Give me liberty and death: Assisted suicide in Oregon: A year after the Death with Dignity Act

by <u>Courtney S. Campbell</u> in the <u>May 5, 1999</u> issue

A 43-year-old Oregon man is progressively paralyzed by the advance of amyotrophic lateral sclerosis (ALS). Cared for by a hospice and his family in his travel trailer, the man requests a lethal dose of medication so that he can end his life. A physician, acting under the state's Death with Dignity law, prescribes a sufficient supply of barbiturates. The man uses a straw to mix the barbiturates with a chocolate nutrition drink. When his paralysis makes it difficult for him to swallow the mixture, a brother-in-law helps the man to die, though the brother-in-law refuses to talk about how he did it (the *Oregonian*, March 11, 1999).

A new professional and moral era in medicine began in Oregon in 1998--the state entered a brave new world in which physicians assume the responsibility for hastening the death of their terminally ill patients, and patients determine the timing, circumstances and means of their deaths. Patients now can give their physicians a revolutionary command: "Give me liberty and give me death." How and why did this come about?

Oregon is a state that takes immense pride in its pioneer history. As people pushed westward in the 19th century, they left behind older social patterns and moral and religious traditions. That frontier spirit is still alive. Oregon's approach to assisted suicide displays the ethos and sentiments of libertarianism: personal autonomy, choice and self-determination are regarded as sovereign, and institutions with authoritarian pretensions, whether the government, the church or professional associations, are viewed with suspicion.

The Oregon Death with Dignity Act exemplifies both this ethos and the frontier imperative to continually expand and revise boundaries. Those who formulated the act had three purposes in mind: 1) To provide terminally ill patients with the right to

"a humane and dignified death" through ingestion of a lethal medication; 2) to provide physicians with immunity from legal and professional sanction for participating (whether by offering a diagnosis, providing information or writing a prescription) in hastening patients' deaths; 3) to assure the public that such a practice could be subject to regulation and public accountability (in contrast to the unregulated methods of Dr. Jack Kevorkian and the absence of accountability of physicians in the Netherlands).

The Death with Dignity Act was initially approved by voters in 1994, though legal appeals postponed its implementation until fall 1997. It made Oregon the first jurisdiction in the world to give physicians the legal permission to assist in the suicide of terminally ill patients. The law was widely heralded as illustrating the "pioneering" role of Oregon in patient-directed medical practice and in ensuring "dignity" at death.

While the language of dignity and compassion gave the act its conceptual foundation, the legislation's practical focus was on enabling physicians to write prescription for lethal medication. What follows such authorization is largely unregulated and ambiguous, as the opening story illustrates; the state's deputy attorney acknowledges that the act is silent on many questions about implementation.

What the act does make clear are certain rights and responsibilities of both patients and physicians prior to the writing of the prescription. For example, adults with a diagnosed terminal illness (meaning that according to reasonable medical judgment, the patient's life expectancy is less than six months) have the right to request medication that will end life in a "humane and dignified" manner. (The act does not refer to the patient's request or the physician's action by the term "physicianassisted suicide.") Patients may ask for information about their diagnosis and prognosis; about the potential risks and probable results of ingesting lethal medication; and about alternatives, including palliative care and hospice. They may rescind their request.

To be eligible for this kind of assistance, people must be legal residents of the state. They must make two oral requests to the physician for a prescription to end life, and at least 15 days must elapse between the two requests. Finally, they must give the physician one written request for lethal medication, and 48 hours must pass before the prescription is written. Physicians are responsible for determining whether patients are terminally ill and whether they are capable of making voluntary choices about their care. They must give patients the information they need to make informed decisions, and refer them to a consulting physician to confirm their health and mental status. If there is any suspicion that a sick person's judgment might be impaired, the doctor must refer him to a counselor. Finally, physicians must document the process and report it anonymously to the state health division. Doctors are not required to be present when the patient dies.

Physicians who act in good-faith compliance with the law are immune from legal prosecution or professional discipline. They have the right to refuse a patient's request. In formulating these provisions, authors of the act sought to protect the rights of all three constituencies: patients, physicians and the public.

While popular arguments for physician assistance in suicide commonly refer to the need to relieve pain or suffering, these appeals have no legal standing in the act. Rather, the act is framed exclusively in terms of patients' "control" over their lives and their "right" to end those lives in a humane and dignified way. In political campaigns, advocates for the act relied entirely on the argument that people have the right to control the manner and timing of their death. Terminally ill patients need not be in pain or suffering to exercise this right.

Organized opponents of the act essentially conceded the moral ground to those who advocated autonomy. That concession left the moral argument to those who opposed it on medical or religious grounds--groups vulnerable to the charge of being morally authoritarian. The medical argument--that in individual instances of assisted suicide things could go very badly for the patient--was not persuasive.

