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How California Prepared for Implementation of Physician-Assisted Death: A Primer

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Abstract

Physician-assisted death is now legal in California, and similar laws are being considered in many other states. The California law includes safeguards, yet health care providers will face practical and ethical issues while implementing physician-assisted death that are not addressed by the law.

To help providers and health care facilities in California prepare to provide optimal care to patients who inquire about physician-assisted death, we brought together experts from California, Oregon, and Washington. We convened a conference of 112 stakeholders in December 2015, and herein present their recommendations.

Themes of recommendations regarding implementation include (1) institutions should develop and revise physician-assisted death policies; (2) legal physician-assisted death will have implications for California's culturally and socioeconomically diverse population, and for patients from vulnerable groups; (3) conscientious objection and moral distress for health care providers must be considered; and (4) palliative care is essential to the response to the law. The expert conference participants' insights are a valuable guide, both for providers and health care facilities in

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CONTRIBUTORS

L. A. Petrillo and E. Dzung are co–first authors of the article. L. A. Petrillo, E. Dzung, L. Forbes, and B. A. Koenig originated the idea for the article. K. L. Harrison and B. Scribner collected the data. L. A. Petrillo, E. Dzung, K. L. Harrison, and L. Forbes analyzed the data. L. A. Petrillo and E. Dzung wrote the article. K. L. Harrison, L. Forbes, B. Scribner, and B. A. Koenig critically reviewed the article. All authors approved the final version of the article.

California planning or revising their response, and for other jurisdictions where physician-assisted death laws are being considered or implemented.

On October 5, 2015, California's End of Life Option Act (EOLOA) became law, making California the fifth US state with legal physician-assisted death (PAD).¹ Oregon, Washington, and Vermont preceded California in enacting PAD laws, and PAD is permitted in Montana by legal ruling.² Colorado became the sixth state with legal PAD in 2016. The California EOLOA gives qualified patients with a prognosis of 6 months or less the ability to ask their physicians for a lethal prescription to end their lives. It also grants health care providers the right to choose not to participate.

The legalization of PAD profoundly shifts the scope of physician practice in California. The use of PAD in Oregon has been limited, accounting for 0.4% of deaths in 2015.³ However, a greater proportion of seriously ill patients, between 10% and 56%,⁴⁻⁶ consider hastening death. Patients may ask their physicians about PAD because of unmet psychosocial, physical, or spiritual needs.^{6,7} Physician interventions, such as intensification of pain control, lead many patients to reconsider whether to use PAD.⁸ Yet if providers are not trained in end-of-life care (as only very few in California are),⁹ or resources like hospice are not readily available (as is true in rural counties),⁹ patients are at risk for receiving a lethal prescription when their goals could be achieved through other means.

The legalization of PAD thus places a responsibility on health care providers to optimize their approach to caring for seriously ill patients. This includes ensuring that patients learn about all available alternatives to maximize quality of life and independence, as recommended by the American Public Health Association's policy statement, "Patients' Rights to Self-Determination at the End of Life."¹⁰ Health care facilities must also balance providing access to patients against the right of providers to opt not to participate in the law.

When the EOLOA became law, there was limited time for California to prepare before it went into effect in June 2016. Given the myriad challenges the law posed, we convened a conference of stakeholders and sought their opinions on the most important issues related to the law's implementation. The California Health Care Foundation funded the conference. A steering committee planned the agenda and invited representatives from throughout California to attend.

The End of Life Option Act Response Conference brought together 112 participants, including California health care providers from multiple disciplines, administrative leaders, state officials, and patients' rights advocates (Table 1) in December 2015. We included California Assemblywoman Susan Eggman—one of the bill's authors—and researchers and clinicians from Oregon and Washington to inform the discussion. A major goal was to build trust among proponents and opponents of the law, to shift the focus to a shared objective: improving end-of-life care.

We focused on practical and ethical issues that may arise as organizations develop their responses to the law. "Responses" might include local policies or processes, or provider education. Plenary speakers addressed topics such as the role of palliative care and the needs

of specific patient populations. Plenary sessions were video-recorded. Participants engaged in small-group breakout discussions, which were recorded by note-takers, with participants' permission. We conducted a thematic review of the notes. We categorized the conference comments into themes, summarized here and illustrated by select quotes from participants and presenters. The conference themes are a guide, not only for California health care providers planning their response, but also for other jurisdictions where PAD laws are being considered or implemented.

