

May 2016

Implementing Aid in Dying in California: Experiences from Other States Indicates the Need for Strong Implementation Guidance

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SUMMARY: In late 2015, California passed the End of Life Option Act (AB 15), which allows residents at the terminal stage of an illness to request a prescription for medications meant to hasten death. As California seeks to implement the law in June 2016, findings from other states that practice aid in dying (AID) may guide implementation. This policy brief provides an overview of the use of AID, outlines outstanding questions about practice and ethics, and

recommends steps for improving California's implementation of AB 15. Specifically, the implementation of AB 15 would be improved by adjusting surveillance data-collection requirements and encouraging additional research investment, using the legalization of AID to improve knowledge of and practices for end-of-life care generally, and creating ongoing educational opportunities for providers and the general public.

“The passing of AB 15 presents a unique opportunity to improve knowledge of and practices for end-of-life care.”

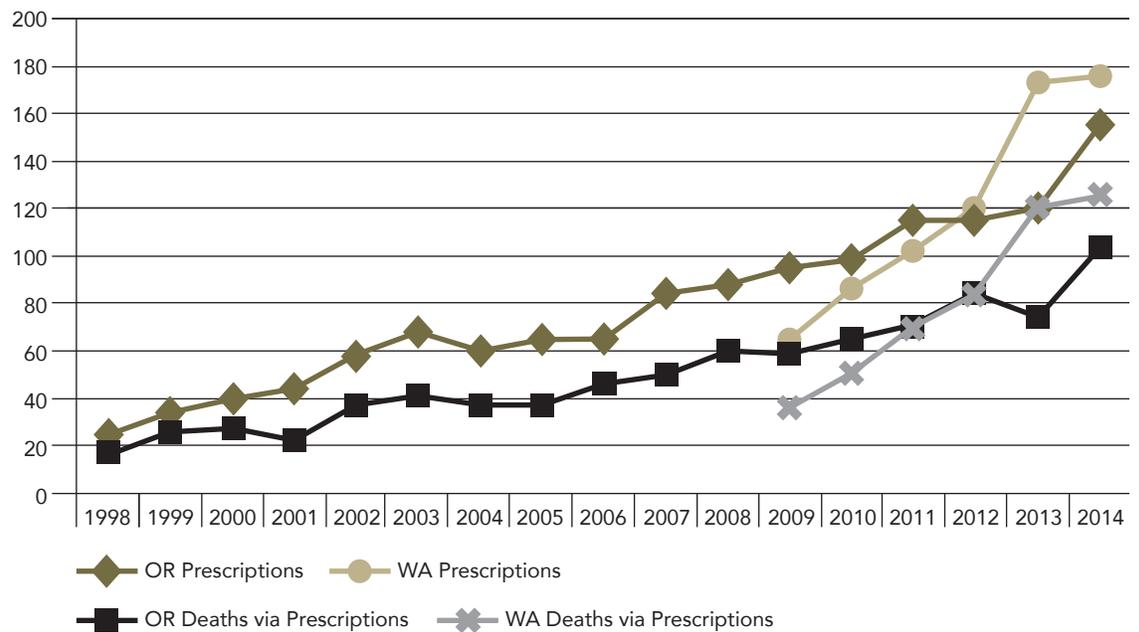
Aid in dying (AID) is a practice whereby a capable adult in the terminal stage of an illness may ask the attending physician to prescribe medications meant to hasten death. In the United States, five states currently permit AID. Oregon was the first to pass the Death with Dignity Act, in 1994 (implemented in 1997); Washington passed similar legislation in 2008, and Vermont in 2013. Montana has permitted physician-aided dying since 2009 via a Montana State Supreme Court ruling.

In late 2015, California became the fifth state to pass such legislation with the End of Life Option Act (AB 15). While California's population, health delivery system, and medical insurance systems differ from Oregon's, AB 15 is largely modeled after Oregon's Death with Dignity Act. AB 15 outlines the procedures and documentation required in the process of requesting, receiving, and using lethal

dosages of medications. The legislation also contains detailed checks and balances to be sure that the hastening of death is performed only for those who are fully informed and are making the choice themselves, without undue influence. Specifically, adults diagnosed with a terminal illness—defined as an illness expected to be fatal within six months—must make two oral requests to their attending physician. The requests must be separated by at least 15 days. The individual must also provide the physician with a written request that follows standards outlined in the legislation, including signatures from witnesses. The physician must assess the patient's mental capacity in order to assure that the patient is choosing freely and intentionally, and the physician must also inform the patient of alternative options. A consulting physician must then certify the diagnosis and prognosis, the patient's mental capacity, and voluntary nature of the request before the medications

