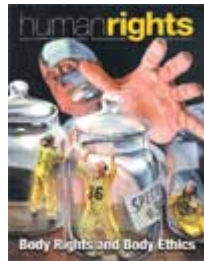


## HUMAN RIGHTS MAGAZINE



### **End of Life Care: A Human Rights Issue**

**By Kathryn L. Tucker**

The American Medical Association's Code of Medical Ethics states "physicians have an obligation to relieve pain and suffering and to promote the dignity and autonomy of dying patients in their care. This includes providing effective palliative treatment even though it may foreseeably hasten death." During the past decade, authoritative literature from medical journals has also exhorted physicians to treat pain attentively and aggressively. And the companion cases of *Quill v. Vacco*, 117 S. Ct. 2293 (1997), and *Glucksberg v. Washington*, 117 S. Ct. 2258 (1997), recognized that dying and suffering patients have a right to adequate pain management.

Nevertheless, patients in the United States, including those seriously ill and dying, are routinely undertreated for pain. In a landmark study published in the *Journal of the American Medical Association* in 1995, researchers found that 50 percent of all patients who died during hospitalization "experienced moderate or severe pain at least half of the time during their last three days of life." At the same time, medical research has established that perhaps only 10 percent of dying patients have conditions in which alleviation of pain is truly difficult or impossible. That one out of two dying patients endure pain unnecessarily is a little noticed human rights tragedy.

#### **The Bergman Case**

Bill Bergman represents the human consequences of inadequate pain management. In 1998 Mr. Bergman was admitted to a California hospital complaining of excruciating pain. Bill was dying of lung cancer. The attending physician treated him with Demerol during his five days in the hospital. Leading authorities, however, specifically recommended against using Demerol for cancer pain. Even so, Mr. Bergman's dose was several times below the recommended starting level. The physician ordered the medication "as needed" instead of continuously, a method inappropriate for reducing and controlling pain. Further, although Bill continued to complain of pain at levels between seven and ten on a ten-point pain scale, with ten representing the worst pain imaginable,

his medication was not adjusted during the hospitalization. When discharged, Mr. Bergman reported pain at level ten.

The Medical Board of California (MBC) later determined in response to a complaint filed by Bill's daughter, Beverly Bergman, that the physician had failed to provide adequate pain care. In a letter to complainant Beverly, it stated: "Our medical consultant did agree with you that pain management for your father was indeed inadequate." Nonetheless, the board declined to file charges against the physician. Disappointed and outraged, the Bergman family filed suit alleging that the physician had failed to adequately treat Mr. Bergman's pain. Evidence in the case revealed that the doctor had not bothered to stay current with the many developments in the field since graduating from medical school and was ignorant of the great body of authoritative literature governing pain management, as a result using outmoded and discredited strategies and causing Mr. Bergman unnecessary suffering during his final week of life. The jury determined that the physician's conduct was reckless and awarded the family \$1.5 million under the state elder abuse statute for Mr. Bergman's pain and suffering.

#### Causes of Undertreatment of Pain

Although many factors contribute to inadequate pain management, two stand out as most significant: the fear of oversight and the lack of education. Oversight is accomplished by prescription monitoring programs, which were originally designed to prevent the diversion of strong medications to the black market. Yet these programs have had the collateral effect of discouraging doctors from prescribing such medications. Highly publicized cases such as *Hoover v. Agency for Health Care Administration* and *Hollabaugh v. Arkansas State Medical Board*-in which physicians were investigated and punished for prescribing strong pain medications, even when such actions met guidelines for pain management-have created a climate of fear that deters appropriate prescribing.

New programs of scrutiny and sanction are particularly alarming. The most recent notable effort involves a directive from Attorney General John Ashcroft. The directive holds that any physician determined to have intended to hasten a patient's death by provision of pain medications is subject to punishment under the federal Controlled Substances Act (CSA). Ashcroft's effort is an attempt to overturn the will of the Oregon people, who have twice voted in favor of a law permitting dying patients to obtain self-administered medications to achieve a humane hastened death. The directive threatens good pain management for all dying patients nationwide. Clinicians point out that determining a physician's intent in prescribing pain medication at the bedside of a suffering, dying patient is open to an investigator's after the fact second-guessing: was the intent to relieve pain and suffering or to hasten death? If the Ashcroft directive is permitted to take effect, the desire to avoid investigation will make physicians even less willing to treat the pain of dying patients. As discussed below, the directive currently is enjoined by order of a federal district court.

