

## Covenant in Conflict with the Law: Pain Relief in Terminal Illness<sup>1</sup>

*We all must die. But that I can save him from days of torture,  
that is what I feel as my greatest and ever new privilege.  
Pain is a more terrible lord of mankind than death himself.<sup>2</sup>*  
—Albert Schweitzer

If more people suffered visibly from the pain of terminal illnesses, it would no longer be a hidden public policy issue. Unrelieved pain would not be the unseen killer of the spirit that it is for so many people today. It would no longer test the resolve of the dying to live out the final days of their lives. It would no longer force families to confront the awful choices of the end days, including those choices of assisted suicide.

People today suffer, but they do not suffer visibly. They are most often at home or in nursing homes. Sometimes, but not always, they are in hospice care. Occasionally, they are in hospitals, where pain relief may not present any technical challenges, but will be fraught with social and legal hurdles. At any rate, those suffering among us are out of sight and out of earshot. They do not grimace as they pass us by in shopping malls, do not cry out at movie theaters, and do not shed their tears getting groceries. They and their families are most often alone and too often isolated, consumed with managing the hour-to-hour torment of unremitting pain along with the other aspects of the terminal disease, its frailties, fractures, and bleeding. If suffering people were visible to us, their pain would be front-page news. Their stories would stir action in larger numbers of important medical and policy centers of the nation. If their caregivers were not so overwhelmed with the task of easing the pain as they supported the dying process, they would be organized into effective, policy-changing groups. If their clinicians were not so burdened defending themselves before overzealous law enforcement as they attempted to prescribe, and defend their use of, adequate doses of pain-relieving medications, they would be more available to organize as well. These family members and clinicians could borrow a page from animal rights activist strategies and confront us with our lack of compassion. They would question our humanity toward our fellow men and women.

### *The Extent of Pain in Terminal Illness*

Our best statistics are on cancer deaths and pain. An estimated eight million Americans will die from cancer, of whom 70% will have pain and fewer than one-half will be adequately

treated for it.<sup>3</sup> Coping with the diagnosis of cancer and adjusting to the shocking news are challenges in the early stage of the disease. Coping with the fears of unrelieved pain comes soon thereafter. Becoming a burden on family members is the principal concern of dying people, and the fear of pain is the second most difficult problem they face. The fear itself exacerbates physical pain. Unrelieved pain leads to suffering.

Cancer is not the only terminal condition that creates pain, but it is the one for which we have the best statistics. Nor is pain associated with only terminal illnesses. Many people who are not terminally ill also experience pain.

In our society, many suffer from other causes of pain and rely—or should be able to rely—on our compassion and care. Chronic pain affects over 50 million Americans, and another 23 million experience acute pain from surgery and injuries each year.<sup>4</sup> Back pain affects over 26 million adults and is the leading cause of disability for people under age 45.<sup>5</sup> Arthritis affects one in six Americans,<sup>6</sup> and 25 million suffer from migraine headaches.<sup>7</sup> Pain is estimated to cost \$100 billion each year, causing over 150 million days of lost work.<sup>8</sup> A majority of people with pain cannot engage in the normal activities of daily living, such as grocery shopping, walking, or housekeeping.<sup>9</sup> Pain has been called the “silent epidemic,” and for very good reason.<sup>10</sup>

If we as a society are unable to deliver pain relief—even to those among us who are dying—how can we expect to demonstrate compassion to the living? If we are unable to address the clear and unambiguous needs of pain relief in terminal conditions, how can we address those that are chronic? If we are helpless in the face of the conflicts that cripple our compassion in death, how can we expect any better in life? How can we ask those who suffer pain to bear it silently while we discuss public policy conflicts? How can we ask them to suffer endlessly because we cannot resolve our differences about the management of pain? How can we justify our failures when the covenant to relieve the pain of those who are dying should be so clear?

### ***Addressing Pain: A Critical Test of the Covenant***

The willingness to address pain should not depend on the visibility or invisibility of those who suffer, the number of people who are suffering at any given time, or what the cause of their suffering might be. Whether they suffer in our midst or alone, they suffer. Whether pain is common or rare, they rely on healers for relief. There should be no room in our healing enterprises for judgments about the cause of the nature of pain. Whether those suffering are children dying from cancer or elderly dying from the effects of life-long cigarette smoking, they need supportive and palliative care. Our healers have a covenant with them to relieve their pain, and our communities should share in that covenant by assuring that our public policies do not prevent the best possible palliative relief of their symptoms. All are deserving of compassion. Unlike beliefs common in the Middle Ages, pain is no longer viewed by large segments of society and within the healing professions as a signal of divine retribution or a requirement for eventual salvation. There are some today who value the experience of fully embracing pain, and they should be supported in their choice to do so. But the vast majority of people today would rather have effective pain relief in order to be better able to put their personal affairs in order at the end of life. Regardless of the nature of their disease or the number who suffer or are isolated

in their dying, those who are in pain require care. If that pain is not relieved, it creates suffering, and suffering is another matter altogether.

