Dying in Oregon: A critical look at death with dignity

by Joseph J. Kotva Jr. in the April 13, 2016 issue

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Brittany Maynard, a 29-year-old schoolteacher with grade 4 glioblastoma, became a media sensation in 2014 when she announced in a YouTube video her decision to utilize Oregon's Death with Dignity Act. A *People* story announcing Maynard's death drew more than 16 million unique visitors and became the most-read web-based story in the history of Time Inc. publications.

Today Maynard's case is widely touted by advocates of physician-assisted suicide, or PAS. The *New Yorker* called her the "poster child for assisted death." Marcia Angell, former editor of the *New England Journal of Medicine*, called her "the new face of the movement to give dying patients the choice to end their lives faster and more humanely." Barbara Coombs Lee, president of Compassion and Choices, credits the recent passage of California's Death with Dignity Act to the momentum that Maynard created. Since she ended her life on November 1, 2014, more than half of U.S. state legislatures have introduced PAS bills. Brittany Maynard thrust PAS into public consciousness.

"The Death with Dignity movement has been waiting years for someone like Maynard," said *Time* writer Josh Sanburn. Young, educated, articulate, attractive, compassionate, world-traveling, family-oriented, and dog-loving, Maynard remains a compelling figure for popular media. She attracts the attention of young, healthy adults who identify with her and are pushing PAS into the foreground.

But Maynard is not a typical user of Oregon’s DWDA. As *America* writer James F. Keenan warned, atypical or nonrepresentative cases may be a staple of television programming, but basing public policy on these cases engenders flawed policies that are dangerous to the politically and socially marginalized people they affect.

The most obvious difference between Maynard and others who seek physician-assisted suicide is age. At 29, Maynard was decades younger than the typical 71-year-old who seeks physician-assisted death; since 1997, only seven people under the age of 34 have used Oregon’s DWDA. Focusing on Maynard conceals the fact that most PAS users are elderly, with the increased vulnerability that comes with old age.

Maynard was also more educated than the average recipient of lethal medication. PAS advocates and the Oregon Public Health Division describe people who use the DWDA as well educated. But one has to ask what *well educated* means. Since DWDA’s inception, 56 percent of those who have utilized the law have been people with an education level of “some college” or less. “Some college” does not signify the same social or economic security as does a completed baccalaureate degree. Maynard is again atypical in having a four-year college degree. This difference raises the possibility that many recipients of lethal medication are more vulnerable than Maynard was—a possibility obscured by the focus on her.

Maynard was also atypical in having deep family connections. Numerous stories reveal that she had close, loving relationships with her husband, mother, stepfather, and friends. But strong social connections seem to be less than normative for those making use of PAS. According to the Oregon Public Health Division, 56 percent of those receiving lethal medication since 1997 fall into the categories of widowed, never married, or divorced. Of course, unmarried people can have good social connections and married people can lack them. Still, the fact that more than half of those accessing Oregon’s DWDA lack a spouse raises the possibility that many lack Maynard’s deep familial supports.

In 2000, psychiatrist Linda Ganzini and colleagues interviewed 35 Oregon physicians about their perceptions of patients who requested PAS. Ganzini found that the dominant characteristics of these patients included a greater-than-average preoccupation with self-determination, independence, and self-sufficiency. For those seeking PAS, the “dying process presented too much risk of becoming dependent.” They were described as “interesting, memorable . . . amazing,” but also as “crusty, reclusive, demanding” or as “solitary old ducks.” The descriptions do not suggest patients with deep networks of family and friends.

In another study, nurse practitioner Kathryn A. Smith and colleagues compared 55 Oregonians who were seeking PAS to 39 Oregonians with advanced diseases who were not seeking PAS. Those seeking PAS tended to focus on independence and self-reliance and lacked intimate, trusting relationships. This picture of what the study terms “dismissive attachment” is at odds with our image of Brittany Maynard surrounded by family and friends.

Raymond P. Tucker, a graduate student in psychology, notes that studies from 1996, 1999, and 2005 reinforce this troubling picture by suggesting a relationship between how a person perceives social supports and the likelihood of that same person considering PAS. Tucker and colleagues report that “those scoring high in social support tended to be less likely to consider PAS” than those scoring low. Additional evidence suggests that “terminally ill patients were less likely to consider a hastened death if they felt appreciated by others.” Intriguingly, the combination of “thwarted belongingness” and a perception of “burdensomeness” (risk factors in suicidal desire) seem to correlate with college students’ attitudes toward PAS. The more a student feels burdensome to others and perceives a lack of connectedness to and reciprocal caring with others, the more likely that student is to approve of PAS.

Focusing on Maynard also distorts the argument for PAS when we consider pain. Maynard dealt with severe seizures and migraines and appeared to be afraid that her pain would be unmanageable. She said, “Who thinks they have the right to tell me that I don’t deserve this choice? That I deserve to suffer for weeks or months in tremendous amounts of physical and emotional pain?” Others framed her situation similarly. In an episode of *The Diane Rehm Show* focusing on Maynard, Barbara Coombs Lee contended that PAS is about the relief of unmitigated physical suffering. Lee talks about “agonies, some of the tortures that people consider worse than death.”