Exhibit 1

Prescriptions and Deaths via Prescriptions in Oregon and Washington, 1998-2014



Sources: "Oregon's Death with Dignity Act – 2014"⁷ and "Washington State Department of Health Death with Dignity Act Report"⁸⁻¹³

“The option of AID may provide comfort, thereby improving quality of life, even if the individual chooses not to ingest the medication.”

will be administered. Either physician may request that the patient also have a mental health evaluation if there are concerns that the patient's request for aid-in-dying medications is affected by psychiatric or psychological considerations.

Opponents of AID have voiced concerns that legalizing aid in dying could encourage the early death of vulnerable persons through discrimination or coercion.¹⁻³ Some fear that the use of AID will decrease the use of palliative care services, services that could improve patients' quality of life and reduce the need for AID.⁴ Others, drawing on various religious traditions, state that AID diminishes the sanctity of life.⁵ Finally, some medical practitioners regard AID as a violation of their professional duties.⁶

Overview of Current Use of AID

Debates surrounding the use of AID are enriched through an examination of data on requests for AID, prescriptions provided, and deaths as a result of requested medications. Most of these data come from Oregon and

Washington, where AID has been legal for multiple years, the statutes require data collection and reporting, and enough data have accumulated to alleviate concerns about the confidentiality and privacy of those who make requests. As Exhibit 1 shows, the number of persons receiving prescriptions has steadily risen but still remains very low. In fact, until 2014, fewer than 100 people per year had requested and received the prescribed medications in Oregon and had then died using those medications.⁷ It is noteworthy that across both states there is a gap between the number of persons requesting the medications and the number of those who ultimately use it to hasten death. This finding suggests that for many, the option of AID may provide comfort, thereby improving quality of life, even if the individual chooses not to ingest the medication. While these data offer an overview of the practice of AID, some have raised concerns that the data are incomplete—something that California policymakers have an opportunity to improve.

Ethical Critiques of AID

Concerns about vulnerable persons (members of racial and ethnic minority groups or persons who have low incomes or low levels of education, publicly funded health insurance, or disabilities) being encouraged to hasten their own death are not supported by the data from Oregon and Washington. While we do not currently have data on the disability status of AID participants, in both states AID participants were overwhelmingly white and highly educated and had private health insurance. Exhibit 2 summarizes demographic information for individuals in Oregon who died after receiving a prescription. While these data may alleviate most concerns in Oregon, California is much more racially and ethnically diverse than Oregon and Washington. Because of this diversity, it is important to continue to assess data for disparities.

Persons requesting AID may also be vulnerable because of underlying psychiatric or psychological conditions that impair their decision making. Some have expressed concerns that individuals with depression or other mental health disorders will decide to hasten their own deaths because of the underlying disorder and might make other decisions if given treatment for psychiatric or psychological conditions.¹⁴ AB 15 is written to protect against this by requiring mental health evaluations if either physician has concerns, but the evidence in Oregon shows that some patients with depression do still request, receive, and use medications.¹⁵ This is legally permissible as long as the depression is deemed not to impair decision making, but it can be challenging to recognize and diagnose depression in persons with terminal illnesses.¹⁶

Another concern is that the legalization of AID will discourage the use of palliative care or hospice services.⁴ This is especially a concern if health insurance pays for AID but not for other forms of end-of-life care. The payment system may encourage some people

Demographic Characteristics Among People Who Died After Receiving AID Drugs in Oregon, 1998-2013 (N=754)

Exhibit 2

Race	
White	97.1%
Non-White	3%
Education	
Less than High School	6%
High School Graduate	21.9%
Some College	26.2%
Baccalaureate or Higher	45.9%
Insurance	
Private	60.2%
Medicare, Medicaid, Other	38.3%
No Insurance	1.5%

Source: "Oregon's Death with Dignity Act – 2014"⁷

to choose hastened death over attempts to alleviate suffering. While more research is needed on how insurers should pay for a range of end-of-life services, the data from Oregon indicate that the legal existence of AID does not decrease the use of palliative care.¹⁷ In fact, studies in Oregon show that palliative care services spending and patient satisfaction have risen since 1997, when AID became legal.¹⁸ It is likely that the request for information on AID leads to beneficial conversations between patients and their physicians about a range of end-of-life options.¹⁹

A related concern is that by assisting individuals in ending their lives, we as a society are undermining the sanctity of life. Some disability rights activists have claimed that laws such as AB 15 convey that some lives are worth living, while others are not.¹ The concern is that AID may lead to additional life-limiting practices, such as physician-directed euthanasia. AB 15 is written to protect against such concerns by requiring extensive documentation by physicians.