### ***Beyond Pain: Suffering***

The terms “pain” and “suffering” are sometimes used interchangeably, but they are actually quite different. Pain is “an unpleasant sensory and emotional experience associated with actual or potential tissue damage.”<sup>11</sup> It can include aching, burning, numbness, loss of sensation, itching, and tightness. Suffering is a broader concept and goes beyond the sensations to encompass the hopelessness that some dying persons experience. In suffering, people feel a threat to their existence and to their “integrity as persons.”<sup>12</sup> Suffering reaches into the heart of personal, family, and spiritual experiences and generates feelings of helplessness as well as hopelessness.

Regardless of how intimately we know a dying person or how remote they may be from our daily lives, the importance of this problem merits more concern. Those who are healthy and active have the means to reach for an analgesic to deaden our ordinary daily pains. Shouldn't we devote a portion of our efforts to helping people in our communities whose pain is more overwhelming and more compelling than our headaches, stiffness, and muscle strains? Society should be concerned that people suffer needlessly. Instead, we have made them and the pain in their terminal illnesses invisible and have refused to come to terms with our responsibilities to help.

There are many methods to relieve pain. Some require long-term efforts of caring individuals to teach meditation and relaxation techniques and to assist at the bedside to help patients change positions, remain comfortable, prevent fractures, and be free of sores and wounds. Doing this, however, requires devoting time and attention to these patients. Many people are not inclined or cannot be helpful in this way; and few participate as caregivers and volunteers in hospice and respite programs. Although approximately 500,000 patients use hospice services each year and the costs are covered by Medicare most Medicaid, and many private insurers, a recent survey found that only 22% of all families who experienced a terminal illness used hospice services. Sixty percent of those patients had cancer, yet only one-half of all cancer patients used hospice services.<sup>13</sup>

### ***Relieving Pain and Easing Suffering***

The quickest method of relieving pain and easing suffering, and the one that demands the least effort, involves the use of medication. This method would seem to be best suited to those who cannot or will not take the time for the more personal forms of care that might be effective for many dying patients. Medication also appeals to the quick-fix inclinations and demanding lifestyles of those who are still healthy. Drug methods, however, are precisely at the crux of the controversies in caring for the pain of the terminally ill. Communities have negative biases about powerful drugs and have allowed fears to interfere with the relief of soul-crushing pain. Fear of powerful medications and the ways they can be misused increasingly prevents the compassionate care that should be given to the dying.

Ever since soldiers returned from modern-era wars with addictions to the pain-relieving medicines used to treat their physical and emotional wounds, society has become suspect and fearful of the power of legitimate medicines. Solving the problem became the task of law enforcement, which monitored the practices of physicians to ensure that they were not enabling addicts and creating new ones. These intrusions led to physicians' fears of prescribing these medicines for legitimate purposes and to regulatory barriers to make it more difficult for them to do so.<sup>14</sup> Special prescription pads were needed, special records were kept in pharmacies and forwarded to state authorities, and physicians could be questioned at any time about patients who were using these medicines.

Newer, more effective pain-relieving products became available. Physicians were not well educated about them because the legal barriers and risks to using these pharmacotherapeutics were so great that physicians preferred not to use them at all. Why engage in becoming expert in the value and appropriate use of new medicines one would be unlikely to prescribe? Old biases about the nature of the drugs and their effects on patients were therefore left to prevail. Even patients with terminal illnesses feared addictions, and many people avoided discussions about pain. Of all the families experiencing a death, only 2% had given any prior consideration to issues involving pain relief.<sup>15</sup>

Everyone—families, patients, physicians, and law enforcement—was ill informed and wrong. Patients treated with medications to relieve pain in terminal illness rarely become addicted.<sup>16</sup> Some physicians feared that increasing the dosage to the point necessary to relieve the pain would result in the patient's death. Research debunked that theory.<sup>17</sup> Others feared that, left in the hands of patients, overdoses would be common in suicide attempts. Again, the popular notions were wrong; patients would rather live than die.<sup>18</sup> It is the pain they wish to avoid, not life.

### ***Families Seek Better Relief from Pain***

The impact of unrelieved pain for patients and the loved ones they leave behind is profound. Only recently have we been able to document that family members giving care to seriously ill or disabled relatives suffer higher rates of mortality.<sup>19</sup> It is one of the most stressful times in family life, and one for which little financial or community support exists. Caregivers, who provide somewhere between \$100 billion and \$200 billion in uncompensated care, receive few returns from the communities that might otherwise support them with respite and other services.<sup>20</sup>

Beginning in the 1970s, this suffering led to the formation of a number of organizations dedicated to seeking a way out of the fear through political and legal solutions. Unable to find pain relief from healers and incapable of negotiating through the restrictions imposed by law enforcement intrusions into their care, families turned to politicians for intervention.

Their efforts over ten years of working with Congress brought their concerns to a head in 1982, when the National Committee for the Treatment of Intractable Pain succeeded in getting the attention of sufficient members of Congress. They were able to introduce legislation, force

hearings, and even gain a vote on a bill to change national policy on the treatment of pain in terminal illness. The Compassionate Pain Relief Bill would have legalized heroin for the treatment of pain of the terminally ill and would have required the Department of Health and Human Services to manufacture and distribute it to pharmacies so that it could be prescribed for terminally ill patients with intractable pain. Advocates for the bill argued that on simple humanitarian grounds the pain of terminal illness should be relieved and the dying should not be required to suffer. They pointed to the use of heroin in England, which for one hundred years had provided effective pain relief. They argued that the British model of pain management should be copied because some patients, especially those with terminal cancer, could not be treated effectively with currently available analgesics in the United States.

