REPORT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS*

CEJA Report 5-A-18

Subject:

Study Aid-in-Dying as End-of-Life Option

(Resolution 15-A-16)

The Need to Distinguish "Physician-Assisted Suicide" and "Aid in Dying"

(Resolution 14-A-17)

Presented by:

Dennis S. Agliano, MD, Chair

Referred to:

Reference Committee on Amendments to Constitution and Bylaws

(Peter H. Rheinstein, MD, JD, MS, Chair)

2 3

1

At the 2016 Annual Meeting, the House of Delegates referred Resolution 15-A-16, "Study Aid-in-Dying as End-of-Life Option," presented by the Oregon Delegation, which asked:

4 5 6

7

8

That our American Medical Association and its Council on Judicial and Ethical Affairs, study the issue of medical aid-in-dying with consideration of (1) data collected from the states that currently authorize aid-in-dying, and (2) input from some of the physicians who have provided medical aid-in-dying to qualified patients, and report back to the HOD at the 2017 Annual Meeting with recommendation regarding the AMA taking a neutral stance on physician "aidin-dying."

9 10 11

12

At the following Annual Meeting in June 2017, the House similarly referred Resolution 14-A-17, The Need to Distinguish between 'Physician-Assisted Suicide' and 'Aid in Dying'" (presented by M. Zuhdi Jasser, MD), which asked that our AMA:

13 14 15

16

17

18 19

20

(1) as a matter of organizational policy, when referring to what it currently defines as 'Physician Assisted Suicide' avoid any replacement with the phrase 'Aid in Dying' when describing what has long been understood by the AMA to specifically be 'Physician Assisted Suicide'; (2) develop definitions and a clear distinction between what is meant when the AMA uses the phrase 'Physician Assisted Suicide' and the phrase 'Aid in Dying'; and (3) fully utilize these definitions and distinctions in organizational policy, discussions, and position statements regarding both 'Physician Assisted Suicide' and 'Aid in Dying.'

21 22 23

24

25

26

This report by the Council on Ethical and Judicial Affairs (CEJA) addresses the concerns expressed in Resolutions 15-A-16 and 14-A-17. In carrying out its review of issues in this area, CEJA reviewed the philosophical and empirical literature, sought input from the House of Delegates through an I-16 educational program on physician-assisted suicide, an informal "open house" at A-17, and its I-17 Open Forum. The council wishes to express its sincere appreciation for participants' contributions during these sessions and for additional written communications received from multiple stakeholders, which have enhanced its deliberations.

27 28 29

^{*} 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.

The council observes that the ethical arguments advanced today supporting and opposing 1 "physician-assisted suicide" or "aid in dying" are fundamentally unchanged from those examined 2 in CEJA's 1991 report on this topic [1]. The present report does not rehearse these arguments again 3 as such. Rather, it considers the implications of the legalization of assisted suicide in the United States since the adoption of Opinion E-5.7, "Physician-Assisted Suicide," in 1994.

5 6 7

"ASSISTED SUICIDE," "AID IN DYING," OR "DEATH WITH DIGNITY"?

8 9 10

11

12

13

14

15

16

Not surprisingly, the terms stakeholders use to refer the practice of physicians prescribing lethal medication to be self-administered by patients in many ways reflect the different ethical perspectives that inform ongoing societal debate. Proponents of physician participation often use language that casts the practice in a positive light. "Death with dignity" foregrounds patients' values and goals, while "aid in dying" invokes physicians' commitment to succor and support. Such connotations are visible in the titles of relevant legislation in states that have legalized the practice: "Death with Dignity" (Oregon, Washington, District of Columbia), "Patient Choice and Control at the End of Life" (Vermont), "End of Life Options" (California, Colorado), and in Canada's "Medical Aid in Dying."

17 18 19

20

21

22

23

Correspondingly, those who oppose physician provision of lethal medications refer to the practice as "physician-assisted suicide," with its negative connotations regarding patients' psychological state and its suggestion that physicians are complicit in something that, in other contexts, they would seek to prevent. The language of dignity and aid, critics contend, are euphemisms [2]; their use obscures or sanitizes the activity. In their view such language characterizes physicians' role in a way that risks construing an act that is ethically unacceptable as good medical practice [3].