OVERVIEW OF CONFERENCE THEMES

We include in this commentary the most commonly discussed themes, which threaded across several conference sessions. For example, providers from Oregon and Washington emphasized in a plenary session how developing a policy was a critical part of their preparedness. Later, participants explored more granular questions of how policies might address issues specific to particular settings or populations in small group discussions. We highlighted ideas that are of greatest practical value. We included both topics that the conference organizers planned to discuss and themes that arose organically. Readers can find more detail about conference discussions on <http://eoloptionacttaskforce.org>, which includes video recordings of the conference and additional references.

The Policy Development Process

Every health care organization that seriously ill patients encounter (e.g., clinics, pharmacies, residential facilities) should have a plan for managing issues related to PAD, regardless of whether the institution opts to participate by allowing physicians to prescribe (participation is optional under California law). In developing policies, institutions have an opportunity to shape their response to the law according to their values, and may opt to add additional safeguards or develop a common framework for responding to inquiries about the law. Policy development should be an iterative process, because unanticipated issues are bound to arise. For example, a health care system in Washington that participates in PAD under the Death With Dignity Act¹¹ faced the unexpected issue of how to deal with “destination patients,” those who present solely to seek a PAD prescription. After deliberation, the clinic opted to limit participation in the law to patients who had previously received care at the clinic. Many additional questions that may guide policy development are listed in the box on the next page. The questions are based on conference participants' experiences and ideas, and issues raised by the Oregon Death With Dignity Act Guidebook, a resource developed by one of the conference presenters and her colleagues.¹²

Providers will encounter issues with PAD that vary by practice setting. For example, health care providers who care for patients in their homes must decide whether to be present when patients ingest PAD drugs. For these providers, the idea of “opting in” or “opting out” is less clear-cut; a home hospice provider stated, “We can opt out in terms of writing a prescription, but we won't opt out of caring for the patient.” Long-term-care facilities face the dilemma that the facility is itself “home” for its patients, and therefore if the facility opts out, patients would have to find not only a provider, but also a new living space to use the law. This

justice concern may tip the balance for facilities in making the opt-in versus opt-out decision.

Considerations for California

California is extraordinarily diverse in socioeconomic status, race/ethnicity, language, and cultural background, and has the greatest number of adults living with disability in the United States. There are also major urban centers and a large rural population. California is thus a truer test ground for issues that might arise in vulnerable populations (e.g., individuals with disabilities, or who are non-English-speaking, or unbefriended) than other states where PAD is now legal, and has the potential to provide more comprehensive evidence for other states that might legalize PAD in the future. Conference participants were concerned that groups at socioeconomic disadvantage in California might disproportionately request PAD to preserve family financial resources, or as a substitute for symptom management in areas that lack access to health care. Safeguards to prevent harm to vulnerable patients are essential. Multidisciplinary teams can ensure that patients have access to such resources as home safety evaluations and skilled language translation.

Besides the concern for disproportionate use among vulnerable patients, conference participants voiced concern that the legalization of PAD may be perceived as an implicit devaluing of patients' lives by the health care system. This concern particularly applies to communities with a long history of disparate treatment and distrust of the medical system, such as African Americans and patients with disabilities. A disability rights advocate at the conference pointed out that physicians and patients might disagree about what makes a "life worth living." Another conference participant asserted that PAD "happens because we as a society are telling people at the end of life that they are not valuable and are a burden."

The safeguards in PAD laws reflect the efforts of legislators to anticipate and prevent harm, but are not informed by practical health care experience or evidence. Conference participants identified issues that may arise when California's law is implemented as a result. For example, the California requirement of private conversations between patients and providers to prevent coercion¹ may be inappropriate for patients from cultural traditions that prioritize family over individual decision-making. Another example is the assumption in the California law that all physicians are skilled at assessing decision-making capacity, which conference presenters discussed. They also questioned the ability of another California safeguard, the "final attestation form" (a document signed by the patient within 48 hours of death), to ensure that a patient is acting autonomously.¹

Conversely, there is a risk that safeguards in PAD laws create such a burden as to prevent qualified patients from accessing PAD. A conference presenter from Washington commented that making it through the process of obtaining a PAD prescription "is actually a marker of fortitude." In addition, safeguards disqualify patients with dementia from using PAD because of dementia's relatively longer prognosis and patients' waning decision-making capacity. Interested but underresourced patients may experience differential access because of the prohibitive cost of the medications, or because of a shortage of providers who will participate in the law, or disparate access to information about the law. The barbiturate that was most commonly used in Oregon and Washington costs approximately \$3000

because of a pharmaceutical company price hike¹³; the California state legislature has since budgeted for PAD drugs to be covered under Medi-Cal (California's Medicaid) and an alternative, cheaper combination drug is gaining popularity in Oregon and Washington.

