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Suffering, Compassion, and Dignity in Dying

Courtney S. Campbell*

I. THE "HARD CASES" PARADIGM OF SUFFERING

The argumentative strategy of the proponents of legalized physician-assisted suicide has displayed several recurrent features in debates over the practice in philosophical, legal and policy contexts. These features include:

- * An identified patient (or patients) who possess decision-making capacity;
- * A brief account of the patient's life story, prior to a terminal diagnosis and anticipated protracted and painful dying;
- * A narrative of the patient's current suffering, experienced physically through severe, debilitating pain, and psychically or spiritually through a perceived loss of dignity and diminished quality of life relative to the patient's prior life story;
- * An acknowledgement of the limits of medicine; that is, that current methods of pain control have failed to alleviate the patient's suffering;
- * The conclusion that denying the patient access to a lethal medication is cruel, callous, and unconstitutional.

These features constitute the "hard cases" paradigm that advocates of physician-assisted suicide present to the public and courts in their political and legal efforts to sway support for the legalization of the practice. The features were perhaps first displayed by Dr. Jack Kevorkian in 1990 when he described his first "medicide" case, that of Ms. Janet Adkins. The "hard cases" paradigm was proffered to Oregon citizens in 1994¹ as Oregon voters approved a "death with dignity" initiative that permitted physicians to prescribe life-ending medication to competent, terminally ill patients.² The paradigm is also embedded in the

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^{1.} OREGON HOSPICE ASSOCIATION, REQUEST FOR PHYSICIAN-ASSISTED DEATH: HOW WILL YOU VOTE? (1994); Jann Mitchell, *Deliberations on Death*, SUNDAY OREGONIAN, Oct. 30, 1994, at L1, L4-6.

^{2.} See Lee v. Oregon, 891 F. Supp. 1439 (D.Or. 1995). Implementation of the initiative (Measure 16) has been blocked by a federal district court judge, and is currently under review by a three-judge panel of the Ninth Circuit Court.

majority opinion of the Ninth Circuit Court in its Compassion in Dying v. Washington decision, which overturned a Washington statute prohibiting physician-assisted suicide on the grounds that it violated the liberty interest guaranteed to patients by the Fourteenth Amendment.³

What makes the cases in the "hard cases" paradigm hard turns in large measure on the claims and conclusions made in the cases about the unmitigated evil of suffering. However much individuals may in general deny, rebel or fight the prospect of an end to their mortality, the "hard cases" present death as a benefit relative to protracted suffering. The suffering associated with a terminal condition assumes the status of the greatest evil arising out of the human condition in public discourse, judicial reasoning and medical morality.

This claim about suffering means, in effect, that only the most morally callous individuals could deny the remedy of physicianassisted suicide to the terminally ill. Stated another way, the suffering experienced by such patients demands a practical response directed by the virtue of compassion. If suffering cannot be alleviated by conventional methods, then ending the suffering by ending the life of the sufferer becomes a patient right and a professional option, if not an imperative.

What the "hard cases" paradigm has accomplished for advocates of legalized physician-assisted suicide should not be underestimated. Under this paradigm, the long-standing presumption in medicine that taking the life of a terminally ill patient is proscribed has changed; this action is now presumed to be one of compassion towards the dying individual as it relieves the individual's suffering. Notably, this shift is plausible only because suffering is presumed to be a greater evil than death, and indeed the greatest evil a terminally ill person can experience, for it implies a dying process that is a living hell of pain, isolation and indignity.

This essay argues that the critical assumptions of the "hard cases" paradigm are mistaken. In particular, this essay illustrates that the paradigm and its judicial articulation misconstrues the nature of patient suffering and its role in the human condition, confuses the relationships of pain and suffering and suffering and dignity, and distorts the philosophical and practical understandings of compassion. Finally, it follows from this analysis that the paradigm should not be used as a basis for the legal sanctioning of physician-assisted suicide.

^{3.} Compassion in Dying v. Washington, 79 F.3d 790 (9th Cir. 1996) en banc, cert. granted, Washington v. Glucksberg, 65 U.S.L.W. 3254 (U.S. Oct. 1, 1996) (No. 96-110).

