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End of Life Option Act Update

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Editor's Note

I would like readers to take special note of this article about a topic we do not find commonly addressed.

Background

Signed into law in October 2015 and implemented on June 9, 2016, the End of Life Option Act[1] has been helping terminally ill Californians end their lives, at the time of their choosing. At the bill signing, Governor Brown stated, "In the end, I was left to reflect on what I would want in the face of my own death. I do not know what I would do if I were dying in prolonged and excruciating pain. I am certain, however, that it would be a comfort to be able to consider the options afforded by this bill. And I wouldn't deny that right to others."[2]

As a refresher, the bill states that a California resident who is at least 18 years old with a terminal disease (prognosis of fewer than six months to live) can consent on their own to (without undue influence or duress) obtain approval for a prescription from a California physician that will end their life. The prescription would be filled by a pharmacist in the usual course of business. It would be obvious to a pharmacist that the prescription was written to end the life of the patient because of the large quantity of medication being prescribed. The law does not require a specific type or quantity of medication. It is up to the prescribing physician's professional judgment.

The individual must be able to make their own medical decisions and take the medication without assistance. Safeguards are in place to help ensure there is no undue influence on the patient (two oral requests of the patient's physician, at least 15 days apart, and a final written attestation). If necessary, based upon the individual's physician, a psychologist or psychiatrist may need to assess the patient's ability to make a sound medical decision. This law is legislated to expire on January 1, 2026.

This law was passed in the California legislature largely due to the story of Brittany Maynard. In 2014 she was diagnosed with terminal brain cancer. Unable to end her own life at the time of her choosing, and fearing morphine-resistant pain, she moved to Oregon to take advantage of its Death with Dignity Act. She partnered with the organization Compassion and Choices to help get the new End of Life Option Act passed in 2015.[3] The intention of this law was to provide a safe, effective mechanism for terminally ill, adult, mentally competent Californians to end their lives in a safe way at the time of their choosing.

Aid in dying is legal in 10 states plus the District of Columbia. This includes Montana, in which aid in dying became legal by State Supreme Court Decision. The first state to pass such a law was Oregon in 1997. Legislative efforts continue in many states and can be tracked on advocacy websites.[4]

On the provider side, healthcare professionals do not have to participate or assist patients in the process of obtaining the aid-in-dying medication(s). And if they choose not to participate, they do not have to help patients find providers that are willing to help them die at the time of their choosing. When a patient dies because of this law, the resulting death will not be considered suicide. The cause of death should be reported as the underlying condition.[5] Healthcare providers that participate are protected civilly, criminally, and administratively from liability. An in-depth description of how the law applies to California pharmacists was published in 2017,[6] as well as descriptions of Kaiser Permanente's experience with the new law[7] and an early comparison of California versus Oregon and Washington statistics.[8] The article by Tony Park, PharmD, JD,[6] provides an analysis of the original law, comprehensive definitions of legal terms, and the checklist a physician must go through in order to assess a patient for the aid-in-dying prescription. An in-depth analysis of how California pharmacists relate to counseling and dispensing the life-ending medication was published in 2021.[9] This 2016 study is important, as it explores the moral and ethical concerns pharmacists have in dispensing medication that is intended to be lethal.

Legislative Update – Proposed Amendment to the End of Life Option Act

On February 11, 2021, an amendment to California's End of Life Option Act, SB 380, was introduced by Senator Susan Eggman (D).[10] The amendment, if passed, will reduce the 15-day waiting period to 48 hours, and if the attending physician determines a patient will die before the end of the waiting period, the 48 hours may be waived. The bill adds or clarifies additional language, including eliminating the January 1, 2026, repeal clause in Section 10. The list of healthcare providers approved to determine if patients can make their own medical decisions is expanded to include licensed clinical social workers or professional counselors. The proposed law also penalizes individuals who obstruct or mislead a patient who is seeking aid-in-dying drugs (civil liability). The law has been passed by the Senate and Assembly. It awaits the governor's signature. If signed by Governor Newsom, it would become effective January 1, 2022.

Trend Data

In compliance with the original legislation, the California Department of Public Health releases annual statistics relating to the End of Life Option Act, with reports from 2016 to 2019 being made available to the public.[11] This information is submitted to the California Department of Public Health by participating physicians. Compiled for comparison, this information sheds light on many areas from patients initiating the process, to physicians writing prescriptions, to patients ending their lives from ingesting the medication. Biographical information about the participants' ages, races/ethnicities,

underlying illnesses, types of insurance, drugs prescribed, and locations of ingestion are also provided. Graphically represented, this information gives healthcare providers, patients, consumers, and policymakers a clearer picture of the impact of this law over time.

