

# An Ethics of Permission: A Response to the California End of Life Option Act

Craig Nelson, PhD, CLS

Perm J 2016 Fall;20(4):16-023

E-pub: 08/17/2016

<http://dx.doi.org/10.7812/TPP/16-023>

## ABSTRACT

An ethics of permission can be helpful in framing a response to the ethical differences surrounding the California End of Life Option Act. Law does not define morality, and reaching a moral understanding demands thorough reflection. An ethics of permission examines the ethical demands of a permissive law for both clinician and patient. Serving the good of the patient, respecting professional conscience, and following the law are three ethical elements. Although developing an ethics of permission includes these three elements, these elements do not exhaust all the moral implications involved. An ethics of permission also includes the importance of exercising professional tolerance in the honoring of clinicians who choose to participate or refuse to participate. In addition, an ethics of permission also provides insight in implementing just and fair behavior among medical professionals.

## INTRODUCTION

On October 5, 2015, California Governor Jerry Brown signed into law the End of Life Option Act (EOLOA),<sup>1</sup> legalizing physician aid in dying in that state. The law took effect June 9, 2016. Before the enactment of this law, a physician who provided a lethal agent would be liable to criminal charges of homicide or of assisting suicide. The law specifies the process a physician must follow to prescribe any aid-in-dying medication, including referral to another physician for medical confirmation of diagnosis, prognosis, and capacity. The process is entirely voluntary, with liability protections for both those who choose to participate and for those who

decline to participate. Eligible patients must be age 18 years or older, residents of California, and of sound mind, and have a diagnosis of a terminal illness that, subject to reasonable medical judgment, will prove fatal within 6 months. These patients also must be capable of self-administering the aid-in-dying drug. In addition, eligible patients must make 2 oral requests to a physician separated by a 15-day waiting period, which must be followed by a witnessed written request. The prescribing “attending physician” must be appropriately licensed and registered with the Drug Enforcement Administration. It is the responsibility of this physician to inform the patient of alternatives such as palliative care. A “consulting physician” must certify the diagnosis and reassess the mental competence of the patient in question. If either physician deems the judgment of the patient to be impaired, the patient must be referred for a psychiatric evaluation. An important distinction should be made between the anticipatory grief of finality and depression.

The State of California is continuing to walk through a new legal and moral threshold but not without ethical questions. Ethical questions existed before the law was written. Physicians have prescribed medications that may relieve pain and have the double effect of sedating or diminishing respiratory function under the common practice of palliative sedation. Questions that recur include themes such as providing compassion and beneficence in the presence of terminal physical pain and disability; the right of patients to exercise free choice and autonomy; and deeply held views on the sanctity of life, faithfulness to the healing, and the “first do no harm” imperative of medicine. Other

ethical questions include the professional autonomy of clinicians, the risk of coercion for the elderly and the debilitated, and the ethical obligations of those who opt out of participating.

Terminally ill Californians are now able under law to request life-ending drugs. Is there a helpful way to describe an ethical approach to recurring ethical questions? Ethical expertise in the work of clinical ethics has been both principle centered and context centered.<sup>2</sup> This knowledge of ethical conversation has historically relied on theories and principles such as teleology (describing which action would bring about the goal being sought), deontology (defining what one’s duty is), justice, autonomy and beneficence, and casuistry (adapting ethical principles to circumstances and emphasizing sensitivity to particular cases).<sup>3</sup> These theories and principles all help us focus more clearly on patient preferences, quality-of-life questions, contextual issues including patient and family values, monetary resources, religious beliefs, and cultural factors.

The questions surrounding the EOLOA represent moral diversity; because universally accepted normative answers are unreachable, we should not expect to discover a monolithic right or wrong answer. It is important to describe a reflective approach that is capable of providing direction in forming a moral understanding for the recurring ethical questions. The adversarial issues around physician-assisted death ultimately are of primary concern to the patient, the family, and the local community. Political debate at the state level is less important than are religious and cultural attitudes confronting patients asking permission of their family and their God to take life-ending medication.

Craig Nelson, PhD, CLS, is the Director of Medical Bioethics at the South Bay Medical Center in Harbor City, CA, and a Claremont School of Theology Library Scholar in CA. E-mail: [cnelson540@aol.com](mailto:cnelson540@aol.com).

## ETHICS OF PERMISSION

In California, how can clinicians begin to talk about the EOLOA with respect for diversity and still embrace a personal moral position? I propose exploring what we mean by an ethics of permission. An ethics of permission is not advocating for a “permissive society” but provides a common understanding that shapes some basic ground rules for coexisting ethical positions. An ethics of permission used in this commentary is not championing the permission to engage in the EOLOA. I am not trying to defend the rationale of the EOLOA. Rather, an ethics of permission is describing how to treat one another regarding the EOLOA. A permissive law creates an ethical demand. This demand is both the recognition that there is an ethical obligation for all because of the existence of the law and a particular ethical behavior because the law affects those individuals who appreciate the actions permitted in the aid-in-dying statute and those who may hold a different moral position. In other words, regarding the EOLOA, how should professionals act toward one another and toward their patients?

