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 <i>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*

Subject: Expanding Access to Palliative Care

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Referred to: Reference Committee on Amendments to Constitution and Bylaws

1 2 3

BACKGROUND

4 The majority of deaths in the United States result after months to years of treating complications of 5 underlying chronic illness and comorbidities, including cancer, heart disease, and stroke [1]. 6 Although many deaths in America are anticipated, patient preferences, values, and goals for 7 medical treatment during serious and critical illness are not often elicited prior to the initiation of 8 life sustaining interventions including mechanical ventilation, artificial nutrition and hydration, and 9 cardiopulmonary resuscitation [2]. The stress and uncertainty surrounding medical decisions during 10 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 11 ineffective mechanical and pharmacological life sustaining interventions that cannot restore the 12 patient to an acceptable level of health and function [3]. The patient and their family's experience 13 of suffering during their serious illness is often avoidable or mitigatable by physicians through 14 palliative care [3]. 15

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17 Palliative care focuses on improving quality of life by providing physical and emotional support to 18 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) 19 [5]. When the patient's and/or their family's needs are more complex, specialty palliative care can 20 21 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 22 23 symptom burden, uncertainty about what to expect in the future, or spiritual/existential distress is 24 identified. Failure to provide palliative care is in direct conflict with the well-established ethical 25 duty for physicians to address the pain and suffering of their patients [6]. Furthermore, American 26 Medical Association (AMA) policy H-70.915 encourages the provision of "good palliative care" 27 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 28 29 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 30 advocated for the use of palliative care [7]. 31

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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.

- 3 4
- RELEVANT LAW(S)
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6 There are several definitions of palliative care from the Centers for Medicare and Medicaid 7 Services (CMS), the World Health Organization, the World Medical Association, and the Center to 8 Advance Palliative Care. Common elements include physical and psychological symptom 9 management, focusing on the patient and caregivers as the unit of care, provision throughout the 10 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 11 12 and Hospice Education Training Act (PCHETA) is under consideration in the Senate and has been 13 introduced with bipartisan support and the official support of over 90 national and state 14 organizations [9]. PCHETA would create and promote education programs, research programs, and 15 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 16 17 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 18 19 commitment of approximately \$12 million [10].

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RELEVANT POLICY PROVISION(S)

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23 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 24 relieve pain and suffering and to promote the dignity and autonomy of patients in their care. 25 Furthermore, policy encourages the provision of "good palliative care" and "encourages all 26 27 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 28 the "use of palliative care techniques and interdisciplinary team care." D-295.969 "encourages 29 30 palliative training for physicians caring for elderly and terminally ill patients in long-term care 31 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." 32

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34 RELEVANT *CODE* PROVISION(S)

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36 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 37 practice and palliative care are followed when implementing any decision to withdraw a life-38 39 sustaining intervention" and Opinion 5.6 requires physicians to consult "an expert in the field of 40 palliative care, to ensure that symptom-specific treatments have been sufficiently employed" prior 41 to engaging in palliative sedation to unconsciousness. Additionally, Opinions 2.2.5 and 5.2 mention 42 palliative interventions; however, the *Code* does not directly address what qualifies as palliative 43 care, nor does it provide ethical guidance on the delivery of palliative care.

- 44
- 45 ETHICAL ISSUES
- 46

47 Delivering palliative care during clinical practice is inextricably linked with navigating ethical

48 dilemmas. For example, physicians must balance the often-competing values, preferences, and

- 49 goals of the patient, the health care entity, the clinical care team, the payer, and their surrogate or
- 50 support persons while making complex medical decisions such as when to withhold or withdraw
- 51 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 1 2 sources including the profession itself, society, community, family, religious beliefs, and personal 3 desires and experience. While navigating various perspectives and competing values during 4 palliative care delivery, physicians must also balance complex ethical questions such as when it is 5 ethically appropriate to withhold or withdrawal life sustaining interventions or provide sedation or 6 analgesia to relieve symptom distress when the unintended potential effect is hastened death. The 7 concept of double effect permits, under appropriate conditions medical treatments or interventions 8 that could have the effect of hastening death so long as the primary intention of providing the 9 medical treatment or intervention is not to hasten death but is for some other clinically and