Individual Results

The number of patients beginning the process of obtaining a prescription to end their lives started with 258 in 2016 and increased to 736 by 2019, dropping slightly to 662 in 2020.[11] Not everyone who starts the approval process obtains a prescription. That number started as 191 in 2016, increasing to 677 in 2020. The number of individuals who ingested the medication and died as a result has increased from 111 in 2016 to 435 in 2020. The resulting death rate per 10,000 has increased from 6.06 in 2016 to 15.4 in 2020. There have been a range of participating physicians, beginning with 173 physicians in 2016 and concluding with 262 in 2020. It is not known if the physicians are equitably distributed geographically throughout California.

Participation rates are highest in those 70 to 79 years old.[11] This group is represented at a greater percentage than those 60-69 or 80-89 years old. There are far fewer patients older than 90 or younger than 60. The largest range of ages occurred in 2019, with the youngest being 23 and the oldest 104.

Figure 1. Participant Age Percentages.

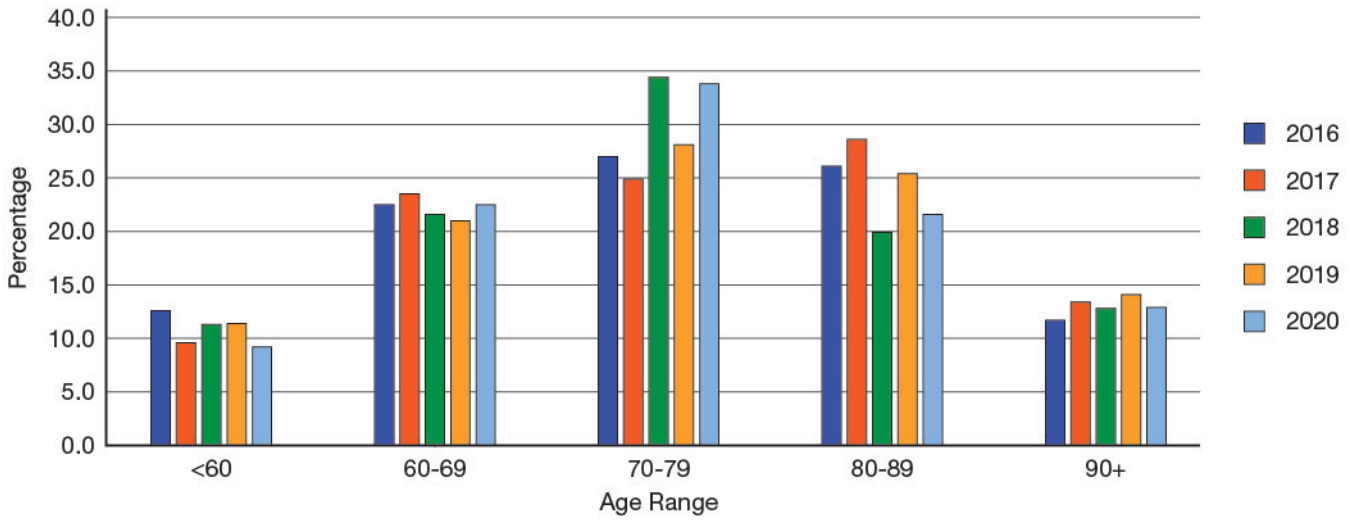


Figure 2. Participant Race/Ethnicity.