Because the EOLOA was created as a permissive law, no one is obligated to engage in its formal activity. Clinicians to one degree or another become materially involved in its activity. But how? Should health care professionals answer questions about the EOLOA and even refer patients interested in it to a health care professional who may have a comfortable conscience in participating in what the law outlines? Is it ethical to be a barrier to a patient wanting referral to a health care professional who is comfortable in participating in what the law permits? Is it an ethical obligation to refer a patient to a willing clinician? Is there an implied obligation to refer patients interested in exercising their right to participate in the EOLOA that should be an essential component of the conscientious objection process? An answer to these questions should never produce actions that legitimate patient abandonment.

In a culture of diversity, such as in California, health care professionals coming from different moral viewpoints must find a way of relating to each other without primarily saying that those embracing the opposing viewpoints are morally suspect.

It is important to work together by creating an approach to moral diversity that will preserve teamwork, collaboration, and communication. This is not advocating for a broad brushstroke of ethical relativism and that anything is morally acceptable as long as it is what you say you believe. An ethics of permission for physician-assisted death emphasizes the importance of understanding professional tolerance, the value of honoring conscientious refusal to participate, and the goal of promoting fairness and justice. In reviewing the potential adversarial nature of discourse surrounding the ethics of physician-assisted death, being in favor or against physician-assisted death is not simply divided into two opposing positions. People may be in favor of it for others but not for themselves or vice versa, or under some circumstances but not others. The downside of not employing an ethics of permission can hinder a realization of moral understanding and lead to moral cacophony in the delivery of compassionate, integrated health care.

Once a patient enters a clear trajectory of clinical decline caused by a terminal disease that includes a likely prognosis of death within six months, the limits of medicinal cure are realized. Some patients may want to avoid living in such a state of clinical decline and believe that the burdens of treatment outweigh the probability of life extension.

The conceptual balance dwells between questions of how patients survive and thrive with illness and how they minimize the prolongation of their dying process by taking aid-in-dying medication in the face of terminal and severely disabling illness. The distinction between treating the disease and relieving suffering is important. Healing moves into more of an existential expression when palliation can help minimize the suffering from disease and help the patient search for peace and meaning for the quality of life that remains.<sup>4</sup> Sometimes the reach of effective palliation is perceived as falling short of realizing its goal.

The good of the patient must be sought in one’s own particular existential circumstance through both curing and healing,<sup>5</sup> but healing involves the whole person, not just his/her physiologic condition. An ethics of permission applies to those clinicians in good conscience who believe

participating in the law helps terminal patients deal with existential suffering in their specific context in the only possible way they can,<sup>5</sup> and there seems no other way for a quality of life to be experienced that honors their lived values.

An ethics of permission should nurture fairness, tolerance, and justice. For an ethics of permission to be fair, it should uphold professional tolerance for all involved. In other words, to adopt fairness as a procedural notion hinges on choosing to adopt a shared moral point of view.<sup>6</sup> This can mean that those who choose to participate and those who choose not to participate are both enjoined to exercise professional tolerance toward the other. Fairness is a key concept in social and professional tolerance as we all perform our duties in a social context in which we are affected by the opinions and actions of other decision makers. These have been noted as “interdependence situations,”<sup>7</sup> and the intent to be fair is important to uphold.<sup>8</sup> Some research indicates that when people from different ages, cultures, religions, and educational backgrounds judge cases involving helping or harming others, they do so in a universally informed and shared way.<sup>9</sup> The key, however, is discerning how to define help and how to define harm. This is an important distinction involved in physician aid in dying. This will be perspectival, and a specific and contextual understanding of the “good of the patient” from the patient’s perspective will always play a major role in the distinction.<sup>10</sup>

Physicians who decide not to formally participate in the EOLOA should exercise tolerance toward those who in good conscience participate in the law believing that they are serving the good of the patient from the patient’s perspective. Physicians who do opt to participate should exercise tolerance toward physicians who decide not to participate. This tolerance does not imply that they are accepting their colleague’s moral posture as their own. Tolerance allows for plurality of belief and can be the ingredient of reciprocal exchange; tolerance and goodwill are exchanged in a cooperative act between individuals who possess different moral positions.<sup>11</sup>

For an ethics of permission to be just, it must treat all professionals as they deserve, whether they choose to participate

in the law or choose not to participate in validating a patient's request for life-ending drugs. Justice should also facilitate social cooperation.<sup>12</sup> Hayek<sup>13</sup> reminds us that an objective standard of justice must not make one either too powerful or too weak and should be embedded in a dialogue of human experience and reflection. This means that each clinician has a specific human experience and moral reflection that should be allowed expression, while refraining from believing that s/he possesses proprietary knowledge about what is morally acceptable for all. Justice hinges on accepting difference with respect.

