

5.9 Palliative Care

Physicians have clinical ethical responsibilities to address the pain and suffering occasioned by illness and injury and to respect their patients as whole persons. These duties require physicians to assure the provision of effective palliative care whenever a patient is experiencing serious, chronic, complex, or critical illness, regardless of prognosis. Palliative care is sound medical treatment that includes the comprehensive management and coordination of care for pain and other distressing symptoms including physical, psychological, intellectual, social, spiritual, and existential distress from serious illness. Evaluation and treatment are patient-centered but with an additional focus on the needs, values, beliefs, and culture of patients and those who love and care for them in decision-making accordingly.

Palliative care is widely acknowledged to be appropriate for patients who are close to death, but persons who have chronic, progressive, and/or eventually fatal illnesses often have symptoms and experience suffering early in the disease course. The clinical ethical responsibilities to address symptoms and suffering may therefore sometimes entail a need for palliative care before the terminal phase of disease. Moreover, the duty to respect patients as whole persons should lead physicians to encourage patients with chronic, progressive, and/or eventually fatal conditions to identify surrogate medical decision makers, given the likelihood of a loss of decisional capacity during medical treatment.

When caring for patients' physicians should:

- (a) Integrate palliative care into treatment.
- (b) Seek and/or provide palliative care, as necessary, for the management of symptoms and suffering occasioned by any serious illness or condition, at any stage, and at any age throughout the course of illness.
- (c) Offer palliative care simultaneously with disease modifying interventions, including attempts for cure or remission.
- (d) Be aware of, and where needed, engage palliative care expertise in care.

Physicians as a profession should:

- (e) Advocate that palliative care be accessible for all patients, as necessary, for the management of symptoms and suffering occasioned by any serious illness or condition, at any stage, and at any age throughout the course of illness.

AMA Principles of Medical Ethics: I,IV,VIII

Background reports:

CEJA Report 1-I-24 Expanding Access to Palliative Care

REPORT 1 OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS (I-24)
Expanding Access to Palliative Care
(Reference Committee on Amendments to Constitution and Bylaws)

EXECUTIVE SUMMARY

Palliative care focuses on improving quality of life by providing physical and emotional support to the patient and their family during serious and critical illness. Failure to provide palliative care is in direct conflict with the well-established ethical duty for physicians to relieve the pain and suffering of their patients. Although the term “palliative treatment” is referred to in both the *Code of Medical Ethics* (*Code*) and numerous House of Delegates policies, the ethical provision of this medical practice is neither discussed nor defined in house policies or in the *Code*. This Council on Ethical and Judicial Affairs (CEJA) report recommends the adoption of a new opinion in the *Code* which addresses the ethical provision of palliative care.

REPORT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS*

CEJA Report 1-I-24

Subject: Expanding Access to Palliative Care

Presented by: Jeremy A. Lazarus, MD, Chair

Referred to: Reference Committee on Amendments to Constitution and Bylaws

BACKGROUND

The majority of deaths in the United States result after months to years of treating complications of underlying chronic illness and comorbidities, including cancer, heart disease, and stroke [1]. Although many deaths in America are anticipated, patient preferences, values, and goals for medical treatment during serious and critical illness are not often elicited prior to the initiation of life sustaining interventions including mechanical ventilation, artificial nutrition and hydration, and cardiopulmonary resuscitation [2]. The stress and uncertainty surrounding medical decisions during serious illness often results in patients and their families experiencing needless physical and emotional suffering such as anxiety, depression, and the prolonged use of unwanted or likely to be ineffective mechanical and pharmacological life sustaining interventions that cannot restore the patient to an acceptable level of health and function [3]. The patient and their family's experience of suffering during their serious illness is often avoidable or mitigatable by physicians through palliative care [3].