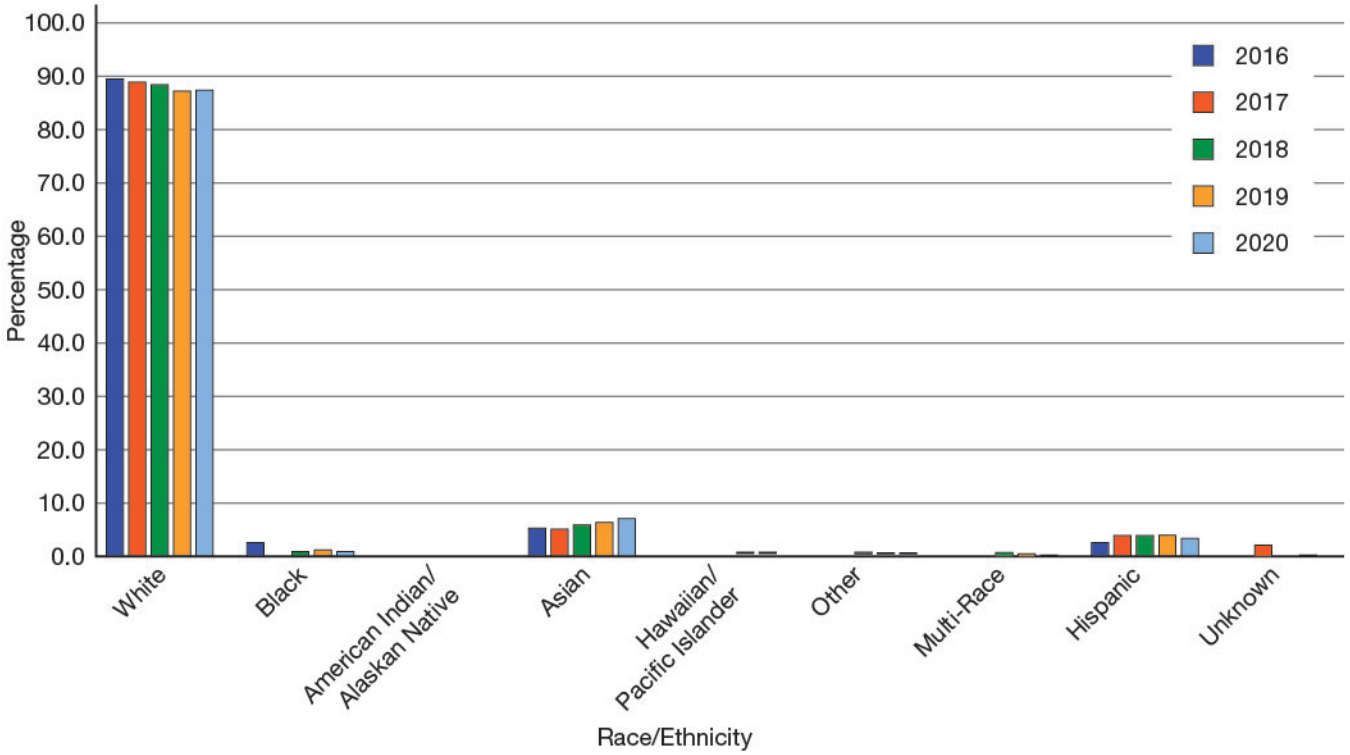


Figure 3. Underlying Illness.

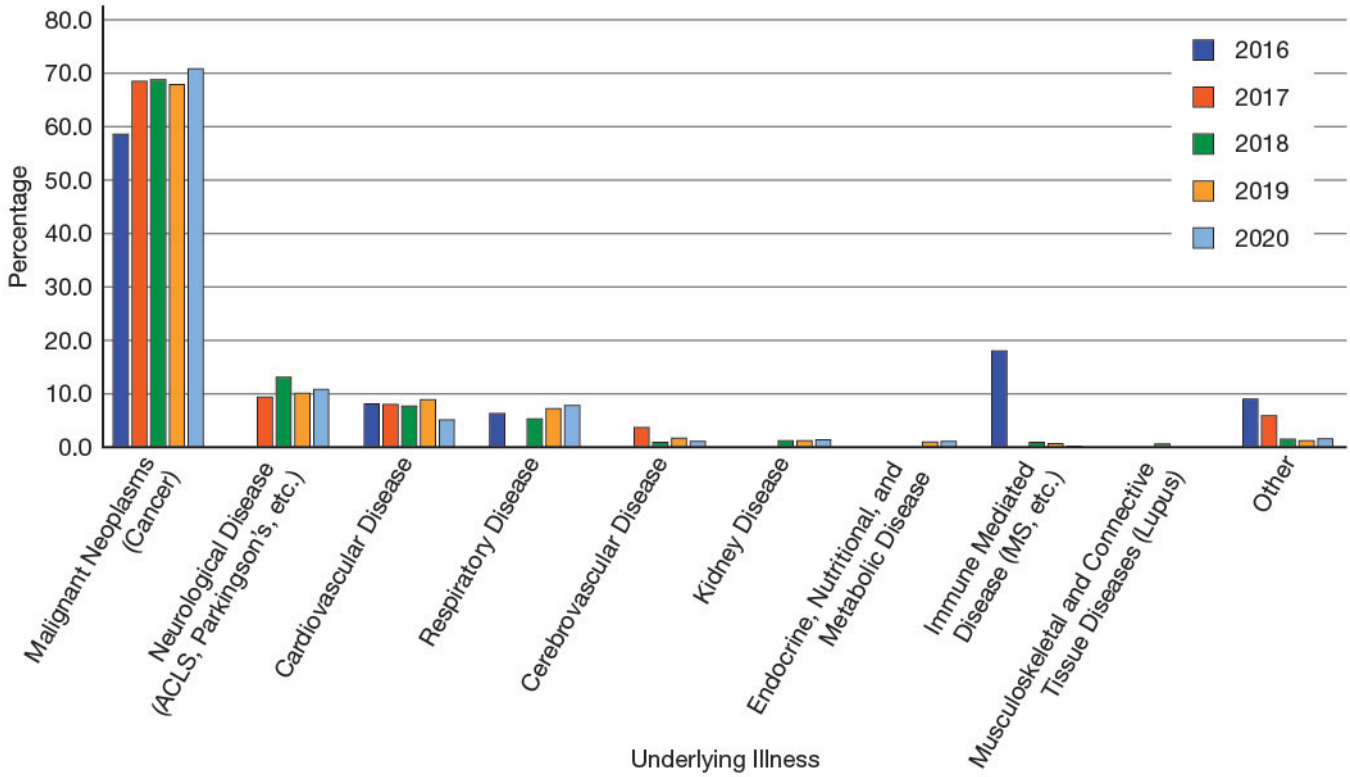
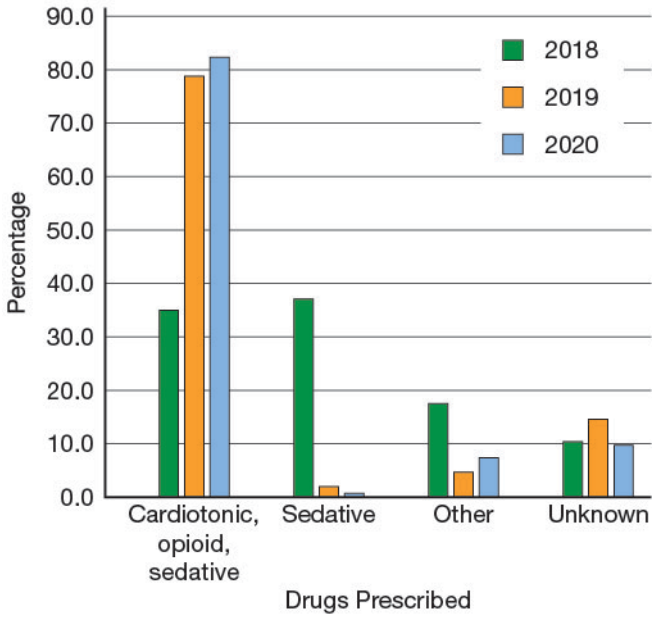