At the time, the Reagan Administration officially opposed the bill on scientific grounds. Well-controlled clinical trials of the day demonstrated that morphine was just as effective as heroin in pain relief and newer (at the time) and more potent analgesics had just become available.

The debate had one positive effect: It exposed the nature of the problem. The dilemma in the United States was not that there were not adequate medicines, but that the way in which physicians managed pain was inadequate. Physicians in this country medicated for pain in a more limited and ineffective way because of their unfounded fears of addiction and well-founded fears of law enforcement intrusions into their practice. With no such fear abroad, physicians in England used more medication more often on a routine schedule intended to anticipate and prevent the recurrence of pain. It was not, in fact, the heroin they used, but the way they used it that made the difference. The patient advocacy groups were right, but for the wrong reason. We needed change in this country, but not in the pharmaceutical arsenal. We needed a change of law and of heart that would allow for the use of appropriate medications that were already on the shelf.

The Reagan Administration feared that the use of heroin, even in medical circumstances, would signal that its use for other purposes would be tolerated. In addition, it feared that the presence of heroin in communities would increase the rates of pharmacy and drug-seeking crime and cause its diversion into the illegal drug markets. The bill was defeated. Families, desperate for a solution, forced a vote in Congress. There was not yet adequate consensus at the time about the need for a change in pain-management policy, and anti-drug-abuse forces won the debate. This brought defeat to years of effort to create change. However, the effort did not die. The families were effective in setting the stage for more attention focused on the treatment of pain. The Department of Health and Human Services and the American Medical Association embarked on a campaign to educate physicians in practice. These efforts prompted major policy and educational discussions within the clinical community. Have they been successful?

### ***Healers Respond to Patient Needs***

Nearly twenty years have passed. In some ways the situation has improved. New research has produced better pain management strategies. Media coverage of pain management has increased. Recognition of pain as a clinical issue has expanded, its own set of side effects and

sequelae are understood, and pain has been acknowledged in other previously undertreated groups, such as newborns and children.<sup>21</sup> The National Cancer Institute turned its attention, though less than 1% of its budget, to the issue of pain management for cancer patients. Congress requested that the Medicare Payment Advisory Commission (MedPAC) study inpatient and outpatient reimbursement barriers to appropriate pain management. A number of new pain management societies formed within the medical profession. Two of the most important groups, the American Academy of Pain Management and the American Pain Society, issued a joint statement recognizing pain relief—including with therapies that may hasten death—as the ethical obligation of all health care providers. . They concurred that pain is often treated inadequately, despite available medicines.<sup>22</sup>

Patients, families, caregivers, and physicians continue to struggle with the task of caring for the dying and how best to relieve their suffering. The debate on the moral and medical challenges of care for the dying requires a response. That response demands extraordinary efforts to improve end-of-life care and optimal management of pain and suffering. We have the knowledge and ability to deliver skillful and effective control of pain and suffering at the end of life.

The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) escalated the concern for health care facilities on matters of pain. Its new long-term care manual gives residents the right to expect a quick response to reports of pain and calls for statements to be posted in every patient room that notify patients of this right. In JCAHO-accredited facilities, patients are told they can expect that their reports of pain will be believed, that they will be given information about pain relief from concerned staff, and that pain will be responded to quickly and effectively. The JCAHO standard recognizes pain as common, as having serious consequences if not relieved, and as an important part of the ethical care of patients. It encourages education and involvement of the family.

Some State Medical Boards and legislatures have also recognized the problems of overzealous monitoring of pain medications and have initiated pain study groups and educational efforts. A majority of states already protect physicians from disciplinary, criminal, or civil action for prescribing medications to relieve pain through laws, regulations, and Medical Board Guidelines.<sup>23</sup> Most recently, the North Carolina Medical Board ruled that physicians will not be subject to disciplinary action, even if the medications they prescribed or administered to relieve a patient's pain hastened death. Ten states have passed legislation protecting medical professionals and family members who prescribed or administered medications for the relief of pain, even if the medications hastened the death of the patient, as long as the intent was not assisted suicide.<sup>24</sup> By 1999, another seven states had sought to protect physicians and families and had introduced similar legislation.<sup>25</sup>

Have these efforts been effective? A number of physicians, and a significant number of medical organizations, studied this issue and are on record as agreeing that despite the legal and regulatory protections offered them by their states and Medical Boards, law enforcement still intimidates physicians in their actual practices.<sup>26</sup> Actions, like that of the North Carolina Medical Board, were intended to respond to those physicians' concerns. In the words of Hospice for the

Carolinas President Judi Lund Person, “I think this is sending a message. What we have all been trying to do is to quell real or perceived fear that if doctors prescribe what they think is enough pain medication, the medical boards may go after them.”<sup>27</sup> Even other healers have “gone after” clinicians. Harvard Professor of Medicine Jerome Groopman, tells a compelling story of a physician who, with the consent of a dying patient and her husband, administers pain-relieving morphine that all knew might have the effect of reducing breathing or lowering blood pressure. The respiratory therapist attending the patient objected and accused both the treating physician and the patient’s husband with hastening her death. Both the hospital review board and district attorney found the charges unfounded, but what impact will this experience have on the next such case that the clinician confronts?<sup>28</sup>

Have we gone far enough in reassuring physicians? Can we assure patients that actions such as these will help to relieve the pain of the illnesses that devastate their loved ones?