Palliative care focuses on improving quality of life by providing physical and emotional support to the patient and their family during serious and critical illness [4]. Palliative care can be provided at any point in the illness trajectory by any physician, in any specialty (a.k.a. primary palliative care) [5]. When the patient's and/or their family's needs are more complex, specialty palliative care can be consulted [5]. [Opinion 5.3](#) of the *Code of Medical Ethics (Code)* calls for the provision of palliative care, which is appropriate when patient or family distress, physical and psychological symptom burden, uncertainty about what to expect in the future, or spiritual/existential distress is identified. Failure to provide palliative care is in direct conflict with the well-established ethical duty for physicians to address the pain and suffering of their patients [6]. Furthermore, American Medical Association (AMA) policy [H-70.915](#) encourages the provision of "good palliative care" and "encourages all physicians to become skilled in palliative medicine." [Opinion 5.3](#), "Withholding and Withdrawing Life-Sustaining Treatment," calls for the provision of palliative care when such transitions in care are considered. Additionally, a 1991 Council on Ethical and Judicial Affairs (CEJA) Report was adopted entitled "Decisions Near End of Life" which advocated for the use of palliative care [7].

Although there is a strong basis supporting the provision of palliative care for patients facing serious illness, the *Code* does not address the ethical provision of palliative care for serious or critical illness. This gap should be filled by the creation of a new opinion which describes the

* Reports of the Council on Ethical and Judicial Affairs are assigned to the Reference Committee on Amendments to Constitution and Bylaws. They may be adopted, not adopted, or referred. A report may not be amended, except to clarify the meaning of the report and only with the concurrence of the Council.

ethical provision of “good palliative care” and provides ethical guidelines for implementing palliative care during clinical practice.

RELEVANT LAW(S)

There are several definitions of palliative care from the Centers for Medicare and Medicaid Services (CMS), the World Health Organization, the World Medical Association, and the Center to Advance Palliative Care. Common elements include physical and psychological symptom management, focusing on the patient and caregivers as the unit of care, provision throughout the course of the illness, and continuity of care across settings and over time. Reimbursement for palliative care is funded through the CMS as well as other insurers [8]. Also, the Palliative Care and Hospice Education Training Act (PCHETA) is under consideration in the Senate and has been introduced with bipartisan support and the official support of over 90 national and state organizations [9]. PCHETA would create and promote education programs, research programs, and public education programs to support and expand the palliative care workforce, delivery of palliative care, and public awareness about palliative care. In support of furthering the evidence base for palliative medicine, the National Institutes of Health recently established a Consortium for Palliative Care Research Across the Lifespan, a cross-institute funding initiative with an annual commitment of approximately \$12 million [10].

RELEVANT POLICY PROVISION(S)

Numerous AMA policies support the provision of palliative care for patients and the education of palliative care for physicians. AMA policy [H-140.966](#) states that “physicians have an obligation to relieve pain and suffering and to promote the dignity and autonomy of patients in their care. Furthermore, policy encourages the provision of “good palliative care” and “encourages all physicians to become skilled in palliative medicine.” [H-295.875](#) encourages “the inclusion of palliative medicine in the core curriculum of undergraduate and graduate medical education” and the “use of palliative care techniques and interdisciplinary team care.” [D-295.969](#) “encourages palliative training for physicians caring for elderly and terminally ill patients in long-term care facilities.” [H-85.949](#) supports “increased access to comprehensive interdisciplinary palliative care services by Medicare patients.” [H-55.999](#) “supports palliative care procedures for cancer patients.”

RELEVANT *CODE* PROVISION(S)

The *Code* references and supports the provision of palliative care numerous times. For example, Opinions [5.3](#) and [6.1.2](#) both require physicians to “ensure that relevant standards for good clinical practice and palliative care are followed when implementing any decision to withdraw a life-sustaining intervention” and Opinion [5.6](#) requires physicians to consult “an expert in the field of palliative care, to ensure that symptom-specific treatments have been sufficiently employed” prior to engaging in palliative sedation to unconsciousness. Additionally, Opinions [2.2.5](#) and [5.2](#) mention palliative interventions; however, the *Code* does not directly address what qualifies as palliative care, nor does it provide ethical guidance on the delivery of palliative care.