“Concerns about vulnerable persons being encouraged to hasten their own death are not supported by the data.”

Exhibit 3

Concerns Identified by Physicians About AID Requests

	Dobscha et al. ¹⁹	Ganzini et al. ¹⁷	Lee et al. ²¹
Lack of Knowledge			
How to alleviate suffering	X		
How to properly prescribe	X		X
Details of the law	X	X	
Possible complications			X
Making 6-month prognosis			X
Privacy			
Privacy of patients and family members	X	X	
Privacy of providers who participate	X	X	
Legal Consequences			
Challenges make providers vulnerable	X	X	
Family may take legal action			X
Other may use the meds			X
License jeopardized in other states			X
Other Consequences			
Ostracism by colleagues		X	X
Hospital sanctions			X
Problems in the Process			
Do not know patient well enough	X	X	
Cannot get a second opinion		X	
Medications not available		X	
Fears of abandoning patients	X		

“Providers need continued education to alleviate their concerns and help them improve patient care.”

Finally, some health care providers have expressed concern that AID violates professional codes of ethics.⁶ Because of this concern, AB 15 and other similar laws permit physicians (and all other health care providers) to opt out of participation in AID.

What Providers Want: Guidance on Implementation

More education on how to approach all end-of-life options, including AID, would be useful for encouraging ethical, person-

centered care.²⁰ Exhibit 3 summarizes the concerns of providers who have received or anticipate receiving requests for AID. Several of the most prominent concerns are related to lack of knowledge, especially in terms of how to alleviate suffering (with or without AID), how to properly prescribe the medications, what the law permits, what to do about complications after a patient has ingested the medications, and how to be sure about the six-month prognosis of patients making requests. While AB 15 was not intended to answer all of these questions, offering continued education for providers would help to alleviate concerns and improve care.

Providers would also benefit from continued conversations on how to discuss AID as one of many options at the end of life. Providers may seek guidance regarding the ethics of refusing to participate in AID. Some providers have been concerned that refusing to participate leaves patients without care, abandoning them during a vulnerable time.¹⁹ Providers who opt not to participate in AID may refer their patients to other providers. However, it can be difficult to know which other providers are willing to prescribe. Additionally, unlike previous attempts to make AID legal in California, which focused on positive obligations of physicians, the current End of Life Option Act does not require that this option be discussed even if patients ask about all end-of-life care options. While some have concerns that physicians' decisions regarding whether or not to discuss AID may coerce or disrupt trust with patients, further research is needed to determine how to ethically discuss options.

With reference to Exhibit 3, concerns about privacy and legal consequences should be approached through interdisciplinary work groups that include medical as well as legal expertise. Concerns over legal and professional sanctions against providers and problems in the process of AID may be best solved through professional organizations and providers working together to form appropriate policies

and procedures. Finally, fears about abandoning patients and other forms of emotional distress related to AID should be confronted through formal and informal support networks wherein providers are encouraged to discuss difficult cases. By better understanding both patients' and providers' needs, interdisciplinary groups can work together to refine practice.²² These are issues that are not discussed in AB 15, but that may be important for professional and provider organizational policies on AID practice.

Recommendations

Better data collection

To develop knowledge about improving end-of-life care, data are needed on how patients and family members make decisions about treatment, how health care providers respond to those decisions, and how the health care system either supports or undermines person-centered care.

- ***Required surveillance of AB 15 should be adjusted to collect higher-quality data.*** California requires that physicians complete forms recording prescriptions meant to hasten death, patients' final attestation, physician compliance procedures (attending and consultant), and a follow-up report after the patient dies. While data from these forms are helpful, small refinements can provide even more useful information to guide future practice. For example, the follow-up form asks for the patient's reason for the request. Asking this question on the initial request form would permit better and more complete data on patients' motivations at the time of the request.
- ***Documentation at each step.*** Currently, the law only requires that physicians submit forms upon completion of the entire process. A more comprehensive data-collection process would be to require documentation at each step in order to collect data on requests that are not fulfilled. This will offer better insight into who is requesting, who then obtains a prescription, and who eventually

self-administers the AID medications. Implementing this recommendation requires careful examination of the benefits of more data weighed against concerns for privacy for persons requesting information about AID.