All clinicians deserve to exercise their professional conscience. This conscience can cause a physician to find merit in participating in the validation described within the law or to find merit in abstaining from providing such validation. The law allows for restitution for those physicians who find their moral posture to differ from that of physicians who choose to participate. Their conscientious refusal to participate should be tolerated by physicians who believe in participating in the law. In this way, those physicians from each moral position receive what they deserve: tolerance and respect. Forrester<sup>14</sup> emphasizes that justice must remain robust enough to face real conflicts of interest and understanding, and visionary enough to call forth a passionate commitment to thoroughly examine one's self-interest while being mindful of the other.

## CONCLUSION

This brief commentary introduced an ethical approach to questions surrounding the enactment of the EOLOA. It suggested that an ethics of permission should be considered as a lens and guide for those who have different ethical positions.<sup>15,16</sup> An ethics of permission is one step in developing a more practical understanding of professional tolerance, of how to encourage conscientious refusal, and how to provide a fervent commitment to promote justice and fairness that maintains a focus on the good of the patient. ❖

## Disclosure Statement

*The author(s) have no conflicts of interest to disclose.*

## Acknowledgment

*Kathleen Loudon, ELS, of Loudon Health Communications provided editorial assistance.*

## How to Cite this Article

Nelson C. An ethics of permission: A response to the California End of Life Option Act. *Perm J* 2016 Fall;20(4):16-023. DOI: <http://dx.doi.org/10.7812/TPP/16-023>.

## References

- California Assembly Bill No. 15. AB-15 End of life. Ch 1, Part 1.85, Sect 443 (2015 Oct 5).
- Walker MU. Keeping moral space open. *New images of ethics consulting. Hastings Cent Rep* 1993 Mar-Apr;23(2):33-40. DOI: <http://dx.doi.org/10.2307/3562818>.
- Frankena WK. *Ethics. Foundations of philosophy series.* 1st ed. Upper Saddle River, NJ: Prentice Hall; 1973.
- Frankl VE. *Man's search for meaning.* Boston, MA: Beacon Press; 2006. p 121.
- Nelson C. Curing and healing. *Oneing: Evidence* 2014 Oct;2(2):57-62.
- Hollis M. *Trust within reason.* Cambridge, United Kingdom: Cambridge University Press; 1998. p 92, 96.
- De Cremer D, van Dijk E. Fairness and ethics in social decision making. *Soc Justice Res* 2003 Sep;16(3):191-4. DOI: <http://dx.doi.org/10.1023/A:1025989927725>.
- Guroglu B, van den Bos W, Rombouts S, Crone E. Unfair? It depends: neural correlates of fairness in social context. *Soc Cogn Affect Neurosci* 2010 Dec;5(4):414-23. DOI: <http://dx.doi.org/10.1093/scan/nsq013>.
- Hauser M. What's fair? The unconscious calculus of our moral faculty. *Novartis Found Symp* 2007;278:41-50, discussion 50-5,89-96,216-21. DOI: <http://dx.doi.org/10.1002/9780470030585.ch4>.
- Pellegrino E. *The philosophy of medicine reborn: a Pellegrino Reader (ND Studies in Medical Ethics).* Notre Dame, IN: Notre Dame University Press; 2008. p 164-73.
- Molm LD, Collett JL, Schaefer DR. Conflict and fairness in social exchange. *Social Forces* 2006 Jun;84(4):2331-52. DOI: <http://dx.doi.org/10.1353/sof.2006.0100>.
- MacIntyre A. *Whose justice? Whose rationality?* Notre Dame, IN: University of Notre Dame Press; 1988. p 3.
- Hayek FA. *Law, legislation and liberty, volume 2: the mirage of social justice.* 2nd edition, Chicago, IL: University of Chicago Press; 1978. p 75.
- Forrester DB. *Christian justice and public policy.* Cambridge, UK: Cambridge University Press, 1997. p 128.
- Quill T. Physicians should "assist in suicide" when it is appropriate. *J Law Med Ethics* 2012 Spring;40(1):57-65. DOI: <http://dx.doi.org/10.1111/j.1748-720X.2012.00646.x>.
- Pellegrino ED. Some things ought never be done: moral absolutes in clinical ethics. *Theor Med Bioeth* 2005;26(6):469-86 DOI: <http://dx.doi.org/10.1007/s11017-005-2201-2>.

## Wisdom

To die well is the height of wisdom of life.

— Søren Kierkegaard, 1813-1855, Danish philosopher, theologian, poet, social critic, and religious author