ETHICAL ISSUES

Delivering palliative care during clinical practice is inextricably linked with navigating ethical dilemmas. For example, physicians must balance the often-competing values, preferences, and goals of the patient, the health care entity, the clinical care team, the payer, and their surrogate or support persons while making complex medical decisions such as when to withhold or withdraw life sustaining interventions or when to counsel cessation of ‘curative’ treatments that become

ineffective or harmful [3,11]. These competing values, preferences, and goals arise from many sources including the profession itself, society, community, family, religious beliefs, and personal desires and experience. While navigating various perspectives and competing values during palliative care delivery, physicians must also balance complex ethical questions such as when it is ethically appropriate to withhold or withdrawal life sustaining interventions or provide sedation or analgesia to relieve symptom distress when the unintended potential effect is hastened death. The concept of double effect permits, under appropriate conditions medical treatments or interventions that could have the effect of hastening death so long as the primary intention of providing the medical treatment or intervention is not to hasten death but is for some other clinically and ethically appropriate reason such as pain and symptom management.

Many of the ethical complexities of palliative care are discussed in detail within the 1991 CEJA report entitled “Decisions Near End of Life”; however, guidance regarding ethical palliative care is absent within the *Code* [7]. This is problematic for several reasons. Importantly, palliative care as a discipline has substantially evolved since 1991 when it was first recognized as a medical specialty. Despite the rapid evolution of palliative care as a medical specialty, the ethical issues highlighted in the 1991 report remain; however, the understanding of palliative care and the role palliative care plays in resolving ethical dilemmas has evolved. Additionally, palliative care is often misunderstood as being limited to comfort care for patients imminently facing end of life. This misunderstanding often results in palliative care being initiated late in the disease course and typically only after the decision to discontinue curative or life prolonging interventions [12]. Additionally, this misunderstanding often results in palliative care not being offered concurrently with curative treatments, even for patients with substantial distress during a serious or complex critical illness. Furthermore, due to the underutilization of palliative care throughout the full course of the patient’s illness trajectory, patients are too often referred for palliative care consultation prior to imminent death, and thus, often receive high burden life sustaining interventions where burden outweighs benefit [13,8]. This is problematic because delaying the provision of palliative care results in patients and their families facing unnecessary suffering which is in direct conflict with a physician’s ethical duty to relieve pain and suffering. Providing ethical guidance in the *Code* will help alleviate misnomers and barriers to implementing and practicing ethical palliative care during clinical practice.

RELEVANT PRACTICAL MATTERS FOR CLINICAL PRACTICE

Amending the *Code* to include ethical guidance on providing palliative care for patients facing serious, chronic, complex, or critical illness will positively affect clinical practice. First, the benefits of palliative care have been well studied and include improved quality of life, decreased symptom burden, increased goal-concordant care, increased caregiver support, reduced anxiety, decreased hospital mortality, and reductions in unnecessary medical costs [14]. In some cases, it may even result in longer survival than those treated with chemotherapy [15]. Second, palliative care improves the quality of care the patient (and their care partners) receives, while providing support for the physician and their team and has been associated with both improved physician satisfaction and patient satisfaction. Third, serious and critical illness care is often a source of stress for physicians and has been associated with physician burn out [13]. Palliative care provides support to physicians in four important ways through the provision of: 1) dedicated time for intensive family meetings and goals of care conversations; 2) skilled communication over time to help patients and their families determine the medical treatment options that match their preferences, values, and goals as illness evolves; 3) expert pain and symptom management of both physical, emotional, social, and spiritual distress; and 4) comprehensive coordination of communication among all providers involved in the patients care [5,14,11].