24 25 26

27

28

29

30

31

32

The council recognizes that choosing one term of art over others can carry multiple, and not always intended messages. However, in the absence of a perfect option, CEJA believes ethical deliberation and debate is best served by using plainly descriptive language. In the council's view, despite its negative connotations [4], the term "physician assisted suicide" describes the practice with the greatest precision. Most importantly, it clearly distinguishes the practice from euthanasia [1]. The terms "aid in dying" or "death with dignity" could be used to describe either euthanasia or palliative/ hospice care at the end of life and this degree of ambiguity is unacceptable for providing ethical guidance.

33 34 35

COMMON GROUND

36 37

38

39

40

41

42

Beneath the seemingly incommensurate perspectives that feature prominently in public and professional debate about writing a prescription to provide patients with the means to end life if they so choose, CEJA perceives a deeply and broadly shared vision of what matters at the end of life. A vision that is characterized by hope for a death that preserves dignity, a sense of the sacredness of ministering to a patient at the end of life, recognition of the relief of suffering as the deepest aim of medicine, and fully voluntary participation on the part of both patient and physician in decisions about how to approach the end of life.

43 44 45

46

47

48

49

50

Differences lie in the forms these deep commitments take in concrete decisions and actions. CEJA believes that thoughtful, morally admirable individuals hold diverging, yet equally deeply held, and well-considered perspectives about physician-assisted suicide that govern how these shared commitments are ultimately expressed. For one patient, dying "with dignity" may mean accepting the end of life however it comes as gracefully as one can; for another, it may mean being able to exercise some measure of control over the circumstances in which death occurs. For some

physicians, the sacredness of ministering to a terminally ill or dying patient and the duty not to 51

abandon the patient preclude the possibility of supporting patients in hastening their death. For others, not to provide a prescription for lethal medication in response to a patient's sincere request violates that same commitment and duty. Both groups of physicians base their view of ethical practice on the guidance of Principle I of the AMA *Principles of Medical Ethics*: "A physician shall be dedicated to providing competent medical care, with compassion and respect for human dignity and rights."

So too, how physicians understand and act on the goals of relieving suffering, respecting autonomy, and maintaining dignity at the end of life is directed by identity-conferring beliefs and values that may not be commensurate. Where one physician understands providing the means to hasten death to be an abrogation of the physician's fundamental role as healer that forecloses any possibility of offering care that respects dignity, another in equally good faith understands supporting a patient's request for aid in hastening a foreseen death to be an expression of care and compassion.

IRREDUCIBLE DIFFERENCES IN MORAL PERSPECTIVES ON PHYSICIAN-ASSISTED SUICIDE

How to respond when coherent, consistent, and deeply held beliefs yield irreducibly different judgments about what is an ethically permissible course of action is profoundly challenging. With respect to physician-assisted suicide, some professional organizations—for example, the American Academy of Hospice and Palliative Medicine [5]—have adopted a position of "studied neutrality." Positions of studied neutrality neither endorse nor oppose the contested practice, but instead are intended to respect that there are irreducible differences among the deeply held beliefs and values that inform public and professional perspectives [5,6], and to leave space open for ongoing discussion. Nonetheless, as a policy position, studied neutrality has been criticized as being open to unintended consequences, including stifling the very debate it purports to encourage or being read as little more than acquiescence with the contested practice [7].

CEJA approaches the condition of irreducible difference from a different direction. In its 2014 report on exercise of conscience, the Council noted that "health care professionals may hold very different core beliefs and thus reach very different decisions based on those core beliefs, yet equally act according to the dictates of conscience. For example, a physician who chooses to provide abortions on the basis of a deeply held belief in protecting women's autonomy makes the same kind of moral claim to conscience as does a physician who refuses to provide abortion on the basis of respect for the sanctity of life of the fetus" [8].

Importantly, decisions taken in conscience are not simply idiosyncratic; they do not rest on intuition or emotion. Rather, such decisions are based on "substantive, coherent, and reasonably stable" values and principles [8]. Physicians must be able to articulate how those values and principles justify the action in question.