### *Suffering Continues*

The family of William Bergman filed a complaint with the Medical Board of California against his physician after Mr. Bergman’s death. The complaint requested that the physician be disciplined for failing to prescribe the medications that would have relieved the lung cancer pain he was suffering as he died in his daughter’s home. The Board agreed that the pain management for Beverly Bergman’s father was inadequate, but they rejected her request and declined to discipline his physician.

Subsequent to the Medical Board action, the family sued in court. Since California law prohibits awards for pain and suffering after the death of the patient, the family sued under “elder abuse” statutes and was awarded \$1.5 million in damages. Since the failure to treat was not malicious, there were no punitive damages, and the award was subsequently reduced in a higher court to \$250,000, but the impact at the time of the trial was predicted to be far reaching. It has been. Since that time, pending legislation in California would require physicians to receive continuing education in pain management in order to renew medical licenses.

Few families have made such disciplinary requests and even fewer have resorted to litigation, but family support and lobbying groups are currently recommending this as a strategy for driving change. This may well be the harbinger of a new trend in patient and family activism and empowerment. If so, it may also prove to be an unfortunate one.

Physicians practicing today, regardless of whether they are educated and experienced in pain management—and most of them are not—are caught in the middle between drug abuse and pain management tensions. Claims similar to those of the Bergman family were recently successful in Oregon, where the Board of Medical Examiners disciplined a physician for grossly undertreating pain in six patients. As a part of the disciplinary action, the physician must complete an extensive educational and counseling program.

Although some will hail this as the right prescription for bringing doctors into the proper practice of pain management, it is not. Healers who fail to act within their oaths and according to the standards of practice should be disciplined, but witch-hunting will not solve the dilemmas we

confront in managing tough issues such as pain management, which are more social and legal than technical and clinical. Actions such as this, if they are abused, will place healers, patients, and families in an increasingly tenuous position. To subject those who prescribe and administer medications to the tensions between law enforcement and medical boards without a community-based policy and political resolution places both the healer and the patient at even greater risk. It encourages the physician to abandon the patient altogether. It encourages the family to limit whatever medicines are prescribed. As in ancient days, if physicians are made to walk clinical and regulatory tightropes and risk retribution for their attempt to treat the most needy of the sick and dying, they will be inclined to select their patients carefully. Left with no other choice, they may decline to treat those in greatest need of palliative care. If, at any time, healers might be called to defend their practices to drug enforcement agencies and medical boards—neither of which treat patients and both of which are charged with limiting drug use—they might become reluctant to provide that care. If, at any time, families are questioned about their methods and motives for using medication, they, likewise, will be reluctant to do so. The inevitable result for patients will be the painful deaths so many of them fear.

If these actions become witch-hunts, a cycle of fear will be created that will become even more deeply embedded in the care of the dying. Physicians' fears about prescribing important and necessary medicines would exacerbate the undertreatment of patients' pain, which causes unrelieved pain and in turn creates fear among patients and others who watch them suffer. Fear comes full circle. It is the greatest irony of all when patients suffer because the two gifts from the gods—the law and the healing arts—cannot resolve the tensions between them for the benefit of the mankind they were intended to serve.

### ***Congress Muddles the Issues***

Unfortunately, healing and law enforcement clashes were renewed when Oregon voters sanctioned a law allowing assisted suicide under some circumstances. In 1994, and again in 1997, the voters in that state approved a “Death With Dignity Act,” which allowed patients to seek the assistance of their physicians to end their lives. Unrelieved pain was one, but by no means the only, aspect of dying that was cited by those who encouraged adoption of the voter referenda.

After Oregon passed the law, the federal Drug Enforcement Administration (DEA) informed physicians in the state that they risked losing their federal license to prescribe controlled substances if they used controlled drugs to assist in a suicide. The letter impacted physician practices and the number of prescriptions for controlled substances declined. Physician/healers, obviously concerned about the implications of being accused of misusing powerful, pain-relieving medications wrote fewer prescriptions for pain relievers. In June 1998, United States Attorney General Janet Reno issued an opinion that the DEA could not prosecute a physician who acted in compliance with the Oregon Death With Dignity Act. As a result, some members of Congress decided to act, launching another round of volleys in the conflicts over medical use of these medications for the pain of terminal illness.