Many physicians lack knowledge of modern pain management practices and principles. Medical schools have failed to adequately teach pain and symptom management, and

licensing boards have failed to require continuing medical education in pain and symptom management as a condition of maintaining a license to practice medicine. A number of states, including California and West Virginia, are addressing these issues by passing legislation to require such training. Hopefully such initiatives will serve as models for other states to follow.

### Ineffectual Reform Efforts

The American Society of Law, Medicine & Ethics launched an effort to mitigate the problem of undertreated pain. The Project on Legal Constraints on Access to Effective Pain Management developed a model Pain Relief Act that created a "safe harbor" sheltering physicians prescribing pain medications from disciplinary and criminal action so long as they "demonstrate by reference to an accepted guideline that his or her practice substantially complied with that guideline." The Act also required doctors to keep appropriate records, abide by the CSA, and refrain from writing false prescriptions or diverting medications to personal use. *The Pain Relief Act*, 24 J. LAW MED. & ETHICS 317 (1996).

Many state laws have incorporated safe harbor provisions, often called Intractable Pain Treatment Acts (IPTAs), but these statutes contain a critical shortcoming that has rendered them largely ineffectual. While the acts provide a safe harbor for doctors who prescribe pain medications—an essential part of alleviating physicians' fears of scrutiny—they fail to include an accountability mechanism for doctors who do not administer the drugs. Only when physicians face adverse consequences for undertreating pain will they need a safe harbor—and will patients receive the treatment they deserve.

### Creating Accountability

Accountability for inadequate pain management can arise in various contexts. The most appropriate mechanism stems from the state medical licensing boards that have the authority to supervise the conduct of the licensees in their jurisdiction and to protect the public from injurious medical care. A second correction results from tort exposure.

State medical boards have been slow to recognize their responsibility to correct physicians who undertreat pain. These bodies should adopt policies that require disciplinary action when there is failure to adequately prescribe, order, administer, or dispense controlled substances, including opioid analgesics, for the relief or modulation of pain in accordance with prevailing clinical practice guidelines. In 1998 the Compassion in Dying Federation (CIDF), a nonprofit organization dedicated to improving end of life care, urged all fifty state medical boards to improve care by pursuing corrective action with physicians who fail to treat pain adequately. Fortunately, signs of change can be seen: in a case similar to the Bergman case, the MBC filed charges earlier this year, and the subject of the role of medical boards in correcting undertreatment of pain is now on the agenda of the state medical boards and the Federation of State Medical Boards, whose annual conference featured the issue this year.

The tort system may also provide accountability. Until recently, the tort system has not punished physicians for failing to adequately treat the pain of their dying patients. However, we stand at the threshold of a new era, with real exposure for physicians and health care facilities in cases of inadequate pain management. Tort liability would be made easier if the safe harbor laws were amended to provide a private cause of action for the patient or survivors, with recovery of attorneys' fees, when there is failure to adequately prescribe, order, administer, or dispense controlled substances, including opioid analgesics, for the relief or modulation of pain in accordance with prevailing clinical practice guidelines. Such an explicit cause of action, with the attorneys' fees recovery provision, would make tort accountability a powerful corrective mechanism. Such verdicts reverberate in the medical community and apply a strong prompt to correct such behavior. But even absent an explicit private cause of action, liability may be founded upon conventional theories of medical negligence or creative application of other statutes, such as those governing elder abuse, as was done in the Bergman case.

### The Choice of a Humane Hastened Death

Even when physicians provide excellent pain and symptom management, a fraction of dying patients want the option of a humane hastened death if their pain and suffering becomes intolerable. Polls consistently show that a substantial majority of citizens and physicians alike believe that competent terminally ill patients should have this option. Nonetheless, many state laws prohibit assisted suicide. Although *Quill v. Vacco* and *Glucksberg v. Washington* upheld the legality of state statutes criminalizing assisted suicide, the opinions clearly contemplated future legal challenges and political reform. The decisions were plainly influenced by the lack of information on legalized physician-assisted dying, since at the time no state had authorized this option. Five justices, a majority of the Court, wrote or joined concurring opinions that limited the scope of the majority's ruling and carefully reserved issues for future cases.