REVIEW OF RELEVANT LITERATURE

Most people will experience death in a hospital or health care facility after suffering from a chronic serious illness, and one-in-three of the deaths that occur in the hospital will result from a decision to withdraw life-sustaining interventions [12,16-19]. Although it is common for Americans to die in a hospital or health care facility and receive life prolonging interventions at the end of life, this is not how most healthy Americans report that they want their lives to end. This is likely related to multiple factors: the aim of preserving life; the rational assumption that patients and families hold that doctors would not recommend treatments they did not believe to be helpful to the patient so they accede to the doctor's recommendations; and the fact that when death is imminent, patient (and caregiver) desire to hold on often strengthens (this is evident in the observation that despite presence of advance directives specifying comfort measures when recovery is not possible, they are seldom honored) [20]. Evidence is clear that regardless of prognosis and treatments, patients and caregivers living with serious, chronic, complex, and critical illness experience anxiety, depression, and physical and spiritual/existential suffering [11]. One way to remediate this experience is through the provision of palliative care, which is associated with improved quality of life, reduced suffering, and reduced hospital mortality [5,14].

Palliative care is the comprehensive management and coordination of care for pain and other distressing symptoms including physical, psychological, intellectual, social, psychosocial, spiritual, and existential consequences of a serious illness that improves the quality of life of patients and their families/caregivers [5]. The evaluation and treatment are patient-centered, with a focus on the central role of the family unit in decision-making according to the needs, values, beliefs, and culture of the patient and his or her family [14]. Palliative care can be offered in all care settings, by any physician, and at any stage in a serious illness. The provision of palliative care by physicians without subspecialty training in palliative medicine is known as primary palliative care [5]. When a patient and/or their family's needs become complex, specialty palliative care can be delivered through a collaborative team approach involving all disciplines optimally including physicians, nurses, social workers, spiritual care providers, therapists, and pharmacists. Specialist level palliative care teams work alongside the primary treating team as an added layer of support for all- patient, caregivers, and clinicians.

Hospice is a mode of palliative care for patients in their homes or long-term care facilities provided in the U.S. with a specific Medicare payment model. Eligible U.S. patients must have an expected prognostic life-expectancy of six months or less and agree to give up regular Medicare insurance coverage. Most private insurers in the U.S. follow the Medicare model for patients not on Medicare. Hospice care is predominantly provided at home or in nursing homes. In contrast, palliative care has no prognosis or treatment restrictions (delivered at any age, any stage, any setting and whether the illness is curable chronic or progressive) and is provided (depending on local capacity) in any setting- hospital, office, cancer center, dialysis unit, home, or long-term care facility [8]. While patients usually receive palliative care concurrently with traditional medical treatments, hospice care focuses on comfort measures for the patient and their family near the end of life. Comfort measures focus on relieving the stress, anxiety, and physical pain which often occurs during the dying process.

The use of complex disease-specific interventions at the end of life is associated with stress and uncertainty and often results in patients and their families experiencing physical and existential suffering such as intractable pain, anxiety, and depression [13]. The patients and their families' experience of suffering is often avoidable or mitigatable through palliative care [5,14,13]. Although the provision of palliative care is associated with improved quality of life, more days at home, and reduced suffering, palliative care is too often initiated as a last resort, after disease-specific

interventions have become ineffective (i.e. futile or unable to result in a beneficial outcome), and the decision to withdraw life sustaining interventions either needs to be made or has already been made [13]. Due to the underutilization of palliative care throughout the full course of the patient's illness trajectory, patients are too often referred for palliative care consultation prior to imminent death, and thus, often receive high burden life sustaining interventions where burden outweighs benefit [13,8].

ETHICAL ANALYSIS

Palliative Care is the Evidence Based Standard of Care for Patients with Serious and Critical Illness

The need to address palliative care in the *Code* is not a novel concept. At the 1991 Annual Meeting of the House of Delegates (HOD), CEJA Report was adopted entitled "Decisions Near End of Life" which addressed palliative care as an ethical medical intervention [7]. Since the adoption of the CEJA report "Decisions Near End of Life", the HOD passed policy [H-70.915](#) entitled "Good Palliative Care" in 2014. This policy "encourages all physicians to become skilled in palliative medicine" and "encourages education programs . . . in care of the dying patient." Additionally, this policy advocates for reimbursement of palliative care services and research to improve the field of palliative medicine. This policy has been reaffirmed three times since it was originally passed showing the continued interest and support of palliative care in the AMA HOD. In addition to the HOD policy on Good Palliative Care, the HOD has passed eight other policies which have affirmatively advocated for providing palliative care.