The first was the Lethal Drug Abuse Prevention Act, introduced by Senator Don Nickles (R-OK) and Representative Henry Hyde (R-IL) in 1998. The act was intended to stem the tide of assisted suicide, fueled not only by the developments in Oregon but also by Dr. Jack Kevorkian's challenges to laws in other states. The act would have given the Department of Justice the authority to review the medical decisions of physicians with regard to prescribing drugs that relieve pain. More than 30 respected national organizations representing physicians, patients, nurses, cancer survivors, and pain specialists opposed the legislation. The positive aspects of the bill to improve palliative care were more than undone by the fears that federal investigations would create. As a practical result of the bill, not only would the actions of prescribing physicians be investigated, but their motives as well. The legal burden of proof, even in a drug abuse-paranoid society, would have remained on the investigators, but the impact on the physician, left to demonstrate that his or her motive for prescribing the medication was not assisted suicide, would have been extremely disruptive. It was widely feared, and rightly so, that it would have the chilling effect of creating even greater fears among physicians. The most compassionate and technically competent healers, who chose to stand by and assist dying patients in pain, would most certainly have been at greatest risk.

The legislation died. However, it rose again in 1999 under a new name. The Pain Relief Promotion Act of 1999 retains the essential components of the 1998 proposal. A third bill, the Conquering Pain Act, was introduced in response to the other proposals by Senator Ron Wyden (D-OR) and Senator Connie Mack (R-FL). It improves education, develops community resources for pain management, and requires studies to determine how government-funded programs can better manage pain. It calls for a study of pain management by the Institute of Medicine (IOM), a highly respected and visible advisor to government. It will not resolve the problems we have created over the past five decades, but it will be a step in the right direction. The Pain Relief Promotion Act of 1999 passed the House and has been endorsed by a number of clinical groups, pain societies, and patient interest groups. It has redeeming features, particularly related to funding authorizations for education in pain control. However, it also continues to promote the second-guessing of clinical intentions of prescribing physicians. Mr. Wyden threatened to filibuster the bill in the Senate and it eventually failed. It would not be long before the Bush Administration would reverse the position of Attorney General Reno, however, and decide to "target" physicians who prescribed drugs that could have pain-relieving—though lethal—effects. Is this the best step we can take to aid the dying?

### *Communities in Conflict*

At the root of the dilemma is America's drug abuse problem. We know from public service advertising that drugs fry your brain, and a majority of the kids who use drugs don't live in big cities. Full-page ads tell parents how to talk to their kids about drugs and show them how to plan their child's funeral if they don't. Some employers require pre-employment drug screening; others conduct drug tests on a periodic, and sometimes surprise, basis. Statistics from the Drug Abuse Warning Network (DAWN) report on the level and type of drug abuse activity. Local and state police and the federal DEA arrest dealers and users and display their conquests of these illegal networks with pride. There is no doubt that drugs are a problem that both law

enforcement and health care experts need to address. Recent awareness of the abuse of Oxycontin® brought abuse issues to the fore once again.<sup>29</sup>

Preventing and treating drug abuse in this country is a valid objective, but it cannot be the only one. It is necessary, but it is not sufficient. We must also prevent and treat pain in terminal illness, and we know that is a problem for this country as well. It is a part of our lives and of our arts. It is portrayed in *Terms of Endearment* and the Pulitzer Prize-winning play, *Wit: A Play*. In these portrayals, we, as humans who ought to know better about how to care for each other, do not fare well. We speak, in our culture, as if we care about both the drug abuser and the terminally ill patient, and yet we act as if we care only about one to the exclusion of the other. What happens when law enforcement and medicine are at odds? What happens when they clash? Why is it that when some of us abuse drugs, the rest of us, our clinicians, and our caregivers become suspect if we use that same substance for medical reasons? Can we reduce the suspicion about the valid use of medicines to treat pain? Will we ever correct the tragedy of underprescribing the medicines that patients need as they die in pain?

How can we better resolve the tensions between law enforcement and the practice of medicine? How can our communities better balance the need to keep the streets safe from illegal drugs and yet ensure that patients in pain get the medications they need for relief? How can we protect physicians and nurses from harassment and provide patients with medicines while we sort out our differences about drug abuse prosecution and legitimate prescribing? How can we come to agreement more quickly so that more of us do not suffer needlessly as we die?

### ***Confronting the Challenge of Compassion within the Covenant***

“Compassion” means “to suffer with,” and we do precious little of that in the United States today. Dealing with the pain of some terminal illnesses and relieving suffering at the time of death have been among the most sacred responsibilities of healers for thousands of years. It should be no less the case for us today. In fact, the burden of the covenant should be even greater because in this era, unlike in earlier times, we have a panoply of medicines and better methods for accomplishing the goal of pain relief. If we apply those methods well, we can assure virtually all patients that virtually all pain can be relieved.

Compassion for the pain of illnesses that cause death should be the hallmark of a civilized society and a central tenet of the healing covenant. In undertreating pain, we do violence to patients at a critical time in their lives. This problem is not a new one and is in no way related to the proliferation of managed care or other reimbursement changes in health care systems. It is, instead, the result of factors that have their roots in denial, ignorance and conflict—all of which create fear and, in turn, allow pain to rule in the final days of terminal illness for too many people. It is clear that we are at loggerheads in this country on this matter. Law enforcement agencies, and recently some members of Congress, have ignored the very real suffering of the dying. They draw hard lines around the use of pain-relieving drugs and neglect the fact that healing entails the soft side of compassion. Healers, though they have recently become more effective in engaging in the policy debates, remain too silent on the challenges of

pain management. We have failed to resolve our differences, and while we are deadlocked in conflict, our dying suffer.