But it turns out that physical pain is not a major driver in the use of PAS. The 2014 annual Oregon Public Health Division DWDA report says, “The three most frequently mentioned end-of-life concerns were: loss of autonomy (91.4 percent), a decreasing ability to participate in activities that made life enjoyable (86.7 percent), and the loss of dignity (71.4 percent).” By contrast, since 1997, only 24.7 percent of

Oregonians receiving lethal prescriptions listed inadequate pain control or fear of inadequate pain control as part of their reasoning for accessing the DWDA. Even this number is unreliable. It’s unclear what portion of the 24.7 percent had unmanaged pain, what portion feared that future pain might be inadequately controlled, and what portion had consulted a palliative care specialist.

Another sign that pain is not a major factor in seeking PAS comes from the study by Smith. Those Oregonians requesting PAS had low pain scores; they did not have greater measures of pain than those who were not seeking PAS. In Granzini’s study of physician perceptions, the patients requesting PAS either initially or eventually rejected both life-prolonging treatments and palliative care, including referrals to pain clinics. If someone is rejecting pain control, it is unlikely that pain is the main reason for seeking PAS.

People worry about excruciating, unending, torturous pain, and it’s understandable that they endorse legalizing PAS when the policy issue is framed around pain. Most of those favoring legalized PAS assume that the central issue is crippling, unrelenting pain. The Brittany Maynard story is used to reinforce this misperception. But when we’re dealing with public policy, especially issues of life and death, we must get our facts straight. We must determine which cases are typical and which are rare.

The truth is that cases of truly unmanageable pain are rare. The Institute of Medicine’s 2014 report *Dying in America* includes an overview of palliative care’s impressive efficacy at alleviating symptoms and providing more comfortable end-of-life experiences for both patient and family. As Harvard Divinity School professor Arthur J. Dyck observes, “Hospice, and palliative care generally, are highly effective in providing relief of pain and suffering.” Experts repeatedly affirm the capacity of this care to alleviate most severe symptoms and pain at life’s end. And as Oxford theologian Nigel Biggar notes, there really “is no such thing as pain that cannot be relieved, insofar as permanent sedation can always be used as a last resort.”

Are there cases in which doctors cannot sufficiently palliate extreme pain without permanent sedation and in which the patient finds the idea of such sedation a fate worse than death? Yes. But in thinking about public policy, we must admit that such cases are rare. We likewise must acknowledge that most people choosing PAS do so for other reasons. And we need to recognize that even in cases in which patients list pain control as a driving factor in seeking PAS, many seek to avoid *anticipated* pain.

PAS is often an effort to bypass an expected (not certain and not currently existing) forced choice between pain and sedation. Once again we’re a long way away from the story told about Maynard.

Medical ethicist Arthur Caplan says that Maynard changed the optics of the debate about PAS. We should sympathize with Maynard, a wonderful person who suffered from a tragic disease. But identifying with Maynard distorts the public policy debate. “She was younger and better educated than the typical person accessing DWDA, and surrounded by love. She was also preoccupied with pain in ways outside the norm of those seeking PAS.”

Maynard was effusive in her praise of Oregon’s DWDA, and she saw the campaign to create similar laws in every state as giving meaning to her life and death. Advocates for PAS commonly assert that Oregon’s experience with its DWDA should assuage our concerns. Angell says that Oregon’s experience with DWDA shows that all fears about legalizing PAS are misplaced.

But confidence in Oregon’s DWDA arises less from evidence than from the assumption that there are no abuses and that everything is fine. Bioethicist Daniel Callahan describes Oregon’s DWDA as “lacking all transparency and accountability, with no information other than of a statistical kind made available to the public.” Oregon’s Public Health Division has never conducted the type of surveys done in the Netherlands that revealed the full, troubling contours of its euthanasia practices. Common assurances about Oregon’s DWDA echo the same assurances offered in the Netherlands prior to more recent surveys. (See Theo Boer’s article "Rushing toward death?")

Psychiatrist N. Gregory Hamilton says that a “culture of silence” has surrounded legalized assisted suicide in Oregon. “It has permeated medical university departments, governmental agencies, continuing education classes, national discussions, and large HMOs.”

Moreover, Oregon’s DWDA depends entirely on physician self-reporting with virtually no follow-up with those physicians or affected families. What little information we have comes from the self-reporting of the people charged with writing the lethal scripts. A 2013 report looking at legal compliance in the Netherlands, Belgium, Oregon, and Switzerland noted that “it is not known” whether individuals in Oregon receiving PAS were mentally competent, acted voluntarily, executed written requests, or were of legal age. Any confidence that everything is well with the DWDA is premature.

Consider also the requirement that a patient be referred to a psychologist or psychiatrist if there is concern that the patient has a psychiatric disorder, including depression, that may impair judgment. With this requirement in place, we might infer that depression is not a causal factor in patients receiving PAS. Unfortunately, this inference does not withstand scrutiny.