- 10 ethically appropriate reason such as pain and symptom management.
- 11

12 Many of the ethical complexities of palliative care are discussed in detail within the 1991 CEJA 13 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 14 15 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 16 17 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 18 misunderstood as being limited to comfort care for patients imminently facing end of life. This 19 20 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]. 21 22 Additionally, this misunderstanding often results in palliative care not being offered concurrently 23 with curative treatments, even for patients with substantial distress during a serious or complex 24 critical illness. Furthermore, due to the underutilization of palliative care throughout the full course 25 of the patient's illness trajectory, patients are too often referred for palliative care consultation prior 26 to imminent death, and thus, often receive high burden life sustaining interventions where burden 27 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 28 29 physician's ethical duty to relieve pain and suffering. Providing ethical guidance in the Code will 30 help alleviate misnomers and barriers to implementing and practicing ethical palliative care during 31 clinical practice.

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33 RELEVANT PRACTICAL MATTERS FOR CLINICAL PRACTICE

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35 Amending the *Code* to include ethical guidance on providing palliative care for patients facing 36 serious, chronic, complex, or critical illness will positively affect clinical practice. First, the 37 benefits of palliative care have been well studied and include improved quality of life, decreased 38 symptom burden, increased goal-concordant care, increased caregiver support, reduced anxiety, 39 decreased hospital mortality, and reductions in unnecessary medical costs [14]. In some cases, it 40 may even result in longer survival than those treated with chemotherapy [15]. Second, palliative 41 care improves the quality of care the patient (and their care partners) receives, while providing 42 support for the physician and their team and has been associated with both improved physician 43 satisfaction and patient satisfaction. Third, serious and critical illness care is often a source of stress 44 for physicians and has been associated with physician burn out [13]. Palliative care provides 45 support to physicians in four important ways through the provision of: 1) dedicated time for 46 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 47 preferences, values, and goals as illness evolves; 3) expert pain and symptom management of both 48 49 physical, emotional, social, and spiritual distress; and 4) comprehensive coordination of 50 communication among all providers involved in the patients care [5,14,11].

1 REVIEW OF RELEVANT LITERATURE

2

3 Most people will experience death in a hospital or health care facility after suffering from a chronic 4 serious illness, and one-in-three of the deaths that occur in the hospital will result from a decision 5 to withdraw life-sustaining interventions [12,16-19]. Although it is common for Americans to die 6 in a hospital or health care facility and receive life prolonging interventions at the end of life, this is 7 not how most healthy Americans report that they want their lives to end. This is likely related to 8 multiple factors: the aim of preserving life: the rational assumption that patients and families hold 9 that doctors would not recommend treatments they did not believe to be helpful to the patient so 10 they accede to the doctor's recommendations; and the fact that when death is imminent, patient 11 (and caregiver) desire to hold on often strengthens (this is evident in the observation that despite 12 presence of advance directives specifying comfort measures when recovery is not possible, they are 13 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, 14 15 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 16 17 suffering, and reduced hospital mortality [5,14].

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19 Palliative care is the comprehensive management and coordination of care for pain and other 20 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 21 22 their families/caregivers [5]. The evaluation and treatment are patient-centered, with a focus on the 23 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, 24 25 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 26 27 [5]. When a patient and/or their family's needs become complex, specialty palliative care can be 28 delivered through a collaborative team approach involving all disciplines optimally including 29 physicians, nurses, social workers, spiritual care providers, therapists, and pharmacists. Specialist 30 level palliative care teams work alongside the primary treating team as an added layer of support 31 for all-patient, caregivers, and clinicians.