The AMA HOD is not alone in its support of palliative care. The World Health Assembly (WHA) declared that providing palliative care should be considered an ethical duty for health organizations. Additionally, the World Health Organization declared that palliative care is an ethical duty of health professionals and, in 2012, the United Nations Office of the High Commissioner for Human Rights recognized that the failure to provide palliative care and end of life care to older persons is a human rights violation. Furthermore, in 2011, the World Medical Association (WMA) adopted the Declaration on End-of-Life Medical Care which declared that "The objective of palliative care is to achieve the best possible quality of life through appropriate palliation of pain and other distressing physical symptoms, and attention to the social, psychological and spiritual needs of the patient and is part of good medical care" [10]. Three years later, the WMA further expanded their support of palliative care with the adoption of a resolution which called for the integration of palliative care in global disease control and health system plans. Additionally, major world religions also endorse palliative care [21].

Despite the continued support for palliative care within the AMA HOD and from medical organizations across the globe, the *Code* remains silent on what constitutes the ethical provision of palliative care. Providing guidance on the ethical practice of palliative care in the *Code* is important because there is not one standard definition of palliative care and what it entails. Additionally, palliative care is often misattributed as being connected to physician assisted suicide or euthanasia. Misattribution and confusion about the scope of palliative care may be contributing to the underutilization of this high quality, evidence based, medical intervention. As there is an established ethical duty within the *Code* to provide palliative care and HOD policies which encourage the provision of palliative care, it is imperative to offer clinicians guidance on what the ethical delivery of high-quality palliative care entails. Additionally, it is imperative to distinguish palliative care, which is an ethical duty, from other practices which either straddle the line of ethical acceptability or are considered by the *Code* as unethical in the practice of medicine (e.g., knowingly and intentionally hastening death, physician assisted suicide, and euthanasia). Lastly,

given the rapid and vast evolution of palliative care as a medical discipline, it is important to update the 1991 CEJA report's understanding of the scope and way in which palliative care is ethically implemented during clinical practice.

The Aim of Palliative Care is Not Hastening Death

Providing palliative care is ethically distinguishable from physician assisted suicide and euthanasia, both of which are intended to cause death. It is important, however, to recognize that treatments for the relief of intractable pain/agitation/dyspnea may theoretically (and very rarely if the clinician is well trained in symptom management) result in the unintended consequence of hastening death. To the contrary, uncontrolled symptom distress, including moderate to severe pain, agitation, depression, and dyspnea, are all associated with a higher risk of death [21-25]. The ethical concept of "double effect" hinges on the intention of the medical intervention. It stipulates that an intervention is ethically permissible if it is provided with the intention of relieving pain or treating symptoms, even if the intervention has the foreseen but unintended side effect of hastening death, provided that the benefits outweigh the burdens and the relief of symptoms or suffering is not achieved by means of causing death [26]. Conversely, this same intervention would be deemed unethical if the primary intention was to hasten death. Patients and/or their surrogate medical decision makers should be provided informed consent which allows them to determine if the risk of intentionally hastening death is worth the relief of pain and/or suffering.

Palliative Care is Offered Concurrently with Curative Treatments

The *Code* contains many ethical opinions permitting the withholding or withdrawing of medical interventions for life-prolonging purposes. For example, patients with decision making capacity have the ethical right to decline or stop any medical intervention, even if this decision will result in their death ([Opinion 5.3](#)). Additionally, patients have the ethical right to refuse cardiopulmonary resuscitation attempts through the execution of a Do Not Resuscitate Order ([Opinion 5.4](#)). In addition to patients having the ethical right to determine if they want to start or continue an offered medical treatment, physicians also have an ethical duty to not provide interventions that, "in their best medical judgement, cannot reasonably be expected to yield the intended clinical benefit or achieve agreed-on goals for care" ([Opinion 5.5](#)).

