REFORM IN OREGON: PATIENTS, DOCTORS, AND THE STATE

It felt as if my blood froze the first time a patient asked me to help them die. I realized that with all my technical knowledge about diagnosis and treatment, I knew nothing about helping people die. And there was nowhere to turn—not to my colleagues, my association, the literature. There was literally no guidance anywhere.

—Dr. Peter Goodwin, sponsor of the ODDA (Goodwin 1996)

This section chronicles the complex changes in social relationships and cultural values that inspired the death with dignity movement. Beginning with post–World War II changes in the nature of dying, the emergence of the death with dignity movement is explored in reference to claims about negative repercussions of the modern medicalization of life and death. How these processes were manifested in the cultural, political, and economic relationships between patients, doctors, and the state is a key consideration. The transformation of these relationships into claims for and against reforming assisted suicide law is developed.

An attorney behind the ODDA said he has never seen a law that intrudes into the patient-physician relationship as much as this law does (Stutsman 1996). This intrusion marks an amazing shift in power between doctors and patients during the last few decades. There are several reasons why this shift is taking place, including changes in the nature of dying, appeals to compassion and autonomy, the mobilization of support by key physicians and leaders, and the neutralization of some potential opposition.

Two sponsors of the ODDA were Barbara Coombs Lee and Dr. Peter Goodwin. Coombs Lee, a nurse, lawyer, and former legislative aide, and Dr. Goodwin, a practitioner of family medicine and professor of medicine, became involved in euthanasia reform because of their personal experiences in caring for dying patients. Each felt that many physicians have no penchant for, and some are even intransigent about, becoming intimate with their patients, especially with regard to helping them die. According to Dr. Goodwin, this is not the fault of physicians, for nothing in their training teaches them how to help a dying patient die:

Traditionally, patients were generally given very high doses of morphine and left to die by the inch. The family was left waiting somewhere and in most cases not even informed that the patient was officially dying. Physicians were trained that it is harmful to give the family the bad news until it is over. These medical practices were deplorable. (Goodwin 1996)
Other data support Goodwin’s claims about the negative repercussions of the modern medicalization of life and death. In 1961, the Journal of the American Medical Association (JAMA) published a study of physicians’ practices in telling or not telling patients about a diagnosis of cancer. Results showed that 90 percent of the study’s physicians reported a preference for not telling the patients of their diagnoses or prognoses (Oken 1961). In fact, patients were usually treated as children and were expected to submit in quiet deference. Patients who questioned paternalistic doctors were labeled as troublesome, and hospital staff often treated them accordingly.

Patients facing death were worse off. Physicians were not trained to treat patients and families facing death. Moreover, for both psychological and cultural reasons, they typically shunned the actual experience of death when it happened to their own patients. The inadequacies were personal and structural. Physicians labored under their own inadequacies whenever patients and families sought advice. And planning for death, and perhaps even hastening it, had no place in the discourse and practices of institutionalized end-of-life care.

But the very medicalization of life (and dying) that fostered social disparity between patients and doctors gave rise to new tensions and uncertainties in the patient-doctor relationship. As Roy Porter, the British social historian of medicine, observes:

“New tensions and uncertainties in the patient-doctor relationship are in many ways a response to the modern medicalization of life—the widening provision of medical explanations, opinions, services and intervention; the infiltration of medicine into many spheres of life, from normal pregnancy and childbirth to alcohol and drugs related behavior, in line with a philosophy that assumes the more medicine the better. . . . Today’s complex and confused attitudes toward medicine are the cumulative responses to a century of the growth of the therapeutic state and the medicalized society. (Porter 1998:690–691)”

On another level, the growth of the therapeutic state in a medicalized society has invited appeals to compassion and autonomy. There has been an emerging debate about the autonomy of the individual in the face of usually expensive medical options. Some analysts frame the issue in the context of power sharing and competition between physicians and patients. Patients’ rights, which have expanded in many areas (Macklin 1993), and laws about informed consent characterize the rights consciousness that has grown around medical decision making as medical technology has expanded and forced many more people to make end-of-life decisions. And there has been a grow-
ing and changing consciousness regarding death itself among Americans.

The harmful burdens of heroic medicine became anecdotal inside and outside hospitals and nursing homes. People were angry with their own doctors and the medical profession for being so patronizing as to decide how they would live until death. Largely because of such tragedies, and reinforced by sympathetic media coverage, patients and their families began demanding more control over treatment decision making, especially at the threshold of death.

