there may be uniform agreement that a specific intervention is medically futile. For example, most would agree that providing cardiopulmonary resuscitation to a patient who is determined to have brain death would be futile. In contrast, there would not be uniform agreement that the provision of artificial nutrition and hydration to a patient in a persistent vegetative state would be medically futile. Yet, either of these interventions may be considered medically futile, depending on one's definition of medical futility. Thus, unequivocal cases of medical futility are not commonplace.[11]

Although a precise definition of medical futility has been described as an intervention that is ineffective more than 99% of the time or an intervention that does not conform to accepted community standards, a more workable definition describes medical futility as an intervention that will not enable the achievement of the intended goal of the intervention. Thus, in this latter description of medical futility, an intervention is considered useless if it does not conform to the patient's expressed wishes or advance directive if the patient has lost decision-making capacity.[12]

Conflicts regarding futility frequently arise when the dying patient has lost decision-making capacity and decisions about healthcare lie in the hands of the proxy decision maker. Conflicts may result because of the proxy decision maker's misunderstanding of the prognosis, difference in values, or loss of trust in the healthcare system. Often, conflicts can be resolved through education, clarifying the goals and intent of the patient and by encouraging a team approach to decision making after involving clergy. The institutional ethics committee may be a valuable resource for conflict resolution. When a conflict cannot be resolved, a transfer of service may be indicated. On most occasions, effective advance care planning can avoid conflicts related to medical futility.[9,11,12]

## Physician-Assisted Suicide

Most physicians involved in end-of-life care have received requests for physician-assisted suicide. Physician-assisted suicide involves the physician's providing the means to end the patient's life, usually by prescribing a lethal dose of a sedative-hypnotic medication that the patient self-administers. In contrast, euthanasia involves the physician's performing the intervention that takes the patient's life. Currently, physician-assisted suicide in the United States is legal only in the state of Oregon. Although a slight majority of physicians oppose physician-assisted suicide, most physician professional organizations such as the American Osteopathic Association, American College of Osteopathic Internists, American Medical Association, and American Geriatrics Society have identified physician-assisted suicide as morally unacceptable and a violation of the patient-physician relationship.[13,14] Until recently, this relationship has not embraced the provision of a means for ending life. Many believe that acceptance of physician-assisted suicide will negate a societal commitment to hospice care and palliative medicine. Also, many indicate that abuse of vulnerable populations such as the elderly and disabled will occur.[4]

Patients may request physician-assisted suicide because of intractable pain, depression, fear of being a burden on their family, or fear of loss of their dignity. It is important that the physician identify the underlying cause of the patient's suffering. Depression should be assessed and managed, and other professionals such as psychiatrists, psychologists, and the clergy should be engaged when appropriate. Patients should be reassured that physical symptoms such as pain can be effectively managed. Spiritual symptoms of guilt, loss of purpose in life, and abandonment often can be addressed by including the chaplain as part of the healthcare team. The physician should address common fears that the patient may exhibit which lead to the desire for physician-assisted suicide. It is important that the physician work as part of a healthcare team in addressing the varied etiologies that lead to a patient's request for physician-assisted suicide. Through a team approach, nearly all the reasons for which patients may request physician-assisted suicide can be addressed effectively. It is important for the physician to provide support and a commitment to dying patients that they will not be abandoned and their symptoms will be managed throughout the dying process. Physicians must be cautious not to affirm the patient's request for physician-assisted suicide as the request frequently emanates from the patient's feelings of self-worthlessness. Therefore, the patient could interpret the physician's affirmation as supporting that perception of self-worthlessness.[9,15,16]

A survey of osteopathic physicians conducted by my colleagues and me revealed that most opposed physician-assisted suicide (unpublished data). In fact, many cite the holistic and the mind-body-spirit approach to care that characterizes osteopathic medicine as being integral in shaping their view of the issue. Also, many osteopathic physicians indicated that the Osteopathic Oath that they took at graduation had an impact on their view opposing physician-assisted suicide.