The issues are clear. Should we, as a society, formally invite Congress and law enforcement into the covenant between the dying patient and the healer? How would that be accomplished? What experiences of caregiving would serve to educate them on the realities of pain? What remedies would we ask they pursue if these experiences commit them to caring? Are we asking the dying to disengage from the covenant and suffer because we fear our addictions and doubt our ability to manage them? Are we asking them to suffer in isolation because seeing their pain makes our communities wince? How can we balance the needs of our covenant to care for both the dying and the addict? Can we protect healers from bearing the brunt of the conflicts?

### ***Creating a Covenant to Relieve Pain at the End of Life***

Today, we have the most extensive arsenal for the management of pain in the history of medicine. No era has had such powerful pain-relieving technologies. Our medicines, surgery and complementary methods of pain relief are more developed now than at any time in history. Our understanding of the nature of the terminal illness and dying process has never been richer. Each pharmaceutical product is researched, manufactured, and licensed as safe and effective for working its miracles. Today's methods rarely fall short. Yet no healing responsibility has been so severely tested. Even those within weeks or days of dying are frequently denied the pain-relieving medicines that could ease their suffering, enable them to put their personal and spiritual affairs in order, and deal with the grief of their impending death with family and friends.

There are important ways that healers and communities, acting within their covenants with patients, can address these conflicts. The covenant between the healer and the patient was reinvigorated within a new paradigm with the work of Dr. Elizabeth Kübler-Ross, who brought us a new appreciation for the value of living embodied in dying and showed us ways to support the process of living until the end. That work extended through the hospice movement and has been institutionalized by health care reimbursement, patient demand, and volunteer service. The hospice movement has created a critical mass of patients and healers who, working together, have improved care and pain-management options. They entered into a covenant of obligation. The healer provided the supportive caring of human touch and palliative medical technique. The patient allowed the healer into his personal life, shedding intimate and protective boundaries and disclosing the seriousness of his pain and dependence on others. This covenant has not yet succeeded, however, in achieving a final resolution to the intractable conflicts that leave so many in pain, because communities have not yet been engaged to participate. Communities must now enter into a covenant of obligation with their own who suffer and with the healers who relieve that suffering. A number of additional steps are needed to achieve a resolution.

- Those who work in the fields of cancer care, terminal illness, and palliative care are in the best position, because of their knowledge and their standing in their communities, to call for a special covenant with the dying. In the style of all covenants, they are the superior parties who can grant the healing pain relief and who can create the obligations that will sustain the covenant. In the context of their own

covenants with the patients they care for, they should lead the way to crafting a solution that can assure pain relief for those who need it.

- Congress and communities, for their part, should enter in to this covenant, because it is conflicting public policy objectives that created the tensions that have resulted in so much unnecessary pain. This will require an intensified dialogue at the national, state, and local levels among clinicians, families, law enforcement, and policy officials who deal with both concerns—those of drug abuse and those of pain. It will also require extensive education of all parties—and particularly national, state, and local law enforcement agencies—about the nature of pain management in terminal illness. Finally, it will call for those of us in communities to trust our healers to practice the arts and skills we empowered them to use to our benefit. We can no longer explain away our lack of compassion for the dying and lack of trust in our healers with our fears of addiction and abuse.
- Any individual who holds a position of responsibility or influence in policy, clinical care, communications, or law enforcement should be required, as a part of this dialogue, to participate in the care of those who suffer from pain in terminal illness. They should see for themselves what has been hidden. They should learn the value of the medications that have been denied to suffering people. They should understand the consequences of their failure to act quickly.
- Each existing and new legislative initiative or regulatory control to prevent or manage drug abuse must be examined in the context of how best to accomplish not only abuse prevention, but also pain relief.
- The new clinical care groups and study centers, formed in the last several decades to heighten the awareness of pain management and conduct pain research, should be more widely acclaimed for their work. The work of groups such as those who have received “The Circle of Life Awards” should be placed in spotlights by the national media.<sup>30</sup>
- The press should heighten the awareness and knowledge of the public and the professions about the availability of safe and effective means of managing pain and should work to dispel the myths that prevent good palliative care for the dying. Further, the press should avoid sensational reporting about the illicit use of legitimate products, which only creates an increasingly hostile climate for product development and supply.
- In the context of a worldwide covenant of healing, we should recognize that the problem of treating pain is a global challenge. The World Health Organization (WHO) estimates that more than half of those suffering from cancer worldwide have unrelieved pain.<sup>31</sup> The U.S. should enter into projects and participate in efforts with the WHO and the International Narcotics Control Board to ease suffering everywhere, not just in this country.

- Finally, having addressed the most obvious of pain management issues—that is, the relief of pain in terminal illness—we should turn our attention to the relief of the chronic and sometimes unremitting pain endured by many people in this country and throughout the world. Herein lies an obligation created in our covenants with those who are dying. Through their stories and the willingness of their families to address these issues where they cast the sharpest shadows and draw the sharpest lines in public debates, we may accomplish a goal to relieve their pain and those of other dying people like them. Calling us to more compassion, however, may help healers and the nation to deal with the even tougher issues of pain suffered by those who are not terminally ill, and who pose even more difficult questions for medicine and society to grasp.