32

33 Hospice is a mode of palliative care for patients in their homes or long-term care facilities provided 34 in the U.S. with a specific Medicare payment model. Eligible U.S. patients must have an expected 35 prognostic life-expectancy of six months or less and agree to give up regular Medicare insurance 36 coverage. Most private insurers in the U.S. follow the Medicare model for patients not on 37 Medicare. Hospice care is predominantly provided at home or in nursing homes. In contrast, 38 palliative care has no prognosis or treatment restrictions (delivered at any age, any stage, any 39 setting and whether the illness is curable chronic or progressive) and is provided (depending on 40 local capacity) in any setting- hospital, office, cancer center, dialysis unit, home, or long-term care 41 facility [8]. While patients usually receive palliative care concurrently with traditional medical 42 treatments, hospice care focuses on comfort measures for the patient and their family near the end 43 of life. Comfort measures focus on relieving the stress, anxiety, and physical pain which often 44 occurs during the dying process.

45

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

51 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 1

2 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 3 4 illness trajectory, patients are too often referred for palliative care consultation prior to imminent

5 death, and thus, often receive high burden life sustaining interventions where burden outweighs

6 benefit [13,8].

7 8

ETHICAL ANALYSIS

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10 Palliative Care is the Evidence Based Standard of Care for Patients with Serious and Critical 11 Illness

12

13 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 14 15 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 16 17 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 18 policy advocates for reimbursement of palliative care services and research to improve the field of 19 20 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 21 22 HOD policy on Good Palliative Care, the HOD has passed eight other policies which have 23 affirmatively advocated for providing palliative care.

24

The AMA HOD is not alone in its support of palliative care. The World Health Assembly (WHA) 25 declared that providing palliative care should be considered an ethical duty for health 26 27 organizations. Additionally, the World Health Organization declared that palliative care is an 28 ethical duty of health professionals and, in 2012, the United Nations Office of the High 29 Commissioner for Human Rights recognized that the failure to provide palliative care and end of 30 life care to older persons is a human rights violation. Furthermore, in 2011, the World Medical 31 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 32 palliation of pain and other distressing physical symptoms, and attention to the social, 33 34 psychological and spiritual needs of the patient and is part of good medical care" [10]. Three years 35 later, the WMA further expanded their support of palliative care with the adoption of a resolution 36 which called for the integration of palliative care in global disease control and health system plans. 37 Additionally, major world religions also endorse palliative care [21]. 38 39 Despite the continued support for palliative care within the AMA HOD and from medical

40 organizations across the globe, the Code remains silent on what constitutes the ethical provision of

41 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, 42

43 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 44

45 underutilization of this high quality, evidence based, medical intervention. As there is an

46 established ethical duty within the Code to provide palliative care and HOD policies which

47 encourage the provision of palliative care, it is imperative to offer clinicians guidance on what the

48 ethical delivery of high-quality palliative care entails. Additionally, it is imperative to distinguish

49 palliative care, which is an ethical duty, from other practices which either straddle the line of

50 ethical acceptability or are considered by the Code as unethical in the practice of medicine (e.g.,

51 knowingly and intentionally hastening death, physician assisted suicide, and euthanasia). Lastly, 1 given the rapid and vast evolution of palliative care as a medical discipline, it is important to

- 2 update the 1991 CEJA report's understanding of the scope and way in which palliative care is
- 3 ethically implemented during clinical practice.
- 4 5

The Aim of Palliative Care is Not Hastening Death

- 6 7 Providing palliative care is ethically distinguishable from physician assisted suicide and euthanasia, 8 both of which are intended to cause death. It is important, however, to recognize that treatments for 9 the relief of intractable pain/agitation/dyspnea may theoretically (and very rarely if the clinician is 10 well trained in symptom management) result in the unintended consequence of hastening death. To 11 the contrary, uncontrolled symptom distress, including moderate to severe pain, agitation, 12 depression, and dyspnea, are all associated with a higher risk of death [21-25]. The ethical concept 13 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 14 15 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 16 17 achieved by means of causing death [26]. Conversely, this same intervention would be deemed 18 unethical if the primary intention was to hasten death. Patients and/or their surrogate medical 19 decision makers should be provided informed consent which allows them to determine if the risk of 20 intentionally hastening death is worth the relief of pain and/or suffering.
- 20
- Palliative Care is Offered Concurrently with Curative Treatments
 23
- 24 The Code contains many ethical opinions permitting the withholding or withdrawing of medical 25 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 26 27 their death (Opinion 5.3). Additionally, patients have the ethical right to refuse cardiopulmonary 28 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 29 30 medical treatment, physicians also have an ethical duty to not provide interventions that, "in their 31 best medical judgement, cannot reasonably be expected to yield the intended clinical benefit or 32 achieve agreed-on goals for care" (Opinion 5.5).
- 33