Although there is a well-established ethical basis for medical interventions to be withheld or withdrawn from both the patient and physicians' perspective, there is also a well-established ethical "duty to relieve pain and suffering" that is "central to the physician's role as healer and is an obligation physicians have to their patients" ([Opinion 5.6](#)). Further, as noted above, symptom distress is consistently associated with a higher risk of death, adding to the professional obligation to ameliorate it. Additionally, physicians have an ethical duty to "respond to the needs of patients at the end of life", and they "should not abandon a patient once it is determined that a cure is impossible" ([Opinion 5.8](#)).

The provision of palliative care bridges these ethical obligations by providing physical and emotional support to patients and their family/ care partners during the entire illness trajectory. Palliative care is offered to patients concurrently with disease-directed treatments and interventions and, therefore, it is not necessary to decide between continued treatment and palliative care intervention because they are provided simultaneously. As the illness progresses and the patient's medical goals transition from cure or prolonging life towards making the life that remains as peaceful and functional as possible, hospice should be offered to the patient and their family. Although life prolonging interventions (for the terminal condition) are not offered as a Medicare

1 Condition of Participation in hospice during the provision of comfort care, the patient and their
2 family are provided physical, emotional, spiritual, and practical support during the dying process.

3 4 CONCLUSION

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6 Although our AMA adopted a CEJA report in 1991 which recommend “providing effective
7 palliative treatment . . .” a *Code* opinion speaking to what it means to practice ethical and effective
8 palliative care has never been adopted [7]. This is problematic because palliative care is an
9 essential part of a patient’s serious illness experience and provides beneficial outcomes in terms of
10 symptom distress, patient and family understanding of what to expect and how to prepare for it,
11 and reduction in use of Emergency Department and hospital admission for symptom crises. This is
12 further problematic because the term “palliative treatment” is referred to in both the *Code* and
13 numerous HOD policies; however, the ethical provision of this medical practice is neither
14 discussed nor defined in house policies or in the *Code*.

15 16 RECOMMENDATION

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18 Given both the AMA Policy and CEJA’s historical support of addressing the palliative needs of
19 patients and the duty of clinicians to provide optimal palliative care to patients, it is recommended
20 that the *Code of Medical Ethics* be amended to include a new opinion on Palliative Care.

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22 Physicians have clinical ethical responsibilities to address the pain and suffering occasioned by
23 illness and injury and to respect their patients as whole persons. These duties require
24 physicians to assure the provision of effective palliative care whenever a patient is
25 experiencing serious, chronic, complex, or critical illness, regardless of prognosis. Palliative
26 care is sound medical treatment that includes the comprehensive management and coordination
27 of care for pain and other distressing symptoms including physical, psychological, intellectual,
28 social, spiritual, and existential distress from serious illness. Evaluation and treatment are
29 patient-centered but with an additional focus on the needs, values, beliefs, and culture of
30 patients and those who love and care for them in decision-making accordingly.

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32 Palliative care is widely acknowledged to be appropriate for patients who are close to death,
33 but persons who have chronic, progressive, and/or eventually fatal illnesses often have
34 symptoms and experience suffering early in the disease course. The clinical ethical
35 responsibilities to address symptoms and suffering may therefore sometimes entail a need for
36 palliative care before the terminal phase of disease. Moreover, the duty to respect patients as
37 whole persons should lead physicians to encourage patients with chronic, progressive, and/or
38 eventually fatal conditions to identify surrogate medical decision makers, given the likelihood
39 of a loss of decisional capacity during medical treatment.

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45 (b) Seek and/or provide palliative care, as necessary, for the management of symptoms and
46 suffering occasioned by any serious illness or condition, at any stage, and at any age
47 throughout the course of illness.
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49 (c) Offer palliative care simultaneously with disease modifying interventions, including
50 attempts for cure or remission.

1 (d) Be aware of, and where needed, engage palliative care expertise in care.

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3 Physician as a profession should:

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5 (e) Advocate that palliative care be accessible for all patients, as necessary, for the
6 management of symptoms and suffering occasioned by any serious illness or condition, at
7 any stage, and at any age throughout the course of illness.

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10 (New Policy)

Fiscal Note: Less than \$500

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