These are simple steps, but they may be difficult to take. The attitudes of everyone involved have been ingrained through years of practice. The suffering of so many is silent. The denial of death is so great. It is a task that must be embraced with greater energy and attention.

Can it be done? I believe so, and I draw my optimism for the future from my brother, Jim, and his wife Nancy, who for more than twenty years have volunteered their time to a hospice group. Jim wants to write a book. He'd call it, "You Live, Until You Die." It comes from his experience of seeing the old and the sick die well, living—and often laughing—right up to the last moments. It would be a book of warm, tender, and funny stories. His stories echo the words of one cancer patient who helped us understand the importance of pain management back in the 1980s. She said, "I found that when I didn't have the pain, I could forget I had cancer."<sup>32</sup> As healers and as communities, we should offer that to all our dying patients. To do less is to diminish the living of everyone, especially the ones they leave behind.

---

<sup>1</sup> This appeared originally in 2001 in *Covenants: Inspiring the Soul of Healing*. Readers interested in exploring covenants in greater depth can find background in *The Origins of Healing as Divine Gift and History and Modern Applications of Covenant Healing Traditions* which appear in this series.

In summary, healing traditions are based on ancient views that healing skill came from the divine. Healers were aligned with divine forces against the terrible, unknowable and sometimes evil forces of illness. As a result, healer-patient relationships were structured as covenants. Covenants differ from contracts. Contracts have a defined beginning and end and specify the duties of the parties in detail. Covenants do not end and do not detail the duties of the parties.

There are two types of covenants, both are relevant in health care and are expressed in oaths taken by clinicians and others in health care. The first type – a covenant of *grant* – defines what one party does for another, without conditions or expectations. Parents have covenants of this type with their children, providing them food, shelter, clothing and protection. The second type – a covenant of *obligation* – involves mutual promises between the parties. Spouses enter into this type of covenant '...for better or for worse.'

The *Oath of Hippocrates*, a classic covenant statement, contains both types. It creates a covenant of *obligation* with other healers, calling for the oath-taker to "...study, learn and teach my fellows...and to treat his sons as my sons." Then, the oath "...grants health..." to the patient. The *Prayer of Maimonides*, an oath created later, contains the same covenant of *obligation* among healers and calls patients into a covenant of *obligation* as well, asking that

---

patients follow medical advice, take prescriptions and avoid the advice of meddling friends and relatives uninformed about health and disease.

The book suggests that everyone in health care – not just clinical experts but those in any role in research, management, insurance, health reporting and even policy – are the sophisticated extension of ancient tribal healers. Our societies are more complex, as is our knowledge, our data and information, our technology and our systems of providing care. As a result, as healers we have entered healing streams of an ancient origin. Our patients and communities expect us to ascribe to these covenant values.

In my view – and I am not alone in this – health required the integral relationship among healers, patients and communities. I therefore proposed three steps to transform health: first, a covenant of obligation among all healers, as I broadly defined them; second, a covenant of obligation with patients; and third, a covenant of obligation with communities, as well.

This is an application of those ideas to the policy issues addressed here.

<sup>2</sup> Oskar Kraus, *Albert Schweitzer: His Work and His Philosophy*, London: Adam & Charles Slack, 1944, p. 26.

<sup>3</sup> Stuart Grossman, et al., “Correlation of patient and caregiver ratings of cancer pain,” *J Pain and Symptom Manage*, 1991, 6(2):53-57; Jamie H. Von Roenn et al., “Physician attitudes and practice in cancer pain management,” *Ann Intern Med*, 1993, 119(2):121-126.

<sup>4</sup> National Pain Survey, Conducted for Ortho-McNeil Pharmaceutical, 1999; “Acute pain management: Operative or medical procedures and trauma,” *Clinical Practice Guideline No. 1*, AHCPR Publication No. 92-0032, Rockville, MD: Agency for Health Care Policy and Research, Department of Health and Human Services, February, 1992.

<sup>5</sup> Clermont E. Dionne, “Low back pain,” in Iain Crombie, Peter Croft, Steven Linton, Linda LeResche, and Michael Von Korff (eds.), *Epidemiology of Pain*, Seattle, WA: International Association for the Study of Pain, 1999, pp. 283-297.

<sup>6</sup> Reva C. Lawrence et al., “Estimates of the prevalence of arthritis and selected musculoskeletal disorders in the United States,” *Arthritis and Rheum*, 1998, 41(5):778-799.

<sup>7</sup> Marilyn Marchione, “Headaches: Common, painful and expensive,” *Scripps Howard News Service*, November 23, 1999.

<sup>8</sup> “Pain and Absenteeism in the Workplace,” Study conducted for Ortho-McNeil Pharmaceutical, 1997; “International Pain Survey,” conducted for Ortho-McNeil Pharmaceutical, 1999.

<sup>9</sup> *The NIH Guide: New Directions in Pain Research I*, Washington, D.C.: Government Printing Office, 1998.

<sup>10</sup> P. Wall and M. Jones, *Defeating Pain, The War Against a Silent Epidemic*, Plenum, New York, 1991.

<sup>11</sup> International Association for the Study of Pain, Subcommittee on Taxonomy, “Part II: Pain terms: A current list with definitions and notes on usage,” *Pain*, 1979, 6:249-252.