The Supreme Court strongly endorsed continued public debate of the issue and invited legislative reform. As the majority recognized, "[T]hroughout the Nation, Americans are engaged in an earnest and profound debate about the morality, legality, and practicality of physician-assisted suicide. Our holding permits this debate to continue, as it should in a democratic society." 117 S. Ct. at 2275. According to Justice Souter, "[T]he Court should stay its hand to allow reasonable legislative consideration," because "the legislative process is to be preferred." *Id.* at 2293. Justice O'Connor urged that state legislatures be allowed to address the complex issues first. "States are presently undertaking extensive and serious evaluation of physician-assisted suicide and other related issues. In such circumstances, the . . . challenging task of crafting appropriate procedures for safeguarding . . . liberty interests is entrusted to the 'laboratory' of the States." *Id.* at 2303.

### The Oregon Death with Dignity Act

In 1994 the citizens of Oregon used the initiative process to pass the Oregon Death with Dignity Act (ODWDA), the nation's first law to legalize and carefully regulate the

practice of physician-assisted suicide. A lawsuit challenging the ODWDA prevented it from taking effect until the case was dismissed for lack of standing in 1997.

Anti-choice activists have persistently sought to nullify the ODWDA, even after the suit challenging the Act was dismissed. First, the Drug Enforcement Agency (DEA) was encouraged to invoke the CSA to punish ODWDA-compliant physicians. The DEA initially opined that its agents could revoke DEA registrations of physicians who assisted in hastened deaths under the ODWDA. U.S. Attorney General Janet Reno, however, soon overruled this position, concluding that the CSA did not reach such conduct. In an opinion letter issued June 5, 1998, Reno stated, "The Department has reviewed the issue thoroughly and has concluded that adverse action against a physician who has assisted in a suicide in full compliance with the Oregon Act would not be authorized by the CSA." Reno concluded, "There is no evidence that Congress, in the CSA, intended to displace the states as the primary regulators of the medical profession, or to override a state's determination as to what constitutes legitimate medical practice in the absence of a federal law prohibiting that practice." Opponents then sought to amend the CSA to expand its scope to include the ODWDA, in two successive sessions of the federal legislature. Both efforts failed in the face of fierce medical opposition founded on the concern that the proposed measures would exacerbate physicians' fears regarding the use of controlled substances in pain management.

A change in federal administration and philosophy led to a change in legal interpretation. As noted above, Attorney General John Ashcroft issued a directive on November 6, 2001, advising that the Department of Justice had concluded that prescribing controlled substances under the ODWDA violated the CSA because "assisting suicide is not a 'legitimate medical purpose' within the meaning of 21 C.F.R. § 1306.04 (2001)" and "prescribing, dispensing, or administering federally controlled substances to assist suicide violates the CSA." In particular, "[s]uch conduct by a physician registered to dispense controlled substances may 'render his registration . . . inconsistent with the public interest' and therefore subject to possible suspension or revocation under 21 U.S.C. § 824(a)(4)." See 66 Fed. Reg. 56,607 (Nov. 9, 2001).

Plaintiffs challenged the Ashcroft directive in federal court, claiming that it violated the CSA, the Administrative Procedure Act, and the U.S. Constitution. In April 2002 the court issued its decision, reaching only the question of whether the directive was within the scope of the CSA and concluding that it exceeded authority granted under the CSA. A permanent injunction was entered.

The determination of what constitutes a legitimate medical practice or purpose traditionally has been left to the individual states. State statutes, state medical boards, and state regulations control the practice of medicine. The CSA was never intended, and the USDOJ and DEA were never authorized, to establish a national medical practice or act as a national medical board. To allow an attorney general—an appointed executive whose tenure depends entirely on whatever administration occupies the White House—to determine the legitimacy of a particular medical practice without a specific congressional grant of such authority would be unprecedented and extraordinary.

