

Ethical Issues in Palliative Care

Danielle N. Ko, MBBS, LLB^{a,b,c,1}, Pedro Perez-Cruz, MD^{a,b,d,1},
Craig D. Blinderman, MD, MA^{e,*}

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- Palliative sedation

Not a week passes in the practice of the ordinary physician but he is consulted about one or more of the deepest problems in metaphysics and religion—not as a speculative enigma, but as part of human agony.

Richard Cabot, MD¹

Ethical problems in medicine are common, especially when caring for patients at the end of life. However, many of these issues are not adequately identified in the outpatient setting.^{2,3} Primary care providers (PCPs) are in a unique and privileged position to identify ethical issues, prevent future conflicts, and help patients make medical decisions that are consistent with their individual values and preferences. This article describes some of the more common ethical issues faced by PCPs caring for patients with life-limiting illness.

AUTONOMY, INFORMED CONSENT, AND DECISION-MAKING CAPACITY

Autonomy can be defined as the human capacity for self-determination. This concept supports the idea that each person has the right to select among the best alternatives according to a self-chosen plan.⁴ Informed consent is the procedure through which patients' autonomy is respected, legally and ethically. The patient must be informed about the risks and benefits of a specific treatment or intervention to freely accept or refuse it. If the patient lacks capacity, then any form of consent is not valid, even

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¹ Dr Ko and Dr Perez-Cruz are lead authors and have contributed equally to this work.

^a Division of General Internal Medicine, Massachusetts General Hospital, 55 Fruit Street, Boston, MA 02114, USA

^b Palliative Care Service, Massachusetts General Hospital, 55 Fruit Street, Boston, MA 02114, USA

^c Division of Medical Ethics, Harvard Medical School, 641 Huntington Avenue, Boston, MA 02115, USA

^d Department of Internal Medicine, School of Medicine, Catholic University, Lira 44, Santiago, Chile

^e Adult Palliative Medicine, Department of Anesthesiology, Columbia University, 622 West 168th Street, PH5-530B, New York, NY 10032, USA

* Corresponding author.

E-mail address: cdb21@columbia.edu

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if the patient agrees with the physician's suggestions.⁵ For these reasons, the assessment of a patient's ability to make decisions is a fundamental component of every physician–patient interaction.

Physicians often start with the assumption that all patients have capacity unless evidence suggests otherwise.⁶ In general, physicians make a relatively cursory assessment of a patient's ability to make decisions, and only tend to explore the matter more deeply when conflict arises regarding medical management. Physicians are often biased toward believing a patient has capacity (when they do not),⁷ and are frequently unaware of a patient's incapacity to make a decision,⁵ or judge their capacity to be greater than it is in reality.⁸ Another common problem is assuming that certain diagnoses (eg, depression, cerebral metastases) are associated with the inability to make decisions. Although this is not the case, these diagnoses may indicate who should be screened.⁹

Several strategies are available to assess decision-making capacity. In the medical setting, the most frequently used formal criteria include the assessment of a patient's ability to (1) communicate a choice, (2) understand the relevant information, (3) appreciate the situation and its consequences, and (4) manipulate relevant information in a rational way⁵ (**Table 1**).

Some authors have suggested a sliding scale approach when evaluating capacity.¹⁰ That is, the patient's ability to make a decision should be understood relative to the decision at hand, and whether the patient is refusing or accepting the advice of his physicians should be clear. More capacity is needed to consent to medical treatments with high risk and a low likelihood of success (eg, palliative chemotherapy) than to an intervention with low risk and a high likelihood of success (eg, penicillin for group A streptococcus infection). Refusing a low-risk, life-saving treatment should raise suspicion that perhaps the patient does not have capacity. Further evaluation and an opinion of a psychiatrist may be beneficial. Finally, the assessment of capacity should be restricted to a particular decision,¹⁰ rather than evaluating a patient's capacity in general. For instance, one might ask whether the patient has capacity to refuse this specific life-prolonging therapy, rather than whether the patient has decision-making capacity.