The principal moral counterpoint of suffering in the Compassion in Dying decision is that of "dignity." Specifically, it is a competent patient's dignity that is violated if any substantive restrictions are imposed on the patient's desire to choose the manner and time of death. According to the Ninth Circuit, a death arising from the freedom of an individual to determine the manner and time of his or her death and the freedom of the individual from suffering constitutes a death characterized by "dignity." These two forms of freedom are central to the court's finding of a Fourteenth Amendment liberty interest supporting physician-assisted suicide. The court determined that any relevant state interests in physician-assisted suicide are "insufficient to outweigh the terminally ill individual's interest in deciding whether to end his agony and suffering by hastening the time of his death with medication prescribed by his physician."⁴

As noted above, dignity in death was the goal that the Ninth Circuit sought to achieve for competent terminally ill patients through the means of a physician-assisted suicide. According to the court, the achievement of a dignified death requires selfdetermination on the part of the terminally ill patient that is incompatible with the patient's suffering. The court renders the content of "dignity" parasitic on the idea of self-determination and freedom from suffering, and states that dignity characteristically signifies personal control over the dying process and the maintenance of personal independence from biology, time or community through the process.

The dichotomy of dignity and suffering is repeatedly illustrated by the court through the posing of stark scenarios; for example, the "hard cases" paradigm. In such a scenario, dignity is juxtaposed against an undesirable alternative as follows: "A competent terminally ill adult . . . has a strong liberty interest in choosing a dignified and humane death rather than being reduced at the end of his existence to a childlike state of helplessness, diapered, sedated, incontinent."⁵ The juxtapositions, which are themselves merely a mirror of right-to-die political advocacy, endorse the perspective that dignity is incompatible with a dying state in which pain, dependency or loss of control is present to some degree. It is the failure to meet this court-defined standard of dignity that constitutes "suffering" in *Compassion in Dying*.

^{4.} Compassion in Dying, 79 F.3d at 837.

^{5.} Id. at 814. This statement is followed by an illustration of a "hard case," the "tortuous" dying of an AIDS patient. Id.

II. DIGNITY AND SUFFERING

Two kinds of problems emerge here, one experiential and the other conceptual. It is, of course, important to acknowledge that there are preferable and less-preferable methods of dving and that all things considered, most people would prefer a dying process that is short or even "hastened," pain-free, peaceful, and that otherwise exemplifies the qualities of dignity. It is not the case, however, that such conditions cannot be achieved without resorting to physician-assisted suicide. In fact, it is very misleading to present patients entering the terminal phases of life with the choice of either remaining tethered to technology in excessive pain and inhumane degradation, or exiting life peacefully through physician-prescribed medication. It is common knowledge, even among proponents of physician-assisted suicide, that palliative care for pain and suffering tends to significantly diminish the number of patient requests for a hastened and assisted death.⁶ Moreover, there is increasing evidence from the Dutch experience that physician assistance in death is not always peaceful. For example, Dr. Pieter Admiraal, a prominent supporter of euthanasia for the terminally ill, has reported that as many as 25% of patients experience either "botched" suicides or induced comatose conditions subsequent to ingestion of a physician's prescription.⁷ Therefore, the knowledge derived from both the success of palliative care measures and the failure of physician-prescribed deaths should be used to impose certain qualifications on what is medically necessary for dignity in death.

It is also not evident that the attributes of dignity cited by proponents of physician-assisted suicide and the Ninth Circuit are easily achievable in the actual experience of dying. Dr. Sherwin Nuland has argued, for example, that the popular perception of "death with dignity," although comforting, is an illusionary myth. While the ideology of dignity in death has created certain expectations in patients and families about the dying process, these expectations are usually shatteringly betrayed by the actual dying experience. Nuland contends that the idea of dignified death requires demythologization through recounting the stories of actual death processes.⁸

^{6.} Sidney H. Wanzer et al., The Physician's Responsibility Toward Hopelessly Ill Patients: A Second Look, 320 New Eng. J. MeD 844, 846-48 (1989).