The ethical arguments offered for more than two decades by those who support and those who oppose physician participation in assisted suicide reflect the diverging "substantive, coherent, and reasonably stable" values and principles within the profession and the wider moral community. While supporters and opponents of physician-assisted suicide share a common commitment to "compassion and respect for human dignity and rights" (AMA Principles of Medical Ethics, I), they draw different moral conclusions from the underlying principle they share. As psychiatrist Harvey Chochinov observed with respect to the stakeholders interviewed by Canadian Supreme Court's advisory panel on physician-assisted death, "neither those who are strongly supportive nor those who are spread hold a manufacture of the stakeholders."

those who are opposed hold a monopoly on integrity and a genuine concern for the well-being of

people contemplating end of life. Equally true: neither side is immune from impulses shaped more by ideology than a deep and nuanced understanding of how to best honor and address the needs of people who are suffering" [9].

THE RISK OF UNINTENDED CONSEQUENCES

From the earliest days of the debate, a prominent argument raised against permitting physician-assisted suicide has been that doing so will have adverse consequences for individual patients, the medical profession, and society at large. Scholars have cited the prospect that boundaries will be eroded and practice will be extended beyond competent, terminally ill adult patients; to patients with psychiatric disorders, children; or that criteria will be broadened beyond physical suffering to encompass existential suffering; or that stigmatized or socioeconomically disadvantaged patients will be coerced or encouraged to end their lives. Concerns have also been expressed that permitting the practice will compromise the integrity of the profession, undermine trust, and harm the physicians and other health care professionals who participate; and that forces outside medicine will unduly influence decisions.

The question whether safeguards—which in the U.S. jurisdictions that permit assisted suicide, restrict the practice to terminally ill adult patients who have decision-making capacity and who voluntarily request assisted suicide, along with procedural and reporting requirements—can actually protect patients and sustain the integrity of medicine remains deeply contested. Some studies have "found no evidence to justify the grave and important concern often expressed about the potential for abuse—namely, the fear that legalized physician-assisted dying will target the vulnerable or pose the greatest risk to people in vulnerable groups" [10], others question whether the available data can in fact support any such conclusions, finding the evidence cited variously flawed [11], inadequate [12], or distorted [13].

Although cross-cultural comparisons are problematic [14], current evidence from Europe does tell a cautionary tale. Recent findings from studies in Belgium and the Netherlands, both countries that permit euthanasia as well as physician-assisted suicide, mitigate some fears but underscore others [15]. For example, research in the Netherlands has found that "requests characterized by psychological as opposed to physical suffering were more likely to be rejected, as were requests by individuals who lived alone," mitigating fears that "solitary, depressed individuals with potentially reversible conditions might successfully end their lives." At the same time, however, among patients who obtained euthanasia or assisted suicide, nearly 4 percent "reported only psychological suffering." At the level of anecdote, a description of a case of euthanasia in Belgium elicited widespread concern about the emergence of a "slippery slope" [16].

Studies have also raised questions about how effective retrospective review of decisions to provide euthanasia/assisted suicide is in policing practice [17,18]. A qualitative analysis of cases that Dutch regional euthanasia committees determined had not met legal "due care criteria" found that such reviews focus on procedural considerations and do not "directly assess the actual eligibility" of the patients who obtained euthanasia [17]. A separate study of cases in which psychiatric patients obtained euthanasia found that physicians' reports "stated that psychosis or depression did or did not affect capacity but provided little explanation regarding their judgments" and that review committees "generally accepted the judgment of the physician performing EAS [euthanasia or physician-assisted suicide]" [18]. It remains an open question whether reviews that are not able to assess physicians' reasoning truly offer the protection they are intended to provide. To the extent that reporting and data collection in states that permit physician-assisted suicide have similar limitations, oversight of practice may not be adequate.