Figure 4. Drugs Prescribed.



The race/ethnicity of participating patients skews overwhelmingly white.[11] There are very small percentages of Asian and Hispanic participants. This remains consistent from 2016 to 2020. In many years, there were no Black participants.

The underlying illness of the participating patients is also skewed toward malignant neoplasms (cancer).[11] However, neurological diseases, such as ACLS and Parkinson's, are also represented. There are similar percentages of cardiovascular disease and respiratory illnesses.

The data on the types of drugs prescribed is only available for 2018-2020. In 2018, a nearly equal number of prescriptions were written for solely a sedative versus a three-drug combination of a cardiotonic, an opioid, and a sedative. By 2019, that percentage had overwhelmingly changed to the three-drug combination, remaining consistent in 2020.

The numbers and types of drugs prescribed have changed over time. Previously, secobarbital and pentobarbital were used. They became unavailable due to manufacturer issues and price. Recently, the drugs of choice considered by prescribers include diazepam, morphine, digoxin, and amitriptyline.[12]

The data for 2018-2020 (data for 2016 and 2017 was not available) concludes with the majority of participants informing their families of their decision to end their lives with medication (87.5%, 86.4%, and 83.4%, respectively) and ingesting the medication while at home (92%, 88.1%, and 92%, respectively).[11]

Conclusion

The majority of patients in California taking advantage of the End of Life Option Act are in their 70s, white, and terminally ill with cancer. It is not known why other races/ethnicities have not participated at higher percentages. If the proposed amendment to the legislation becomes law, the number of individuals participating may increase slightly. The issue of equity remains present, as program awareness, the number of participating physicians (access to the program), and the cost of the medication (if insurance does not cover it) remain potential factors impacting whether someone chooses to participate in this program.

More Californians may take advantage of this law with additional healthcare provider education at their disposal. All healthcare providers within the continuity of care (physicians, pharmacists, nurses, physician assistants, nurse practitioners, social workers) could help educate patients about this law and how it can be used appropriately. Even if healthcare providers have a moral objection to participating, providing patient education and allowing patients to make up their own minds can give patients all the available options as they make difficult decisions about their lives.

It may be useful for pharmacists to interact with physicians participating in this program to better understand the selection of medication(s), dosage(s), and directions for use. When pharmacists receive a prescription intended to end the life of a patient, they will be better able to counsel the patient on how to use the medication appropriately. Physicians may benefit from hearing the questions patients ask when filling their prescriptions.

Pharmacists wishing to learn more about this topic and potentially earn continuing education credit should explore options at professional pharmacy organizations and conferences. Medical professional organizations may also offer continuing education opportunities on this important topic.

About the Author

Jim Pinder, PhD, JD, MBA, is an Associate Professor of Healthcare Management and Law at La Sierra University in Riverside, California. He has no conflicts of interest to disclose.

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