Reported referrals for psychiatric evaluation are low. In 2014, when 155 prescriptions were written for lethal medication, only three people were referred for psychiatric evaluation. Only 1.9 percent of those progressing toward PAS were candidates for a consultation. Furthermore, studies show that physicians tend to underdiagnose and undertreat depression, especially among the elderly. Why should we expect the situation to be different with those seeking to use DWDA? Most psychiatrists do not believe that they can determine a patient's competency for PAS in a single visit, yet Oregon is relying on therapists to do just that.

The therapists used for consults typically are therapists who affirm PAS. This predisposition seems likely to influence conclusions of patient competency. If one already believes that PAS is a reasonable response to a circumstance, one is more likely to find the person seeking PAS to be competent.

Studies indicate that major depressive disorders are being missed in Oregon. Although the size of its sample group was small, one study using standardized criteria for depression found that one-third of those in the group who died by ingestion of lethal medication were probably clinically depressed. Likewise, Smith found that Oregonians requesting PAS had "higher levels of depression, hopelessness, and dismissive attachment . . . and lower levels of spirituality" than similarly ill Oregonians not seeking PAS.

When it comes to major depression, we do not know what is going on. Some of those receiving lethal prescriptions may be directed more by depression and hopelessness than by any rational calculation of their situations.

Another unknown factor involves doctor shopping. Since the first year of Oregon's DWDA, patients who are turned down for PAS by their physicians contact Compassion and Choices for a referral to a doctor who will be open to the request. How much doctor shopping is happening? How often do the referral physicians consult with the earlier physicians? It’s likely that some patients are getting lethal prescriptions from physicians who have known them only a short time.

Though PAS advocates tout Oregon as the model to follow, the Oregon system lacks transparency and is clothed in secrecy. We know shockingly little about whether guidelines on competency, informed consent, and witness requirements are fulfilled, or how often major depression is missed, or about the relationship between patients and the prescribing physicians.

A more fundamental problem with most arguments for legalized PAS is an inattention to moral formation. We should worry about the character of a doctor who facilitates death. Each time the doctor “aids in dying,” he or she may become more willing to “aid” the next person. We should be discomforted about the kind of doctor who’s shaped in the process of intending death, no matter how compassionate is that doctor’s initial impulse.

An analogy to pet euthanasia illustrates the problem of formation. The analogy made by PAS advocates is that since we put our beloved pets to sleep when they are very sick and in great pain, we should allow people who are very sick and in great pain to choose to die via PAS.

Although many find the pet analogy compelling, it collapses under scrutiny. In fact, the analogy evidences the very problems that PAS opponents fear. For example, pets cannot give consent. The analogy is dangerous in its implied suggestion that we expand “aid in dying” to nonconsenting patients. Moreover, consider the reasons most people euthanize their pets: incontinence, senility, behavioral problems, or conditions too expensive to treat. Sometimes pets are no longer wanted. They outlive their owners, become too costly to keep, or become a burden during a time of transition in an owner’s life. In other words, we euthanize pets because they are inconvenient, expensive, troublesome, and unwanted. It’s a sobering analogy when applied to people.

More tellingly, the practice of pet euthanasia is known to morally shape veterinarians. Dyck tells about a veterinarian who initially struggled to give a lethal injection to a dog. But after performing many such procedures, the veterinarian found that she was killing the animals without hesitation. Many veterinarians recognize a similar development in themselves.

We shouldn’t be surprised. We become better at things as we practice them. Each time a veterinarian euthanizes an animal, he or she likely becomes slightly better at creating emotional detachment and entering a worldview in which pet deaths are acceptable. While many veterinarians initially struggle with euthanizing pets, especially since many of the animals are healthy, studies show that the majority of veterinarians acclimate themselves to the process.

Also worrisome are studies in the United Kingdom indicating that veterinarians are more inclined than other health-care workers to view suicide as a solution to their own problems and that 93 percent of UK veterinarians favor euthanizing humans. Performing euthanasia appears to change veterinarian attitudes toward death. When one intentionally terminates animals that are considered to be family members, a natural next step is to alleviate human suffering by death.

The fundamental policy question comes down to the kind of medicine, people, and society we seek to cultivate. If we aspire to creating and maintaining a society that prizes solidarity, cherishes life, discourages suicide, and sees dependence (even suffering) as normal to human existence, we will have much greater challenges when PAS is legalized.

I’ve focused on policy-oriented reasons to reject PAS. There are also compelling Christian reasons to reject it. Christian freedom is not the freedom of arbitrary choice but the freedom to love and serve both God and neighbor. Even in death, such opportunities remain. Moreover, those who aspire to the Christian virtues of love, hope, patience, hospitality, and gratitude will not look to leave their lives early via PAS or ask others to risk moral malformation by intending death.

As Christians, we must stand with the sick and the dying, reform the mechanized and isolated ways in which people die, and never shrink from the messy and exhausting tasks of caregiving. In the end, the best way to undermine PAS is to show that there is a better way—one of love, service, and virtue.