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"

- 40 at the end of life", and they "should not abandon a patient once it is determined that a cure is
- 41 impossible" (Opinion 5.8).
- 42

43 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.
- 45 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
- 47 intervention because they are provided simultaneously. As the illness progresses and the patient's
- 48 medical goals transition from cure or prolonging life towards making the life that remains as
- 49 peaceful and functional as possible, hospice should be offered to the patient and their family.
- 50 Although life prolonging interventions (for the terminal condition) are not offered as a Medicare

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

- 3 4
- CONCLUSION
- 5

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, and reduction in use of Emergency Department and hospital admission for symptom crises. This is 11 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

17

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.

21

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 care is sound medical treatment that includes the comprehensive management and coordination 26 27 of care for pain and other distressing symptoms including physical, psychological, intellectual, social, spiritual, and existential distress from serious illness. Evaluation and treatment are 28 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 responsibilities to address symptoms and suffering may therefore sometimes entail a need for 35 palliative care before the terminal phase of disease. Moreover, the duty to respect patients as 36 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. 40

- 41 When caring for patients' physicians should:
- 43 (a) Integrate palliative care into treatment.44
- (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.
- 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.
2	
3	Physician as a profession should:
4	
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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9	
10	(New Policy)

Fiscal Note: Less than \$500

REFERENCES

- 1. FASTSTATS Leading Causes of Death. Centers for Disease Control and Prevention, January 17, 2024. https://www.cdc.gov/nchs/fastats/leading-causes-of-death.htm.
- Curtis JR, Lee RY, Brumback LC, Kross EK, Downey L, Torrence J, LeDuc N, Mallon Andrews K, Im J, Heywood J, Brown CE, Sibley J, Lober WB, Cohen T, Weiner BJ, Khandelwal N, Abedini NC, Engelberg RA. Intervention to Promote Communication About Goals of Care for Hospitalized Patients With Serious Illness: A Randomized Clinical Trial. JAMA. 2023 Jun 20;329(23):2028-2037.
- 3. Akdeniz M, Yardımcı B, Kavukcu E. Ethical considerations at the end-of-life care. SAGE Open Med. 2021 Mar 12;9:20503121211000918.
- 4. Wantonoro W, Suryaningsih EK, Anita DC, Nguyen TV. Palliative Care: A Concept Analysis Review. SAGE Open Nurs. 2022 Aug 8;8:237s79608221117379.
- 5. Quill TE, Abernethy AP. Generalist plus specialist palliative care creating a more sustainable model. New England Journal of Medicine. 2013 Mar 28;368:1173–1175.
- 6. American Medical Association. Virtual Mentor. 2013;13(12):1038-1040.
- Council on Ethical and Judicial Affairs. Report B-A-91: Decisions Near the End of Life. Adopted June 1991. Available at http://<u>http://www.ama-assn.org/ama/pub/about-ama/our</u> people/ama-councils/council-ethical-judicial-affairs/ceja-reports.page? Accessed Sep 5, 2024.
- 8. What are palliative care and hospice care. National Institute on Aging. https://www.nia.nih.gov/health/hospice-and-palliative-care/what-are-palliative-care-and-hospice-care. Accessed 27 Feb 20248.
- Coalition T Coalition responds to Senate HELP committee hearing on health care workforce shortages. National Coalition For Hospice and Palliative Care. https://www.nationalcoalitionhpc.org/coalition-responds-to-senate-help-committee-hearing-onhealth-care-workforce-shortages/. Accessed 27 Feb 2024
- 10. World Medical Association. WNA Declaration on End-of-Life Care. https://www.wma.net/policies-post/wma-declaration-on-end-of-life-medical-care/
- 11. Blinderman CD, Billings JA. Comfort care for patients dying in the hospital. New England Journal of Medicine. 2015 Dec 24;374:1692–1693.
- 12. Schofield G, Dittborn M, Huxtable R, et al. Real-world ethics in Palliative Care: A systematic review of the ethical challenges reported by specialist palliative care practitioners in their clinical practice. Palliative Medicine 2020 Dec 10;35:315–334.
- 13. Dijxhoorn A-FQ, Brom L, van der Linden YM, et al. Prevalence of burnout in healthcare professionals providing palliative care and the effect of interventions to reduce symptoms: A systematic literature review. Palliative Medicine. 2020 Oct 16;35:6–26.
- Ferrell BR, Twaddle ML, Melnick A, et al. National consensus project clinical practice guidelines for quality palliative care guidelines, 4th edition. Journal of Palliative Medicine. 2018 Dec 14;21(12), 1684–1689.
- 15. Temel JS, Greer JA, Muzikansky A, Gallagher ER, et. al. Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer. JAMA. 2010;363:733-742.
- 16. Rodriguez KL, Barnato AE, Arnold RM. Perceptions and utilization of palliative care services in Acute Care Hospitals. Journal of Palliative Medicine 2007 Feb 13;10:99–110.
- 17. Sabatino CP. The evolution of health care advance planning law and policy. Milbank Q. 2010 Jun;88(2):211-39.
- QuickStats: Percentage of deaths, by place of death national vital statistics system, United States, 2000–2018. In: Centers for Disease Control and Prevention. https://www.cdc.gov/mmwr/volumes/69/wr/mm6919a4.htm?s_cid=mm6919a4_w. Accessed 27 Feb 2024