Effect on Providers

All PAD laws protect the right of health care providers to choose whether to participate.¹ This right extends to health care providers from all disciplines, not only physicians. Similarly, implementation of PAD gives rise to the potential for moral distress in all health care staff, resulting from the clash between respect for patient autonomy and the professional obligation to do no harm. Policies must simultaneously honor the right of providers to opt out of the law and find ways to help patients and their families feel heard and cared for.

Health care providers have voiced concerns about lack of knowledge about the PAD process.¹⁴ Education is an important tool that health care organizations and clinics can use to prepare staff and reduce distress; providers should be taught about basic aspects of the law and local policy. Providers in each clinical role in the health care system will have specific educational needs, such as training emergency providers to respond to unsuccessful PAD attempts. Providers in solo practice or from rural areas may find guidance from the resources provided by our conference, and by organizations such as the Coalition for Compassionate Care of California.¹⁵ Undergraduate medical training and continuing medical education should teach health care providers about broad issues that are relevant to the care of all dying patients, such as cultural sensitivity, and how to approach difficult end-of-life conversations.

The Role of Palliative Care

Presenters at the End of Life Option Act Response Conference echoed a theme in Oregon at the time of PAD legalization there, that interest in PAD is driven by frustration with the inadequacy of health care for patients with serious illness in the United States.¹⁶ They suggested that some patients who express interest in PAD are not aware of options for symptom management (“excruciating pain should not be a reason for aid in dying [because it can be addressed by other means]”). They also hypothesized that some patients inquire about PAD as a way to initiate end-of-life conversations. California's EOLOA requires that physicians inform patients of the alternative of hospice or palliative care,¹ but does not require that providers be proficient in responding to patients' end-of-life needs. Conference presenters underscored that providers must explore, acknowledge, and address issues that may be contributing to patients' unbearable suffering, including spiritual or physical distress, or lack of social support. A researcher commented that clinician openness to discussion, regardless of personal ethical position, improves the therapeutic alliance and alleviates distress.¹⁷ Providers may need training to develop these skills.

Thus, improving palliative care for patients at the end of life should be an integral part of implementation of PAD, in any locale. Many patients in rural California communities lack access to palliative care,⁹ in contrast with Oregon and Washington, where nearly all patients

who use PAD are also enrolled in hospice.³ Conference presenters advocated federal and state bills to increase the palliative care workforce and funding for palliative care research.

IMPLICATIONS AND RECOMMENDATIONS

With enactment of the EOLOA in California, as well as the Colorado End of Life Options Act, 18% of the US population now lives in a state where PAD is legal,¹⁸ and more states are likely soon to follow. In the early years of PAD implementation in Oregon, providers there published recommendations about best practices that they subsequently updated with their clinical experience.¹² Evidence from that period also quelled fears that PAD would be disproportionately used by patients from vulnerable populations.^{19,20} The End of Life Option Act Response Conference built on historical evidence and advice from Oregon and Washington, and added updated perspectives on issues that will be relevant in California. These lessons also apply to other states that are more diverse and have less well-established end-of-life care than Oregon and Washington.

Future research is necessary to examine how vulnerable groups are affected by PAD, as urged by the American Public Health Association's policy statement, "Patients' Rights to Self-Determination at the End of Life."¹⁰ A recent survey by Periyakoil et al. found that the majority of older adults (72.5%) in California support PAD and did not observe a difference across ethnic groups, but additional data on patient experience after legalization is necessary.²¹ Research efforts should address new disparity concerns in California, which center on unequal access to PAD in patients who qualify but cannot afford medications, or lack resources or time to comply with safeguards. They should also examine the perception that PAD legalization represents devaluation of life by the health care system, and study normative effects of PAD legalization on attitudes about death and dying over time. As suggested by Emanuel et al.,²² the observation of increasing rates of requests is one indication of "routinization" (social acceptance) of PAD. Thus, ascertainment of PAD request rates through physician surveys or other means is an important future research objective.

The End of Life Option Act Response Conference affirmed the importance of palliative care in the EOLOA response and drew attention to areas in need of improvement. Ideally, California providers will use the momentum of change to reach the same "silver lining" of improved end-of-life care achieved by Oregon providers since the Death With Dignity Act went into effect.