PCPs are in a unique position for identifying patients' decision-making capacity: the outpatient setting is a relatively nonstressful environment for patient evaluation, with the absence of severe acute illness that affects patients' cognitive abilities¹¹; the long-term patient–physician relationship can also be used to detect subtle cognitive impairment or changes of the patient's capacity over time; and the assessment can

Table 1
Questions for assessing patient capacity to make decisions

Ability	Example Questions
Communicate a choice	Can you tell me what your decision is?
Understand the relevant information	Can you tell me in your own words what you understand about your health problem and the treatments being offered?
Appreciate the situation and its consequences	What do you believe will happen if you undergo the treatment? How might this impact your health?
Manipulate relevant information in a rational way	What makes treatment X better than Y?

Data from Appelbaum PS. Clinical practice. Assessment of patients' competence to consent to treatment. *N Engl J Med* 2007;357(18):1834–40.

be complemented by family members' perspectives. For all of these reasons, and whenever possible, PCPs should perform a basic capacity assessment on every patient, especially for those near the end of life.

When a patient is deemed to lack decision-making capacity, then the physician should try to identify the causes of impairment and remedy them, if they are reversible. When the cause is fear or anxiety, introducing a confidant or an adviser to the consent process may permit the patient to make competent decisions.⁵ If doubts exist when assessing the capacity of a patient or when a case is likely to be resolved in court, special assessment tools should be used¹² and consultation with psychiatry may be necessary. If the patient has no possibility to regain capacity, then a living will detailing patient preferences or assistance from a surrogate decision-maker becomes necessary to protect patient autonomy.⁵ The surrogate decision-maker should ideally be designated by the patient prior to the loss of decision-making capacity, or in the absence of such an advance directive, the person with the strongest genetic and/or emotional ties to the patient.⁶ This strategy has been supported by courts and legislation.¹³

ADVANCE CARE PLANNING

Advance care planning (ACP) can be defined as the process of planning for future medical care. ACP was developed in an attempt to address the problem of decision-making in patients without capacity and to improve care at the end of life.¹⁴ An advance directive directs the provision of life-sustaining treatment when the patient no longer has capacity to make decisions. Two types of advance directives are available: (1) a health care proxy document, in which a person is legally appointed as a health care decision-maker, and (2) a living will, in which a patient defines instructions regarding future medical care. A durable power of attorney is a legal instrument that allows a person to make decisions regarding financial or legal matters, and is not used for medical issues and therefore is not considered an advance directive.

The usefulness of advance directives has been debated.^{15,16} Supporters of advance directives consider them valuable instruments for several reasons. First, they are believed to help guide health providers and family members in making decisions for incapacitated patients.¹⁷ The underlying assumption is that the patient is the person who can best define the circumstances in which life should continue. Second, advance directives increase a patient's empowerment in medical decision-making and promote discussions about death planning and conversations between patients and their families.¹⁶ For example, these instruments have helped increase the likelihood that patients will die in the place they prefer.¹⁸ Third, talking about planning helps alleviate patients' anxiety regarding the future. Having open discussions about these issues and establishing a trustful patient-physician interaction reduces a patient's uncertainty and provides peace about who and how decisions will be made in the future.¹⁹

However, despite concerted efforts to extend the use of advance directives, the number of people who have completed one is still extremely variable. Studies have shown that anywhere from 5% and 67% of patients complete some form of advance directive.^{15-17,20-25} This wide range can be partly explained by the heterogeneity of the populations studied, but in most studies the frequency of completed advance directives is less than 30%. Furthermore, these documents often are not easily available when physicians or the family need them.²⁶ When available, living wills may be too vague to interpret or are only occasionally followed.²⁷ Some physicians argue that ACP is time-consuming²⁸ and often requires more than one consult to discuss the

different possibilities and their medical, social, legal, and ethical implications. Opponents of ACP also point out that once living wills are defined, the assumption is that the patient's preferences are stable over time, and that they accurately represent a patient's preference when facing serious medical situations.²⁹ However, what one may prefer in a premonitory, healthy state is likely to differ from what one would choose when actually faced with a life-threatening illness.³⁰ In addition, it is common for patients to change their minds about treatment preferences through the course of illness. Factors such as mood disorders, physical decline, and hospitalizations have been identified as influences that could partly explain this instability.²⁹ Therefore, patient predictions of preferences and reactions to hypothetical future events is both inaccurate and unstable over time.³¹