- 19. Steinberg A, Abella BS, Gilmore EJ, et al (2021) Frequency of withdrawal of life-sustaining therapy for perceived poor neurologic prognosis. Critical Care Explorations. 2021 Jul;3(7):p e0487.
- 20. Morrison RS. Meier DE, Arnold RM. What's wrong with advance care planning? JAMA 2021;326(16):1575-1576.
- 21. Centeno C, Sitte T, de Lima L, Alsirafy S, Bruera E, Callaway M, Foley K, Luyirika E, Mosoiu D, Pettus K, Puchalski C, Rajagopal MR, Yong J, Garralda E, Rhee JY, Comoretto N. White Paper for Global Palliative Care Advocacy: Recommendations from a PAL-LIFE Expert Advisory Group of the Pontifical Academy for Life, Vatican City. J Palliat Med. 2018 Oct;21(10):1389-1397. doi: 10.1089/jpm.2018.0248.)"
- Triplett DP, LeBrett WG, Bryant AK, Bruggeman AR, Matsuno RK, Hwang L, Boero IJ, Roeland EJ, Yeung HN, Murphy JD. Effect of Palliative Care on Aggressiveness of End-of-Life Care Among Patients With Advanced Cancer. J Oncol Pract. 2017 Sep;13(9):e760-e769.
- 23. National Palliative Care Research Center. http://www.npcrc.org/news-detail.aspx?id=150
- 24. Macfarlane GJ, Barnish MS, Jones GT. Ann Rheum Dis. 2017;76(11):1815-1822. https://pubmed.ncbi.nlm.nih.gov/28733474/
- 25. Zhang Z, Jackson SL, Gillespie C. JAMA Network Open. 2023;6(10):e2337011. https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2810363
- 26. Sulmasy DP, Pellegrino ED. The rule of double effect: clearing up the double talk. Arch Intern Med. 1999 Mar 22;159(6):545-50. doi: 10.1001/archinte.159.6.545; Sulmasy DP. 'Re-inventing' the rule of double effect. In: The Oxford Handbook of Bioethics, ed. B Steinbock, Oxford: Oxford University Press, 2007, 114-149.).
- 27. Pesola GR. Ahsan H. Clin Respir J. 2016;10(2):142–152. https://onlinelibrary.wiley.com/doi/10.1111/crj.12191.