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OPEN PEER COMMENTARIES

Top Ten New and Needed Expansions of U.S. Medical Aid in Dying Laws

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Pullman argues that when it comes to medical aid in dying (MAID), "Canada … has much to learn from California" (Pullman 2023). Canada and California have similar populations: each about 40 million citizens. But, each year, while fewer than 1,000 Californians take MAID medications, more than 10,000 Canadians use MAID. This ten-fold difference is astonishing and merits attention. But how should we interpret it?

Pullman describes the Canadian numbers as "disturbingly high." I take the opposite approach and contend the California numbers are disturbingly low. Pullman rightly notes that MAID in California is subject to "strict eligibility criteria" and that we take a "more cautious approach in the United States" (Pullman 2023). But even Pullman concedes ingenuousness in how best to strike the balance between safety and access. He does not know whether the Californian "criteria are too restrictive" or the "Canadian criteria are too liberal" (Pullman 2023).

But we already have the evidence. Significant data and testimony gathered by researchers and state legislatures show that U.S. criteria for MAID are too restrictive and impede access to individuals who want to relieve suffering at the end of life (Kusmaul et al. 2023). Similar evidence is emerging in other restrictive MAID jurisdictions like Australia and New Zealand. In this Open Peer Commentary, I describe the top ten new and needed expansions of U.S. MAID laws. These are not the only indicated reforms. We need better data to identify other barriers and disparities (Riley 2023).

PERMIT NON-PHYSICIAN PROFESSIONALS

For decades, only physicians could provide MAID in the United States. But it became increasingly obvious that this limited access (Pope 2020). Especially in rural areas, physicians weren't always available. So, when New Mexico enacted its MAID statute in 2021, it also authorized advanced practice registered nurses and physician assistants to provide MAID. In 2023, Hawaii and Washington followed suit. Today, both current and prospective MAID states are considering legislation that would authorize not only physicians but also APRNs and PAs. Furthermore, the states are also expanding the types of clinicians authorized to conduct the mental health exams always required in Hawaii and required in other states when the attending or consulting clinician is uncertain of the patient's capacity.

SHORTEN OR WAIVE WAITING PERIODS

Another way states are already expanding access to MAID is by reducing or waiving waiting periods. For decades, one of the standard safeguards in U.S. MAID statutes required that the patient make two separate oral requests, the second after a waiting period of at least 15 days. The rationale was to permit patients to calmly reflect and deliberate about their decision. But over two decades of experience with MAID shows that many patients cannot wait that long. Since many patients don't seriously consider MAID until the late stages of their illness, they either die or lose decision-making capacity before the end of the 15-day period. In

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short, the waiting period frequently constitutes an undue burden.

In response, several states have either shortened or waived the waiting period. Both California and New Mexico reduced their waiting periods from 15 days to 48 h. Hawaii, Vermont, and Washington also reduced their waiting periods (Meisel, Cerminara, and Pope 2023). Today, bills in both current and prospective MAID states propose similar reductions. In addition to, or instead of, shortening the waiting period, some states exempt patients from having to satisfy the waiting period, however long it is, when the patient isn't expected to survive that period. New Mexico and Oregon, have already enacted such waiver laws. Bills in both current and prospective MAID states propose the same.

DROP RESIDENCY REQUIREMENTS

Traditionally, states limited MAID to their own residents (Pope 2020). Many patients have been able to satisfy these residency requirements by, for example, briefly renting an apartment in the MAID jurisdiction. But while surmountable, residency requirements still pose an obstacle. Consequently, physicians and patients brought federal lawsuits challenging residency requirements in Oregon and Vermont as violating the privileges and immunities clause of the U.S. Constitution. After settling the lawsuits, those states removed the residency requirement. That opened the door to patients traveling to Oregon and Vermont for MAID from other states. Now, bills in other states similarly propose authorizing MAID without a residency requirement. States appear to recognize that they can't constitutionally limit healthcare services to their own residents. A new lawsuit is proceeding in New Jersey.