Regarding surrogate decision-makers, other problems arise. Studies have shown that surrogates often do not know how the patient would have decided in a certain situation,³² and that decisions correlate more with the surrogate's own preferences rather than the preferences of incapable patients.³³ Researchers have also shown that family members of patients in the intensive care unit are often too impaired by depression and anxiety to make decisions regarding their loved ones.³⁴ Despite these facts, United States courts have supported the idea that surrogates and family members are in the best position to make medical decisions because of their deep investment in the patient's best interests.

It is the authors' view that PCPs are in a privileged position to initiate ACP with patients. Studies have shown that patients expect that their PCP to begin the discussion about advance directives.³⁵ PCPs can guide this process over several visits in a calm setting, focusing on patient values and beliefs. In our experience, this is an intensely rewarding endeavor. The goal of ACP is to respect patient autonomy when the patient is no longer able to make decisions. Through clarifying and documenting patient preferences, PCPs can provide important guidance regarding the future use of medical interventions at the end of life.

WITHHOLDING AND WITHDRAWING TREATMENTS

Discussions about future treatment preferences are essential in ACP and should include discussions regarding withholding and withdrawing life-sustaining treatments. In many instances these decisions are morally troublesome for physicians, patients, and families. Therefore, it is essential for PCPs to be familiar with these topics, understand the ethical implications of these decisions, and recognize some of the moral concerns that might arise through the discussions with patients and families.³⁶

Current technological advances in medicine allow patients to be kept alive who would have previously died, leading to a culture that seems to believe that every possible intervention should be attempted to extend a patient's life, despite the burdens that this decision would carry, and ultimately obscuring the ability to recognize when a patient is actually dying.³⁶ An additional factor affecting the decision to withhold or withdraw treatments is the fear of abandonment. Some families are uncomfortable withholding or withdrawing treatments from their loved ones because they are afraid of not doing "everything possible" or "giving up too soon," and that the subsequent death could be considered abandoning, or even worse, killing the patient. Some evidence also suggests that both African American and Hispanic families are less likely to discontinue life-supportive therapies, perhaps as a response to their distrust of the health care system resulting from the history of racism in medicine.³⁷ These facts make decisions regarding withholding and withdrawing treatment very complex, even for families that have extensively discussed these issues.

Attempting to clarify some of the ethical issues associated with withholding and withdrawing treatments may help mitigate some of the concern from families and clinicians. Firstly, a patient has the right to refuse any and all treatments, even if the removal of the treatment results in hastened death. Secondly, withdrawal of life support after which a patient subsequently dies should be distinguished from intentionally causing a patient's death. A general consensus exists that the former is morally permitted, whereas the latter is unacceptable. Thirdly, it is also widely accepted that withholding and withdrawing life-sustaining treatments are ethically and legally the same,^{38,39} despite the fact that many physicians believe there is a difference between these two actions, particularly related to the proximity of withdrawing a treatment and the subsequent death.⁴⁰

The decision to withhold or withdraw any life-sustaining therapy should be made together with the patient, whenever possible, or with the patient's family and/or surrogate decision-maker. Using guidance from ACP or other documented conversations with providers or family members in which patients have articulated their preferences is the best evidence to provide ethical justification for the withholding or withdrawing of life support. When the treatment is determined to be too burdensome or harmful in proportion to the likely outcome, clinicians should initiate discussions with patients and families regarding withholding and withdrawing life-sustaining treatments.

PROVIDING ADEQUATE PAIN AND SYMPTOM RELIEF

Despite quality improvement efforts and educational initiatives to enhance the assessment and management of cancer pain, the problem of inadequate pain treatment persists.^{41,42} Multiple barriers affect the clinician's ability to adequately address pain, including insufficient education and knowledge, patient and family factors, insurers' limitations placed on medication choices and amounts, regulatory scrutiny from government and legislative bodies, potential prescription drug abuse, and fear of litigation for overtreatment.⁴³

Since the time of Hippocrates, relieving pain and suffering has been a primary goal and duty of physicians. Failure to adequately treat a patient's pain not only would violate the principle of nonmaleficence but also can diminish autonomy and the right-to-self determination, because unremitting pain can have significant effects on one's quality of life and ability to make reasonable decisions.^{44,45} Pain relief is also important from the perspective of justice, because at the individual level it allows patients the opportunity to function normally within society.⁴⁶ Rawls⁴⁷ had considered "freedom from physical pain" as a possible candidate for an expansion of his list of primary goods (ie, those basic conditions that were necessary for a just society).