^{7.} Mark O'Keefe, Dutch researcher warns of lingering deaths, THE OREGONIAN, Dec. 4, 1994, at A1, A32.

^{8.} SHERWIN W. NULAND, HOW WE DIE: REFLECTIONS ON LIFE'S FINAL CHAPTER (1994).

In addition to the above mentioned experiential problems with the account of patient dignity, the conceptual problems with this account are even deeper. The notion that the law confers the characteristic of dignity upon a patient merely by allowing the patient to choose how to die clearly warrants skepticism. Dignity is not a deathbed achievement, but a lifetime art. The dignity of an individual's death is inextricably woven together with the dignity and character of the individual's entire life. Indeed, part of the dignity of living well consists in an individual's willingness to accept the burdens of mortality. It is important in this respect to note that one important historical meaning of "suffering" refers to "undergoing" or "enduring" an experience or process.⁹ The suffering individual "allows" or "lets the experience happen."¹⁰

Following a long day at work, an individual may make a comment such as, "I'm suffering from a headache." In this context, the term "suffering" is explicable as a reminder that, in the penchant for control, no individual is free from the daily ordeals of life or the physiological, psychological or social burdens of mortality. An individual diagnosed with a terminal illness, of course, experiences these burdens in a far more intensive way than other individuals. The correlative moral disposition embodied by an individual who undergoes or suffers these ordeals or burdens of finitude, or who lets go of control, is that of patience. This connection between suffering and patience is reaffirmed in the etymological root of the term "patient," which is drawn from the Latin *pati*, meaning "to suffer." The common frustration of individuals over their aspirations because of their finitude, fallibility and mortality is what is referred to below as "mortal suffering."

Significantly, an underlying current running throughout the *Compassion in Dying* decision is the desire to escape the burdens of mortality. This desire surfaces explicitly in the Ninth Circuit's seemingly innocuous aside following a citation to *Roe*, in which the court comments that "pregnancy... will always be with us," and observes, "[s]o too, *unfortunately*, will terminal illness."¹¹ This evaluation seems so uncontroversial to the court that it does not even bother to explain why the presence of terminal illness is a misfortune that befalls humanity, rather than a facet of the human experience that individuals should accept. It is precisely

^{9.} See Courtney S. Campbell, Must Patients Suffer?, The Philosophy of Medicine and Bioethics (Ronald A. Carson & Chester R. Burns eds., forthcoming Spring 1997); Courtney S. Campbell, Quest and Question: Suffering and Emulation in the LDS Community, Christian Bioethics (forthcoming Spring 1997).

^{10.} CAMPBELL, supra note 9; CAMPBELL, supra note 9.

^{11.} Compassion in Dying, 79 F.3d at 796 (emphasis added) (quoting Roe v. Wade, 410 U.S. 113, 125 (1973)).

this sort of view of death and the dying process that has led astute commentators, such as philosopher Daniel Callahan, to contend that the reigning ideology in contemporary medicine presents patients with a no-win choice with respect to their mortality.¹² The view is that death is something individuals should fight through highly technological medicine or escape through suicide, and that little personal or social benefit is to be gained by confronting mortality directly.

The aspiration to alleviate the burdens of mortality is reiterated by the Ninth Circuit in several instances, such as the initial "hard cases" narratives of the patient-plaintiffs who are portrayed as seeking to avoid a "protracted, undignified, and extremely painful death," and as desiring by contrast to die "peacefully and with dignity." The court describes one patient as being cognizant of the "suffering" that will be imposed on him by a lingering terminal illness due to his prior experiences as a caregiver. Importantly, the language of the court seems to equate "suffering" with "terminal illness." Once this equation is coupled with the historical duty of medical professionals to relieve suffering, it follows that the alleviation of suffering encompasses a duty to remedy terminal illness as well, and if necessary, by physician-assisted suicide. Similarly, the court seeks to sanction the medical procedures that enable patients to escape the "inhumanity" of pain, dependency and loss of control. Since these are also conditions pervasive in mortality, the resort to physician-assisted suicide seems yet again a remedy against the burdens of human experience.