Oregon v. Ashcroft, 192 F. Supp. 2d 1077, 1092 (D. Or. 2002). The decision was appealed and is pending before the Ninth Circuit as Case 02-35587. Oral argument was set for May 7, 2003. The district court points out that Ashcroft's directive would "stifle" the debate ongoing in the states, which the Supreme Court had deferred to in reaching its decisions in Quill and Glucksberg.

The ODWDA has now been implemented for over five years. Each year teams of epidemiologists from the state and federal government review data related to its implementation and issue reports summarizing the data. These reports carry the resounding message that the supposed risks of the option have not materialized. Indeed, many important and measurable improvements in end of life care in general have occurred following implementation in Oregon.

#### Passage of Assisted Dying Laws in Other States

Twenty other states have initiative mechanisms to effect popular reform legislation, and other states may follow Oregon in utilizing the initiative process. However, the initiative mechanism has well-known shortcomings, and it is particularly ill-suited for addressing complex issues such as those related to end of life decision making. In this complex area, a legislative process that allows for extensive fact finding and careful crafting of informed legislation would be preferable to the inflexibilities of initiative measures. The legislative method offers a more responsive process, in which concerns could be addressed and democratically accommodated.

Numerous models have been proposed and provide a useful starting point for development of appropriate legislation. These generally include a range of protective, prophylactic measures designed to ensure accurate diagnosis of the patient's terminal status and mental competency; that the patient's decision is voluntary, rational, deliberative, and enduring; and that patients have been informed of alternatives such as hospice care.

#### State Constitutional Litigation

State constitutions and state courts are often more protective of individual rights and liberties than the federal constitution. The California Supreme Court's observation in a recent case exemplifies this tendency. "The scope and application of the state constitutional right of privacy is broader and more protective of privacy than the federal constitutional right of privacy as interpreted by the federal courts." *American Academy of Pediatrics v. Lungren*, 940 P. 2d 797, 808-09 (Cal. 1997) (holding California Constitution's privacy clause renders statute requiring parental consent to minor's abortion unconstitutional). It is now well recognized that state courts can and will actively turn to their state constitutions to justify protections beyond those mandated by the federal Constitution.

State court challenges to assisted-suicide prohibitions based on state constitutional provisions protecting individual privacy, liberty, or dignity may offer a route to reform in

some states. A declaration from a state's highest court that the state constitution protects the choice of a competent dying patient to obtain medications for the purpose of achieving a humane and dignified death would be of obvious national significance. Such a decision would allow the generation of additional data on how a legalized practice of physician-assisted death actually operates. To date, the two state high courts to have considered the matter have determined that their state constitutions do not protect the choice of a competent terminally ill patient to choose a humane hastened death. *Krischer v. McIver*, 697 So.2d 97 (1997); *Sampson v. Alaska*, 31 P.3d 88 (2001). However, it is likely that as Oregon's experience with the ODWDA yields additional data, concerns about abuse and risk, so central to state opposition, will be assuaged and defused. Indeed, even staunch opponents of assisted suicide have begun to publicly acknowledge that continued opposition to such laws cannot be justified in light of the experience in Oregon. See DANIEL LEE, *PHYSICIAN-ASSISTED SUICIDE: A CONSERVATIVE CRITIQUE OF INTERVENTION*, *Hastings Center Report* 33, no. 1 (2003): 17-19. A courageous high court in a state with strong constitutional protections of individual liberty, privacy, and/or dignity may soon recognize that competent dying patients are entitled to hasten impending death.

## Conclusion

Dying patients deserve to have their pain managed in a manner consistent with modern principles and practices, uninhibited by physician concern that providing attentive and aggressive pain care may be second-guessed by drug enforcement agents. The relatively small fraction of patients who find their dying process intolerable even with responsive pain management deserve to have legal access to a lethal dose of self-administered medications. These are matters of human rights. As Ronald Dworkin so eloquently observed in his book *Life's Dominion*:

Making someone die in a way that others approve, but he believes a horrifying contradiction of his life, is a devastating, odious form of tyranny.

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