<sup>12</sup> E.J. Cassell, *The Nature of Suffering and the Goals of Medicine*, New York: Oxford University Press, 1991, p. 36.

<sup>13</sup> National Hospice Organization (NHO), 1700 Diagonal Road, Suite 300, Alexandria, VA 22314. Available at <http://www.nho.org>. Accessed October 15, 1999.

<sup>14</sup> C.S. Hill, “The negative influence of licensing and disciplinary boards and drug enforcement agencies on pain treatment with opioid analgesics,” *J Pharm Care, Pain and Symptom Control*, 1993, 1:43-62; R. Nowak, “Cops and doctors: Drug busts hamper pain therapy,” *J NIH Res*, 1980, 4:27-28.

<sup>15</sup> National Hospice Organization (NHO), 1700 Diagonal Road, Suite 300, Alexandria, VA 22314. Available at <http://www.nho.org>. Accessed October 15, 1999.

<sup>16</sup> J. Porter, and H. Jick, “Addiction rate in patients treated with narcotics,” *New Engl J Med*, 1980, 302:123; R.K. Portnoy, and K.M. Foley, “Chronic use of opioid analgesics in non-malignant pain: Report of 38 cases,” *Pain*, 1986,

---

25:171-186; E.M. Marks, and E.J. Sashar, "Undertreatment of medical inpatients with narcotic analgesics," *Ann Intern Med*, 1973, 78:173-181.

<sup>17</sup> According to the joint statement of the American Academy of Pain Medicine and the American Pain Society, physicians need not fear respiratory depression and other side effects of pain medicines, which are rare and can be managed with diet and other medical supports. Sedation and nausea are early side effects that usually dissipate with continued use of the medication, 1998.

<sup>18</sup> E. Emanuel, "Euthanasia and physician-assisted suicide: Attitudes and experiences of oncology patients," *Lancet*, 1996, 347(9018):1805; K.M. Foley, "The relationship of pain and symptom management to patient request for physician-assisted suicide," *J Pain and Symptom Manage*, 1991, 6:289-297.

<sup>19</sup> Richard Schulz, and Scott R. Beach, "Caregiving as a risk factor for mortality: The caregiver health effects study," *JAMA*, 1999, 282(23):2215-2219.

<sup>20</sup> Family Caregivers Association, 10400 Connecticut Ave., Kensington, MD 20895-3994. Available at <http://www.nfcacares.org>. Accessed December 3, 1999.

<sup>21</sup> Committee on Psychosocial Aspects of Child and Family Health, American Academy of Pediatrics, and Task Force on Pain in Infants, Children, and Adolescents, "The Assessment and Management of Acute Pain in Infants, Children and Adolescents," *Pediatrics*, 108(3):793-797.

<sup>22</sup> Joint Statement of the American Pain Society and the American Academy of Pain Management, 1998.

<sup>23</sup> Alabama, Alaska, Arizona, Arkansas, California, Colorado, Florida, Georgia, Iowa, Kansas, Louisiana, Massachusetts, Maryland, Minnesota, Missouri, Montana, Nebraska, Nevada, New Jersey, New Mexico, North Dakota, Ohio, Oklahoma, Oregon, Pennsylvania, Rhode Island, Tennessee, Texas, Utah, Vermont, Virginia, Washington, West Virginia, Wisconsin, Wyoming.

<sup>24</sup> Iowa, Rhode Island, South Dakota, Virginia, Oklahoma, South Carolina, Virginia, West Virginia, Arkansas and Maryland.

<sup>25</sup> Alabama, Arkansas, Illinois, Kansas, Maryland, Missouri, Vermont (some of these measures strengthen the language of earlier legislation).

<sup>26</sup> The American Academy of Pain Medicine, The American Pain Society, The Federation of State Medical Boards of the U.S., The Medical Board of California, The National Academy of Sciences, Institute of Medicine, The National Conference of Commissioners on Uniform State Laws, The National Conference of State Legislatures, The State Cancer Pain Initiatives.

<sup>27</sup> Joel B. Obermeyer, "Doctors urged to treat pain," *News and Observer* (Raleigh, NC), October 26, 1999.

<sup>28</sup> Jerome Groopman, "Separating Death from Agony," *New York Times*, November 9, 2001, p.A25, col. 1.

<sup>29</sup> Paul Tough, "The Alchemy of Oxycontin," *New York Times Magazine*, July 29, 2001, pp. 32-38, 52, 62-3. This article was one of many, including front-page stories recounting addiction and trafficking in Oxycontin®.

<sup>30</sup> The "Circle of Life Awards" is a program of the American Hospital Association, the American Medical Association, the American Association of Homes and Services for the Aging, and the National Hospice and Palliative Care Organization, with grant funds from the Robert Wood Johnson Foundation. This award is an annual program recognizing excellence in end-of-life care, including the management of pain.

<sup>31</sup> World Health Organization, *Cancer pain relief*. Geneva: WHO, 1986.

<sup>32</sup> William T. McGivney and Glenna M. Crooks, "The care of patients with severe chronic pain in terminal illness," *JAMA*, 1984, 251(9):1181-1188.