This author is not suggesting that the severe pain attendant with a form of terminal bone cancer requiring constant morphine painkillers can be equated, for example, with the pain of a headache that might be relieved by aspirin. Clearly, there are distinct levels of pain differentiated by intensity, frequency and debility. Different modes of pain control and pain management are therefore appropriate. The *Compassion in Dying* opinion, however, appears to express a deep-rooted intolerance towards allowing a terminally ill patient to experience any pain, suffering or dependency. These conditions are deemed contrary to personal dignity and the unrelieved presence of the conditions is portrayed as "inhumane." How far the court is willing to go in this direction is unclear. Although at times the jurisprudential intolerance toward these conditions is qualified by such language as "excessive," "unusual," or "needless" pain and suffering, these

^{12.} DANIEL CALLAHAN, THE TROUBLED DREAM OF LIFE: LIVING WITH MORTALITY (1993).

forms of suffering by implication accommodate normal, usual or necessary suffering.

The Ninth Circuit does, nonetheless, create a boundary beyond which states must not go; namely, a patient cannot be subjected to experiencing "pain . . . and suffering that is too intimate and personal for the state to insist on."¹³ The problem with this standard, however, is what makes "suffering" actual suffering as distinguished from anxiety or distress, is precisely its intimate and personal nature. The experience of "mortal suffering" should be an occasion for education in the flaws of the ideologies of mastery over mortality and control over contingency. The patient who embodies patience waits for death rather than adamantly requesting that death be "hastened." Such patience presupposes self-control, virtue and empathy, and is the basis for the active expression of responsibility, devotion and love. It is a virtue, therefore, that requires time for expression and refinement, and that is practiced and "protracted" over a lifetime. The individual who suffers patiently embodies an acceptance of his or her own limits and finitude and achieves dignity in death through a continuation of those traits of character displayed during life.

Insofar as medicine and its legal regulation within society are unwilling to tolerate the intimacy and personal nature of suffering, two consequences of great significance follow. First, there is a corresponding unwillingness to allow patients to be patients. Patients must either be warriors in the fight against disease, or consumers that demand control of the situation and immediate results such as a cure or a hastened death. Second, the efforts by either the patients, their advocates or professionals to efface suffering will come at some cost to moral humanity. Individuals will risk losing those traits of identity and integrity that make them who they are. Indeed, to seek to relieve patients of fundamental features of the human condition can itself be dehumanizing.

III. THE CONFUSION OF PAIN AND SUFFERING

The desire to master mortality through medical means reflects an effort to see suffering as a remediable problem of medicine.¹⁴ This desire draws intellectual energy from the medical characterization of suffering, through which suffering is domesticated

Compassion in Dying, 79 F.3d at 834 (quoting Planned Parenthood of Southeastern Pennsylvania v. Casey, 505 U.S. 833, 852 (1992)). In stipulating this boundary, the court is relying on a position taken by the United States Supreme Court with regard to a woman's right to choose an abortion in Casey. Compassion in Dying, 79 F.3d at 834.
CALLAHAN, supra note 12, at 100-02.

under the realm of medicine by being understood as a form of "pain." What this author calls "medically controlled suffering" below reflects the ever-expanding horizons of the biomedical model for almost all human pathologies, and the phrase also contains the following inexorable logic: Since medicine can, or arguably ought to once professional skills, knowledge, and caring consciousness are sufficiently refined, bring pain under its domain, continued research and clinical application and revision of pain control methods will, in due course, advance medical progress along the pain continuum. Since suffering is not distinct from pain, but rather a marker on the continuum of pain, then the mastery and control of suffering will become a medical possibility. In short, suffering will turn out to be no less susceptible to therapeutic intervention and cure as are disease and pain.