Arguments offered from religious perspectives or by particular religious communities were interpreted within the context of the culture wars. State legislators who considered proposing revisions to the act were warned against "imposing religious beliefs on citizens." Proponents also argued that those opposing the act were "held hostage" by the "raw political power" of religious institutions. A vocal political action committee was named, "Don't Let Them Shove Their Religion Down Your Throats Committee." It vigorously warned the public about the prospect of unleashing moral tyranny through the "imposition" of religious positions. The culture wars card was played and, in some circles, warmly received, in part because Oregon's citizens are among the least religiously affiliated of any in the U.S. The argument particularly resonated with voters because it reminded them of recent attempts by an alliance of fundamentalist Christians (the Oregon Citizens Alliance) to make biblical appeals the explicit basis of public policy on such issues as abortion, public education and gay rights. Though those efforts were all defeated, some by quite substantial margins, they made people suspicious of arguments based on religious perspectives.

In the course of the litigation that followed the passage of the act, the marginalization of religious discourse on assisted suicide was vigorously endorsed by the Ninth Circuit Court. The final paragraph of the majority opinion in *Washington v. Glucksberg* (1996) concludes: "Those who believe strongly that death must come without physician assistance are free to follow that creed. . . . They are not free, however, to force their views, their religious convictions, or their philosophies on all the other members of a democratic society, and to compel those whose values differ with theirs to die painful, protracted, and agonizing deaths."

The language of this decision comes very close to suggesting that all opposition to assistance in suicide must have a religious character; that is, it is part of a "creed." Empirically, this is surely false, but as fodder for the polemics of a campaign it can be a compelling suggestion. More disturbing constitutionally is the court's insinuation that to express religious convictions constitutes "force" or "compulsion." The concluding clause raises the specter of religious inquisition: that religious commitments will be used to compel others to "die painful, protracted, and agonizing deaths." It comes as no surprise, then, that some 20 percent of the voters who supported passage of the act indicated that their vote was not so much on the merits of the law, but "about the role of outside religious groups trying to tell Oregonians what to do."

In February 1999 the Oregon Health Division issued a report on the first year of implementation of physician-assisted suicide. It reported that 23 people received prescriptions for lethal medications in 1998; 15 people took the medication and died; six died from their underlying illness, and two were still alive as of January 1, 1999 ("Legalized Physician-Assisted Suicide in Oregon: The First Year's Experience," by A. E. Chin et al., *New England Journal of Medicine*, 1999).

Despite the report's efforts to sanitize suicide through the language of epidemiology and statistics, people should not be misled into thinking that the concerns about moral accountability have been satisfied. For several reasons, it is very difficult to determine the extent of compliance with the law. Other than the first reported death through assisted suicide, which was selectively leaked to the public, a shroud of privacy and confidentiality has veiled efforts to determine how well the process is working. The source for the 23 documented cases was physicians' accounts and death certificates. The public has absolutely no mechanism for understanding and evaluating the experience of patients in these circumstances. And as the Health Division concedes, physicians have no incentives to report a "bad death" experience. In general, we know no more about the practice of physician-assisted suicide now than we did a year ago.

It would be very useful to know at what point in their illness those terminal patients who contemplated or made a request for assistance in dying were referred to hospice care. Usually such referrals occur too late to help the patient to be made comfortable by hospice pain-management methods.

We need to know about the kind and duration of the relationship between patient and physician. In the report submitted by the Health Division, at least 25 percent of the patients who died had had only short-term relations with the participating physician. We need to know who, if anyone, was with the patients when they died. The Health Division indicates that people "who were divorced or had never married were more likely to choose physician-assisted suicide." Are patients requesting a hastening of biological death because they are already experiencing the social death of abandonment?

More information of this kind will not settle the question of whether assisted suicide should be legal, but it can help us evaluate how the practice is working. It is not necessary to identify patients, families or physicians in order to obtain the needed data. Both opponents and proponents of legalization have a stake in ensuring that if assisted suicide is an option for the terminally ill, it is safe for patients and mitigates rather than perpetuates the social and economic problems they may be facing.

The way the Oregon initiative became embroiled in the culture wars reveals the fragility of civic discourse and the widespread suspicion of the value of religious voices in that discussion. Nonetheless, there are, in fact, several common procedural and substantive commitments shared by all parties--patients, providers and advocates--that can provide the basis for a constructive discourse.

Citizens must begin by discussing what they hold in common rather than what is divisive. The debate over physician-assisted suicide presumes a shared commitment to improving care for the terminally ill. This is the core ethical and professional issue that has been obfuscated by the political campaign and sanitized by the reporting process. Second, proponents and opponents both affirm the importance of patient control over dying. This emphasis is already embedded in Oregon's current policy. We need to permit the dying even greater say about where they will die, in whose presence, and with what levels of care provided.

Third, there is a common conviction about the centrality of "dignity" in a meaningful death. People disagree as to the practical ways to ensure a dignified death, but that should not preclude public discourse aimed at coming to a common understanding of such a death. A fourth common conviction is that the option of assisted suicide should be exercised only as a last recourse.

A democratic society should be committed to including religious voices in the policy process while affirming that nonreligious reasons must be provided in justifying policies. We need to recover Alexis de Tocqueville's insights regarding the difference between religion as an influence in public discussion and as an authority for deciding public policy. The former should be welcomed in a society committed to democratic ideals; the voicing of religious views in no way constitutes a tyrannical "imposition" of religion. Such an imposition would be based on dubious theology and political theocracy, and should be forsworn.

Oregon's Death with Dignity Act is being cited as a model in other jurisdictions (such as California). The focus on common commitments rather than on divisive issues will provide the best framework for providing better care for the terminally ill.