Federal and state legislative bodies have enacted statutes and regulations that impact on the treatment of pain. Some directly address how caregivers should treat pain, such as the Pain Relief Act of 1996,⁴⁸ whereas others regulate the distribution of controlled substances.⁴⁹ The latter, in conjunction with medical negligence cases and medical board disciplinary action for overtreatment of pain, have unfortunately deterred many medical practitioners from prescribing adequate pain relief.⁵⁰ More recently, the legal system has deliberated on cases asserting undertreatment of pain in terminally ill patients. In *Bergman v Chin*, a doctor's failure to adequately treat the pain of a terminally ill 85-year-old man who was discharged from a hospitalization with a pain score of 10 a few days before his death was found to constitute elder abuse.⁵¹

Some have argued that the treatment of pain is a fundamental human right and should be a priority for international public health programs.⁵² The United Nations International Covenant on Economic Social and Cultural Rights articulates the right to

“enjoyment of the highest attainable standard of physical and mental health.” Although pain is not explicitly referred to, it has been argued that freedom from pain can be inferred in this right.⁵³ This view is gaining increasing acceptance as both developed and developing countries continue to struggle with the issue of undertreated pain.

Regardless of whether one views the treatment of pain as simply good clinical practice, an ethical obligation, or a legal or human right, the fact that pain is one of the most frequent reasons for consultation in the outpatient setting is sufficient justification for physicians to prioritize pain assessment and management in their practice.

PALLIATIVE SEDATION

Despite high-quality palliative care, a small minority of patients experience intolerable suffering at the end of life. Although palliative sedation is largely in the domain of palliative care specialists, PCPs must be aware of palliative sedation to allow appropriate patients access to this therapy when indicated.

Palliative sedation, a useful but contentious treatment of last resort, is broadly defined as using sedative medications to relieve intolerable suffering caused by refractory symptoms via a reduction in patient consciousness.⁵⁴ Refractory symptoms have been defined as symptoms that cannot be adequately treated using standard palliative interventions within an acceptable time frame.⁵⁵ Suffering, intolerability, and adequate relief are of course subjective and can only be defined by the patient.

The issue of palliative sedation has been somewhat complicated by the fact that no agreed-on nomenclature exists to describe the process of sedation for refractory suffering at the end of life, and no widespread agreement exists as to what acts actually constitutes palliative sedation, its goals, and what medications are appropriate.^{54,56} These factors, along with differing cultural and religious beliefs surrounding death and dying and the retrospective nature of relevant studies, have contributed to a wide discrepancy in reports of the prevalence of palliative sedation, with estimates varying from 3% to 51% of all palliative care deaths.^{57,58}

Palliative sedation has traditionally been justified by the doctrine of double effect, which maintains that it is the intention of the moral actor that matters. The doctrine of double effect originally formulated by Thomas Aquinas applies to moral dilemmas in which it is impossible for a person to avoid all harmful actions. The doctrine of double effect requires that (1) the nature of the act must be good or at least morally neutral (prescribing sedatives is a morally neutral act), (2) the harmful effect must be foreseen but not intended (hastened death), (3) the harmful effect must not be a way of producing the good effect (the good effect—less suffering—is a result of loss of consciousness with sedation), and (4) the good effect must outweigh the harmful effect, proportionately (in terminally ill patients with refractory suffering this is believed to be the case). Thus, the doctrine of double effect has been used to justify the administration of both high-dose opioids and sedatives for the purposes of pain and symptom relief, notwithstanding the unintended but foreseen risk of hastening the patient's death. Many critics have argued that the focus on intention is problematic; focusing on the requirements of informed consent and proportionality in seeking ethical justification for this practice may be more useful.⁵⁹ Informed consent for palliative sedation requires that the patient or surrogate be fully informed about the rationale for using palliative sedation and about the associated risks, and agree to the procedure.⁶⁰ Proportionality helps to balance the conflict between the duty to relieve the patient's suffering and the duty not to cause death. In other words, the risk of hastening death is justified if standard approaches have failed to relieve the severe symptoms. The authors give higher priority to relieving symptoms than to continuing a life filled with suffering.⁶¹