ENFORCE TRANSPARENCY LAWS

All U.S. MAID laws include broad conscience clauses for both institutions and individual clinicians. Invoking these rights, many religiously affiliated institutions have opted out of participating in MAID. But to help patients make informed decisions about where to seek treatment, California and Washington require facilities to publicly post their MAID policies. That way, patients seeking MAID can make informed choices, for example to avoid enrolling in a nonparticipating hospice. Unfortunately, compliance is poor and states have not enforced the transparency requirements. Colorado now seems poised to do a better job.

PERMIT ASSISTED SELF-ADMINISTRATION

Some individuals otherwise currently eligible for MAID are unable to self-administer their medications because of neurological conditions like ALS. A recent debate in this Journal discussed whether the Americans with Disabilities Act permits, or even requires, clinicians or others to assist these patients in self-administering MAID medications when their physical disability prevents them from completing administration by themselves (Shavelson et al. 2023). Even Pullman admits that California should permit this much (Pullman 2023).

DROP THE SIX-MONTH REQUIREMENT

All U.S. MAID jurisdictions require that the patient have a prognosis of six months or less to live. This strict temporal requirement is unusual compared to other countries, such as Canada, which require only that the patient have a "grievous and irremediable medical condition." Indeed, many seriously and irreversibly ill individuals not within six months of dying may still suffer greatly every day from their disease. A growing number of advocates (including within Pullman's target jurisdiction, California) want U.S. laws to be more like broader laws in Australia, Belgium, Canada, Luxembourg, Netherlands, Spain, and Switzerland (www.abetterexit.org).

PERMIT INTRAVENOUS ADMINISTRATION

Under U.S. MAID laws, medications can be self-administered orally, rectally, or through a feeding tube. All three methods require ingestion (through the stomach and intestines). But evidence from other countries shows that intravenous infusion is more reliable and faster than ingestion (Pope 2020). Unfortunately, IV administration is unavailable in the United States because MAID laws specifically prohibit ending a patient's life "by lethal injection." To allow safer and more effective IV administration, state legislatures should repeal that prohibition. This would not cross the line from MAID to euthanasia. While clinicians would set up the IV, the patient would take the final step of opening the valve to let the medication into their body.

REQUIRE PATIENT DECISION AIDS

All MAID laws have multiple safeguards that help assure the patient's voluntary and informed consent. But because the stakes are so high, we should use the best means available. Patient decision aids are evidence-based educational tools that dramatically improve patient understanding of their options compared to clinician discussion alone (Pope 2022). Other end-of-life decisions

are already supported by decision aids. We must develop a PDA for MAID. And we must get it certified by the Washington State Health Care Authority (Pope 2017).

PERMIT ADVANCE REQUESTS

Many older Americans fear living with late-stage dementia. But MAID isn't an option for these individuals. By the time they're terminally ill, they no longer have capacity. And when they still have capacity (for example, in early stages of Alzheimer's), they're not yet terminally ill. In response, some advocates are pushing to permit individuals to arrange MAID through an advance directive. This is already permitted in some European countries and is being actively considered in Canada. In the meantime, there has been a significant interest in VSED advance directives which direct caregivers to stop providing food and fluid by mouth (Pope 2021; Quill et al. 2021).

REPEAL ASFRA

While MAID is primarily a state matter, many terminally ill patients are on Medicare. That impedes access because the Assisted Suicide Funding Restriction Act of 1997 prohibits federal money from being spent on MAID. Consequently, patients must find another way to pay roughly $750 for the medications. Furthermore, ASFRA deters many hospices and other providers from offering MAID because they worry about inadvertently billing Medicare for it. For these reasons, while most advocacy has been at the state level, some advocates seek to repeal ASFRA.

CONCLUSION

The Dubai World Cup is often referred to as the "world's richest horse race." In 2017, one of the favorites was Highland Reel, an Irish thoroughbred racehorse. He took an early lead and kept it for most of the race. But Highland Reel lost his lead 400 meters from the finish line. Worse, he was then passed by the entire field and relegated to a dead last finish. Analogously, the United States took an early worldwide lead with MAID when Oregon enacted its Death with Dignity Act in 1994. But like Highland Reel, the United States has lost its lead. And it is quickly falling to the back of the pack in terms of MAID safety and access.

DISCLOSURE STATEMENT

Professor Pope is a regular consultant to the American Clinicians Academy on Medical Aid in Dying (ACAMAID) and has served as an expert witness in federal litigation challenging the California End of Life Option Act.

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