- ***Expanded data collection.*** Resources should be available for researchers to collect additional data from patients, their family members, and providers. While required surveillance data provide an overview of the practice, concerns about confidentiality and the political uses of data have made data unavailable in raw format for research use. Dedicating more resources for scientific examination of AID practices will improve knowledge and practice, informing political debates. Expanded data collection may also include additional information about patients, including disability status separate from terminal illnesses.

Improve end-of-life care generally

Professional organizations and health care provider organizations should use the legalization of AID as an opportunity to improve all forms of person-centered care at the end of life. While AID is under special scrutiny because of concerns related to the new law, other kinds of end-of-life decisions that may hasten death (including continuous deep sedation, intentional withholding of life-sustaining interventions, and the withdrawal of treatment) do not have documentation requirements, and as a result there is little systematic data about these practices. Understanding when and how these practices take place can help organizations refine shared decision-making approaches. Use of hospice and palliative care services may improve with the legalization of AID, as more patients bring up concerns about end-of-life issues and their providers have an opportunity to discuss a range of options. Studies have found that when patients who have requested AID also receive a hospice referral, they are less likely to ingest medications, indicating that removing

“*The legalization of AID is an opportunity to improve all forms of person-centered care at the end of life.*”

“The general public lacks an understanding of the range of options at the end of life.”

barriers to all end-of-life options improves patient-centered care.¹⁷ Professional and provider organizations should consider:

- **Better measurement.** Measuring a wide range of end-of-life practices as they currently occur and seeking to understand how and why patients prefer some options over others.
- **Broader discussions.** Using requests for AID as opportunities to discuss all end-of-life options and participate in shared decision making.
- **Continuous support.** Once a patient has received a prescription, the law does not require that health care professionals provide additional support through the final decision-making process or ingestion. Patients and their family members would benefit from continuous support regarding all end-of-life options.

Educational outreach

Professional and provider organizations should engage in educational programs for providers, state officials, and the general public. The general public lacks an understanding of the range of options at the end of life. A public education campaign may also improve shared decision making by providing patients with a language for discussing their preferences and needs. State officials charged with surveillance activities may benefit from more education on AID, especially as the sensitivity and controversy surrounding AID make the handling of these data different from other forms of surveillance data. Health care providers from a diversity of professional backgrounds would also benefit from continued education on how to discuss end-of-life concerns. As the analysis above shows, many providers do not feel prepared

to adequately serve patients who make requests for AID. Professional and provider organizations should participate in:

- **Public education campaigns.** Such campaigns should seek to inform the public about end-of-life concerns and options. National efforts are already taking place through mass media, and California policymakers may be able to help raise awareness.
- **Education for state regulators and officials.** Officials in the California Department of Public Health would benefit from discussions of the collection, analysis, and dissemination of surveillance data related to AB 15.
- **Training for providers.** Training could increase providers' comfort and competency in discussing AID as well as hospice, palliative care, and the discontinuation of curative efforts. Such training could be enhanced by bringing experienced clinicians from states already practicing AID to California to lead trainings on AID practice. Interdisciplinary training is especially useful for discussing the range of issues that may occur during the practice of AID.

The continued improvement of practice and evaluation of ethical concerns require participation from policymakers, patient advocates, and professional and provider organizations. More transparency about practices of end-of-life care may also improve trust in health care. The passing of AB 15 presents a unique opportunity to make end-of-life care in California more person-centered.

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Acknowledgments

This publication was made possible with a generous gift to the UCLA Fielding School of Public Health from Thomas Weinberger to establish the End of Life Option Project. The author would also like to acknowledge Alexander Capron, Stuart Finder, Patricia Ganz, Gerald Kominski, Irving Lebovics, Les Rothenberg, Thomas Strouse, Thomas Weinberger, and Neil Wenger, who served as members of the End of Life Option Project Advisory Board and provided guidance on this study.

Suggested Citation

Cain CL. *Implementing Aid in Dying in California: Experiences from Other States Indicates the Need for Strong Implementation Guidance*. Los Angeles, CA: UCLA Center for Health Policy Research, 2016.

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PB2016-4

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