General consensus exists on the appropriateness of sedation for suffering caused by intractable physical symptoms such as pain, delirium, and dyspnea in terminally ill patients.⁶² The argument for palliative sedation in these circumstances has been strengthened by studies indicating that palliative sedation does not appear to hasten death,⁶³ and by the 1997 US Supreme Court decision rejecting physician-assisted suicide as a constitutional right, based on the concept that palliative sedation is a valid alternative treatment option for suffering at the end of life.⁶⁴

Palliative sedation for existential distress or severe psychosocial distress as an ethically acceptable treatment option is controversial, and is likely to remain so in light of the fact that there is still no widespread agreement regarding what constitutes existential distress or when it becomes refractory to standard approaches. The National Hospice and Palliative Care Organization (NHPCO) defines it as “suffering that arises from a sense of meaninglessness, hopelessness, fear and regret in patients who knowingly approach the end of life.”⁶⁵ The arguments for and against palliative sedation for existential distress are complex and beyond the scope of this article.^{66–68}

Various individuals and organizations have proposed or set out position statements and practical guidelines for palliative sedation, some of which endorse palliative sedation for existential suffering.^{62,69} Guidelines, such as those of the European Association of Palliative Care, include (1) the indications in which sedation may be considered, (2) the necessary evaluation and consultation procedures, (3) consent requirements, (4) medications and dose titration, (5) patient monitoring, (6) guidance regarding hydration and nutrition during sedation, and (7) how to address the problem of using sedation for refractory existential distress.⁷⁰

PHYSICIAN-ASSISTED SUICIDE AND EUTHANASIA

Palliative sedation can be distinguished from physician-assisted suicide and euthanasia in that the specific intent of these practices are to end life with either the deliberate use of lethal doses of medication or therapeutically unjustified dose escalation.

Physician-assisted suicide is defined as a physician providing, at the patient's request, a lethal medication that the patient can take by his own hand to end otherwise intolerable suffering. In the United States, physician-assisted suicide is legal only in Oregon, Washington, and Montana. Each year, the Oregon Department of Human Services publishes an annual report on its use.⁷¹ In 2009, 95 prescriptions for lethal medications were written, with 53 patients taking those medications. As in previous years, most participants were well educated, had cancer, and were insured. The most frequently mentioned end-of-life concerns were loss of autonomy (96.6%), loss of dignity (91.5%), and decreasing ability to participate in activities that made life enjoyable (86.4%).⁷²

Euthanasia, defined from the Greek word *euthanatos* meaning “good death,” refers to the active intentional ending of life by a physician. Euthanasia is the subject of intense ethical debate and is beyond the scope of this article. Although legal in the Netherlands, euthanasia is currently not an option in the United States.

SUMMARY

Physicians encounter many ethical issues when caring for patients at the end of life. Their obligation to patient autonomy requires that they consider how and to what extent medical treatments should be used in the face of a life-threatening illness. These conversations ideally should happen while patients have the capacity to decide for themselves. Documentation of patient wishes in a living will and assignment of a surrogate decision-maker are proactive steps that can be taken to protect patients

from undergoing treatments they may not want to endure in the future when they no longer have capacity. Ultimately, the patient's values should guide the use of medical interventions. Regardless of patient preferences, physicians should always strive to alleviate suffering, whether it is physical, psychological, or existential. With patient consent and the principle of proportionality, physicians are ethically justified in using medications and therapies to alleviate pain and suffering, even if these treatments carry a risk of hastening death. This approach should be differentiated from physician-assisted suicide and euthanasia. Consultation with palliative care specialists or clinical ethicists may help address the potential moral ambiguity and discomfort when addressing some of these issues.

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