Representatives from major health systems in California who attended the End of Life Option Act Response Conference have since drawn on knowledge gained from the conference to develop policies and educational materials. Some policies incorporate novel features, such as required palliative care or mental health consultations, as additional safeguards. Examples of policies are available on the End of Life Option Act Task Force Web site.²³ Challenges that were anticipated by conference participants have since arisen in publicized cases in California; in particular, the law's emphasis on protecting providers' right not to participate has effectively limited access for patients and given rise to a mismatch between patient expectations and reality.^{24,25}

The legalization of PAD in California, as in other states, presented an opportunity and an impetus to reexamine standard practices, policies, and aspirational goals for improving end-of-life care. The End of Life Option Act Response Conference was a first step in creating shared vision of the best possible care for Californians. Though new issues are bound to arise in other states that legalize PAD, the body of evidence from states where PAD is legal should form a foundation of knowledge to inform future efforts.

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QUESTIONS THAT INDIVIDUAL PROVIDERS AND HEALTH CARE ORGANIZATIONS MAY CONSIDER IN PREPARING TO RESPOND TO PATIENT REQUESTS UNDER THE CALIFORNIA END OF LIFE OPTION ACT

For all providers

- What are my personal feelings about physician-assisted death, and how are these likely to affect interactions with patients who ask about it or choose to use it?
- If a patient asked me, would I attend a patient's death?
- What will my approach be to talking with families?

For physicians

- If my institution permits it, will I prescribe?
- Do I feel confident in my ability to prognosticate?
- Do I feel comfortable discussing all of the options available to patients at the end of life and initiating palliative measures to address patient needs? If not, do I know where to refer?
- Do I know who among my colleagues is willing to serve as a consulting physician, and where to refer patients for mental health evaluations and hospice?

All health care clinics and facilities

- Will the clinic or facility allow physicians to prescribe aid-in-dying drugs under the End of Life Option Act?
- What education is necessary to prepare all providers (physicians, nurses, social workers, chaplains, administrative staff) to respond to requests, whether the facility opts to participate or not?
- How should the clinic or facility make patients who request physician-assisted death aware of their options for end-of-life treatment?
- If the overall system chooses to participate, how should it allow conscientious objection for individual providers and personnel while still ensuring continuity of care and access for patients?
- Will there be a credentialing process for physicians who choose to participate?
- Will the clinic or facility require any additional steps beyond the recommendations of the law (e.g., psychosocial evaluation, palliative care consult, advance care planning, hospice referral)?
- What new resources need to be put into place to handle patient requests and comply with law requirements and any additional institutional requirements (e.g., patient navigators, educational materials for patients, checklists for staff, phone lines)?
- Should the clinic or facility formalize a process for one-on-one conversations with patients as required by law, and for how to deal with patients that prefer family decision-making?
- Who will be responsible for the collection and submission of forms, including the final attestation form?
- How should the clinic or facility deal with conflict resolution and professional noncompliance?
- How should the clinic or facility support providers and mitigate moral distress?
- If the system chooses not to participate, will it permit physicians to refer patients? How is a referral defined?
- How should the clinic or facility make all employees aware of the institutional policy?
- How should the clinic or facility instruct patients and families to safely dispose of unused aid-in-dying drugs?

Outpatient clinics

- Can new patients request physician-assisted death, or must patients have received care at the clinic or facility for some period of time before being eligible to make a request?
- Which specific drug will participating physicians prescribe?
- Which pharmacy will compound the aid-in-dying drug, if necessary?

Hospitals

- How should emergency department providers manage patients brought in with complications of aid-in-dying drug ingestion?
- Can inpatients begin the process of making a request while hospitalized?

- Can patients ingest an aid-in-dying drug at the hospital?

Long-term-care facilities

- Will residents be permitted to ingest an aid-in-dying drug on the premises?

- If the facility does not participate, is there an ethical obligation to allow residents to seek care elsewhere?

Home health agencies, including hospices

- Can health care workers be present at the time of ingestion?

- How should the agency manage communication with family, especially if patient does not include them in the decision-making process?

Note. Questions were inspired by the Oregon Death With Dignity Act Guidebook,¹² and by the End of Life Option Act Response Conference discussions.

TABLE 1

End of Life Option Act Response Conference Participants, by Profession: California, 2015

| Conference Participants, by Profession ^a | No. (%) |
|---|---------|
| Health care professionals | |
| Physicians (total) | 47 (42) |
| Ethics committee members | 12 (11) |
| Palliative care | 29 (26) |
| Nurses | 9 (8) |
| Social workers | 3 (3) |
| Pharmacists | 3 (3) |
| Chaplains | 3 (3) |
| Health care administrators | 11 (10) |
| Lawyers | 8 (7) |
| Advocates | 13 (12) |
| Government officials | 5 (4) |
| Volunteers | 10 (9) |
| Total | 112 |

^aSum of proportions exceeds 100% because several participants were in > 1 category.

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