**RECOMMENDATIONS FOR ETHICAL CARE AT THE END OF LIFE**

- Adhering to the dying patient's right to self-determination (autonomy) is central to ethical care at the end of life.
- Advance care planning, through a living will and identification of a proxy decision maker, could enable the patient's wishes to be upheld even when patient's decision-making capacity has been lost.
- Conflict regarding end-of-life decisions can be avoided with effective advance care planning, proper education, and good communication between the physician, patient, and caregivers.
- Medical futility may be best described as an intervention that will not enable the achievement of the intended goals; therefore, futile interventions should be avoided in the care of dying patients.
- Withdrawing an initiated intervention has the same ethical significance as withholding an intervention that has not been initiated.
- The provision of artificial nutrition and hydration should be viewed as analogous to other medical interventions.
- Requests for physician-assisted suicide typically reflect an outcry for help resulting from an unidentified problem; the physician is in a key role to identify the issue and address the underlying needs of the patient.
- Effective management of pain at the end of life is a critical role of the physician; the principle of double effect allows for aggressive pain management even at risk of hastening the dying process.
- The physician is a moral agent who serves a major role in the ethical decision-making process; therefore, the physician's values and ethical standards also need to be respected.
- The physician should recognize the importance of spiritual issues at the end of life, be aware of how to do a spiritual assessment, and facilitate available resources for the patient's spiritual care.
- Because the inherent patient-physician relationship calls for physicians to provide care and comfort to their patients, physicians have an ethical obligation to assure the provision of good care for their dying patients.

**Figure 2.**

## Pain Management and the Principle of Double Effect

Traditionally, there has been reluctance on the part of physicians to use higher doses of narcotic analgesics in terminally ill patients because of a fear of causing death due to central nervous system depression. Some have viewed this administration of such medication as euthanasia. Data have indicated that this effect has largely been overstated. Nevertheless, even if administration of a narcotic analgesic may hasten the dying process in patients who are near death, as long as the prime intention of administering the narcotic analgesic is for the purpose of pain management and not the purposeful hastening of death, it is ethically acceptable to administer the analgesic. In this case, the ethical principle of the double effect allows for the unintended, secondary consequences—that is, the hastening of death—because of the good primary intention of the principle intervention—that is, pain management. One assumes that the patient or proxy decision maker is aware of the unintended consequences of aggressive pain management.[1]

## The Ethical Integrity of the Physician

The physician's role as a moral agent in medical ethics is frequently overlooked. Although few argue about the centrality of patient autonomy as it relates to ethical decision making, one cannot lose sight of the fact that the physician is an integral agent in moral acts that take place in healthcare. Therefore, physicians should not be compelled to violate ethical convictions or religious beliefs at the request of a patient or the patient's caregiver. When a patient indicates requests or desires for interventions that may violate the physician's own conscience or ethical standards, the physician should recognize and discuss these differences at the outset. When a patient and physician are at odds regarding proceeding with care that the patient requests, the patient should seek another healthcare provider and the physician should assist and support the transition.[17]

## Spiritual Issues and End-of-Life Care

Physicians frequently hesitate to ask their patients questions about spiritual issues, yet spirituality may become central to a patient near the end of life. Spirituality may span affirmation of specific religious beliefs to simply making sense or identifying meaning in life. It has been recognized that patients at the end of life could experience significant spiritual growth. The physician should explore the patient's past and current spiritual life, whether the patient would value a visit from a clergy person, and the importance of religious rituals to the patient. Physicians should be aware of how important religion may be to a specific patient, and physicians should facilitate available resources to aid their patients in spiritual care.[18]

## Comments

Physicians, patients, and caregivers are confronted with many ethical dilemmas at the end of life. Many of these ethical dilemmas can be avoided with good dialogue between the patient, physician, and caregivers as well as effective advance care planing. The central role of patient self-determination, upholding the ethical principle of autonomy, is critical to good end-of-life care; however, the role of the physician as a moral agent must not be excluded. Withdrawing and withholding interventions at the end of life are morally equivalent and certainly acceptable when consistent with the patient's values and goals. The ethical principle of the double effect provides a basis for appropriate pain management for patients at the end of life. Physician-assisted suicide will alter the integrity of the patient-physician relationship, which has been to care and comfort, not to take life. It is likely to diminish society's resolve to provide good care for dying patients. Osteopathic physicians and other healthcare professionals should promote good care for dying patients as an alternative to the societal acceptance of physician-assisted suicide. Recommendations for ethical care at the end of life are presented in *Figure 2*.

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