The attorney’s remark about the intrusiveness of the OODA signifies how much relationships between doctors and patients have changed and how radically the prospects for legal reform have shifted. The power shift that occurred as informed consent and similar ethical principles transformed physicians’ practices left paternalism largely abandoned (Darval 1993; Jonsen 1993; Griffiths et al. 1998). For example, physicians have abandoned the assumption that patients do not really want to know what is wrong with them or that they cannot possibly understand.

According to the American Hospital Association, about 70 percent of deaths occur after discussion to forgo or withdraw treatment (Kolata 1997). In fact, norms have changed so dramatically that during the fifteen-year period between the seminal case of Karen Quinlan, and the time when reformers began using the ballot initiative to push for greater physician involvement in hastened death, it was estimated that each day in the United States, 6,000 deaths were “in some way planned or indirectly assisted” (Quill et al. 1992:1381). By that same time, all but six states allowed for some sort of living will and do-not-resuscitate provisions (Hoeffer 1994). As mentioned earlier, national polls consistently have shown an increasing majority of public support for greater control over the situation of one’s death.

As dying patients and their families have entered the professional aided-dying discourse, they have brought their own experiences and insights to bear on political analysis. They have sought to transform the cultural image of suicide as a violent, lonely, despairing act that leaves survivors confused and guilty for not having seen it coming, to a compassionate act of self-deliverance that honors choice and relieves suffering. According to these reformers, the fear of death in Western, Judeo-Christian culture, and the resulting laws for dealing with a person who no longer wishes to live, compound the disasters of heroic medicine. Viewed in this light, any facial ban against assisted suicide prevents dying people from deciding the circumstances of their own death, denigrates their moral judgment, and limits their freedom. Most importantly, choice in dying is more than an individual need, private crisis, or hospital staff problem—it is a collective issue because each of us will experience our own and probably a parent or other loved one’s death some time or another.
Because it is a collective issue, choice in dying has shifted from the private sphere into the center of public debates (Battin 1995; Battin et al., 1998; Callahan 1987, 1990, 1992, 1993; Emanuel 1998; Englehardt 1989; Glick 1992; Jonsen 1990; Meisel 1992; Otlowkski 1997; Vaux 1992). For the past decade, legal scholars, medical professionals, public policy experts, ethicists, and ministers, as well as the general public, have grappled with the weighty and complicated issues of the ending of life in medical settings (Battin 1995; Dombrink and Hillyard 1998; Hoeffer 1994; Quill 1996; Rothman 1991; Schneideman and Jecker 1995). The proliferation of advance directives and living wills, following the 1990 United States Supreme Court decision in Cruzan v. Director (1990), has been one outcome of the rights consciousness of people considering end-of-life issues. But despite all the change, patients had still not been permitted to receive medical assistance with suicide until Oregon acted.

Ethicists such as Arthur Caplan have termed the legal referenda analyzed in this book as extremely important events in contemporary American medical ethics, calling Washington's 1991 assisted suicide initiative “the most important biomedical event in the United States” (Hoeffer 1994:196). Caplan has even said that he sees the issue of euthanasia in the near future eclipsing that of abortion as a subject of moral and legal reform in the United States. Ethicist Peter Singer (1995:1) describes the euthanasia-related events in Britain, the Netherlands, and the United States as “surface tremors resulting from major shifts deep in the bedrock of western ethics. We are going through a period of transition in our attitude toward the sanctity of human life.”

As Griffiths explains, physicians' practices are coming under greater legal control in all sorts of countries, and the legal position of patients is growing stronger. This general domestication of medicine is the major sea change that is taking place, and particular legal battles are but local manifestations (Griffiths et al. 1998). The impetus for medicine's domestication is the problem that brought bioethics into being, namely, who shall be saved when all cannot be saved? Moreover, several medical historians have explored the clinical and political aspects of this problem. Jonsen (1990) writes about the shift of moral probabilities from the absolute “Do everything possible for this patient” to the proportionate “Do everything reasonable for all patients.” These questions suggest that changes in the doctor-patient relationship have been stirred by wider social movements to protect consumer and patient rights.

But patients, as sufferers and political actors, moved physicians to a more radical political position. Dying patients and their families insisted that the medical profession listen. Although there were few nasty debates or picket lines as with the abortion movement, much of the medical profession heard the general message as well as individual patients' demands. Communication and negotiation were taking place in public forums between institutions, organi-