Medicine must learn from this experience. Where physician-assisted suicide is legalized, safeguards can and should be improved—e.g., "[t]o increase safeguards, states could consider introducing multidisciplinary panels to support patients through the entire process, including verifying consent and capacity, ensuring appropriate psychosocial counseling, and discussing all palliative and end-of-life options" [19]. Both the state and the medical profession have a responsibility to monitor ongoing practice in a meaningful way and to address promptly compromises in safeguards should any be discovered. It is equally important that strong practices be identified and encouraged across all jurisdictions that permit physicians to assist suicide. Health care organizations in California and Canada, for example, have shared richly descriptive reports of practices adopted in response to the recent legalization of "aid in dying" in those jurisdictions that seek to address concerns about quality of practice and data collection [20,21].

Medicine must also acknowledge, however, that evidence (no matter how robust) that there have not yet been adverse consequences cannot guarantee that such consequences would not occur in the future. As a recent commentary noted, "[p]art of the problem with the slippery slope is you never know when you are on it" [15].

SAFEGUARDING DECISIONS AT THE END OF LIFE

CEJA has found that just as there are shared commitments behind deep differences regarding physician-assisted suicide, there are also shared concerns about how to understand the available evidence. For example, in the council's recent Open Forum, both proponents and opponents of physician-assisted suicide observed that in the U.S., debate occurs against the backdrop of a health care system in which patients have uneven access to care, including access to high quality end-of-life care. They also noted that patients and physicians too often still do not have the conversations they should about death and dying, and that too few patients are aware of the range of options for end-of-life care, raising concern that many patients may be led to request assisted suicide because they don't understand the degree of relief of suffering state-of-the-art palliative care can offer. Participants who in other respects held very different views concurred as well that patients may be vulnerable to coercion, particularly patients who are in other ways disadvantaged; and expressed concern in common that forces external to medicine could adversely influence practice.

These are much the same concerns the Institute of Medicine identified in its 2015 report, *Dying in America* [22]. They are concerns echoed in a February 2018 workshop on physician-assisted death convened by the National Academies of Science, Engineering and Medicine [23]. They underscore how important it is to understand *why* a patient requests assisted suicide as a starting point for care.

Patient requests for assisted suicide invite physicians to have the kind of difficult conversations that are too often avoided. They open opportunities to explore the patient's goals and concerns, to learn what about the situation the individual finds intolerable and to respond creatively to the patient's needs other than providing the means to end life—by such means as better managing symptoms, arranging for psychosocial or spiritual support, treating depression, and helping the patient to understand more clearly how the future is likely to unfold [4,24]. Medicine as a profession must ensure that physicians are skillful in engaging in these difficult conversations and knowledgeable about the options available to terminally ill patients [25]. The profession also has a responsibility to advocate for adequate resources for end-of-life care [14,25], particularly for patients from disadvantaged groups. The availability of assisted suicide where it is legal must not be allowed to interfere with excellent care at the end of life

CONCLUSION

At the core of public and professional debate, the council believes, is the aspiration that every patient come to the end of life as free as possible from suffering that does not serve the patient's deepest self-defining beliefs and in the presence of trusted companions, including where feasible and when the patient desires, the presence of a trusted physician. As Timothy Quill noted more than 20 years ago, "dying patients do not have the luxury of choosing not to undertake the journey, or of separating their person from their disease" [24]. Decisions about how to approach the end of intimacy and the authenticity of those relationships is essential if our common ideal is to be achieved.

RECOMMENDATION

Over the past two years, the Council on Ethical and Judicial Affairs has reviewed the literature and received thoughtful input from numerous individuals and organizations to inform its deliberations, and is deeply grateful to all who shared their insights. CEJA engaged in extensive, often passionate discussion about how to interpret the Code of Medical Ethics in light of ongoing debate and the irreducible differences in moral perspectives identified above. After careful consideration, CEJA concludes that in its current form the Code offers guidance to support physicians and the patients they serve in making well-considered, mutually respectful decisions about legally available options for care at the end of life in the intimacy of a patient-physician relationship. The Council on Ethical and Judicial Affairs therefore recommends that the Code of Medical Ethics not be amended, that Resolutions 15-A-16 and 14-A-17 not be adopted and that the remainder of the report be filed.

Fiscal Note: None.

REFERENCES

- 1. Council on Ethical and Judicial Affairs. Decisions near the end of life. JAMA 1992;267:2229-2233.
- 2. Vamos MJ. Physician-assisted suicide: saying what we mean and meaning what we say. ANZJP 2012;46:84-86.
- 3. Herx L. Physician-assisted death is not palliative care. Curr Oncol 2015;22:82-83.
- 4. Quill TE, Back AL, Block SD. Responding to patients requesting physician-assisted death: physician involvement at the very end of life. JAMA 2016;315:245-246.
- 5. American Academy of Hospice and Palliative Medicine. Statement on Physician-Assisted Dying, June 24, 2016. Available at
- 6. Quill TE, Cassel CK. Professional organizations' position statements on physician-assisted suicide: a case for studied neutrality. Ann Intern Med 2003;138:208-211.
- 7. Johnstone M-J. Organization position statements and the stance of "studied neutrality" on euthanasia in palliative care. J Pain Symptom Manage 2012;44:896–907.
- 8. Crigger BJ, McCormick PW, Brotherton SL, Blake V. Report by the American Medical Association's Council on Ethical and Judicial Affairs on physicians' exercise of conscience. J Clin Ethics 2016;27:291-226.
- 9. Chochinov HM. Physician-assisted death in Canada. JAMA 2016;315:253-254.
- 10. Battin MP, van der Heide A, Ganzini L, van der Wal G, Onwuteaka-Philipsen B. Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in vulnerable groups. J Med Ethics 2007;33:591–597.
- 11. Finlay IG, George R. Legal physician-assisted suicide in Oregon and The Netherlands: evidence concerning the impact on patients in vulnerable groups—another perspective on Oregon's data. J Med Ethics 2010;37:171-174.
- 12. Golden M, Zoanni T. Killing us softly: the dangers of legalizing assisted suicide. Disability and Health Journal 2010;3:16-30.
- 13. U.S. Conference of Catholic Bishops. Assisted Suicide Laws in Oregon and Washington: What Safeguards? September 22, 2016. Available at http://www.usccb.org/search.cfm?site=newusccb&proxystylesheet=newusccb_frontend&q=ass isted+suicide&lang=eng. Accessed October 27, 2016.
- 14. Ganzini L, Back AL. The challenge of new legislation on physician-assisted death. JAMA Intern Med 2016;176:427-428.
- 15. Lerner BH, Caplan AL. Euthanasia in Belgium and the Netherlands: on a slippery slope? JAMA Intern Med 2015;175:1640-1641.
- 16. Aviv R. The death treatment. New Yorker;2015:June 22.
- 17. Miller DG, Kim SYH. Euthanasia and physician-assisted suicide not meeting due care criteria in the Netherlands: a qualitative review of review committee judgments. BMJ Open 2017;7: e017628.
- 18. Doernberg SN, Peteet JR, KIM SYH. Capacity evaluation of psychiatric patients requesting assisted death in the Netherlands. Psychosomatics 2016;57:556-565.
- 19. Gostin LO, Roberts AE. Physician-assisted dying: a turning point? JAMA 2016;315:249-250.
- 20. Nguyen HQ, Gelman EJ, Bush TA, Lee JA, Kanter MH. Characterizing Kaiser Permanente Southern California's experience with the California End of Life Option Act in the first year of implementation [research letter]. JAMA Intern Med 2017; December 26.
- 21. Li M, Watt S, Escaf M, et al. Medical assistance in dying: implementing a hospital-based program in Canada. N Engl J Med 2017;376:2082–2088.
- 22. Institute of Medicine. Dying in America: Improving Quality and Honoring Individual Preferences near the End of Life. Washington, DC: The National Academies Press; 2015.
- 23. National Academies of Science, Engineering and Medicine. "Physician-Assisted Death: Scanning the Landscape and Potential Approaches" Workshop, February 12-13, 2018.

CEJA Rep. 5-A-18 -- page 8 of 8

- 24. Quill TE. Doctor, I want to die. will you help me? *JAMA* 1993;270:870–873.
- 25. Petrillo LA, Dzeng E, Smith AK. California's End of Life Option Act: opportunities and challenges ahead. J Gen Intern Med 2016;31:828–829.