This is a very misguided interpretation and should be discarded on several grounds. It is important to dispense with the professionally self-serving and imperious conflation of pain with suffering, which, as noted above, has been so influential that the Ninth Circuit repeatedly couples pain and suffering in the same phrase without ever suggesting that the two concepts might be different phenomena. The two concepts are, indeed, different phenomena. Consider, for example, the above-mentioned case of Janet Adkins, the first "medicide" victim of Dr. Kevorkian.¹⁵ Ms. Adkins had been diagnosed with early-stage Alzheimers with a prognosis of a "good" quality of life for ten years. The diagnosis clearly induced suffering for Ms. Adkins because she projected her future self in late-stage Alzheimers and found this not to be an acceptable lifestyle. Even as of June 1990, however, when Ms. Adkins sought assistance in dying from Kevorkian, she was not afflicted with pain. On the contrary, Ms. Adkins still engaged in physically vigorous activities with her family.

It is also possible for an individual to experience pain without suffering as exemplified by an individual who has a routine bump or laceration. Thus, while pain can clearly be associated with suffering, the complete conflation of suffering with pain cannot be validated experientially.

With respect to the model of progressive medicine, it is also questionable whether the existence of suffering can be validated epistemically. As Dr. Eric Cassell has perceptively written, "[t]he central assumptions on which 20th century medicine is

^{15.} See Gregory E. PENCE, CLASSIC CASES IN MEDICAL ETHICS, 68-72 (2d ed. 1995) for a succinct summary of the Adkins case.

founded provide no basis for an understanding of suffering."¹⁶ The quest of medical science for objectivity and quantification runs right into the experientially subjective world of suffering. When a patient is asked at the beginning of the day by a caregiver the following question, "on a scale of one to ten, how do you feel today?," two very different worlds collide.¹⁷ The patient is asked to somehow interpret and translate the meaning of his or her qualitative experience of illness, disease and suffering into a ranking scale that holds interpretative meaning only for the professional, who is preoccupied with treating a pathology.

The methodological commitments of medical science thus create a profound tension between the epistemic and ethical foundations of medicine. If these commitments preclude even an understanding of suffering, as Cassell suggests and as patient complaints about "insensitive" caregivers attest, then contemporary medicine lacks the capacity to comprehend what it is professionally committed to relieve. Indeed, as Cassell noted, this tension may even be resolved on the side of denial of suffering: "The dominance and success of science in our time has led to the widely held and crippling prejudice that no knowledge is *real* unless it is scientific, objective and measurable. From this perspective, suffering and its dominion in the sick person are themselves unreal."¹⁸ Society should not be at all surprised to hear that a common complaint of terminally ill patients is that they receive impersonal care.

Suffering, therefore, poses an intractable challenge for the healing profession. There is a professional imperative to relieve suffering, but despite advances in technical proficiency, knowledge and technological application, suffering persists in the dying. The presence of suffering in patients, expressed in the language of pain, dependency or loss of control, cannot on this account be viewed as a failure of medicine and its caregivers. The solution to the problem of suffering proposed by right-to-die advocates helps medicine fulfill its professional commitment in a most ironic and contradictory manner: Suffering is relieved by relieving the sufferer of his or her life. If suffering is not seen so much as a problem to be solved but a condition to be endured, however, it becomes the case that dignity and suffering are not as mutually exclusive as the Ninth Circuit has held.

^{16.} ERIC J. CASSELL, THE NATURE OF SUFFERING AND THE GOALS OF MEDICINE VII (1991). The "assumptions" that Cassell has in mind include scientific objectivity, quantification, and a mechanistic understanding of the human person. *Id*.

^{17.} This writer thanks Dr. David Green of the University of Utah for offering this example of how embedded in medical discourse is the demand for quantification.

^{18.} CASSELL, supra note 16, at x-xi.

IV. THE ORDEAL OF EXISTENTIAL SUFFERING

The above claim can be supported if a second understanding of suffering, which this author refers to as "existential suffering," is explored. Existential suffering is marvelously portraved in Tolstoy's novel, The Death of Ivan Ilyich.¹⁹ Within the book, in the course of decorating his new home, the judge Ivan Ilvich experiences what appears to be an innocuous fall off of a ladder; however, this fall initiates a course of decline in which Ilvich experiences the gradual disintegration of world, body and self. The intensity of Ilvich's pain disrupts his vocational and social world. He can no longer work, attend the theater with his family, or play cards with his friends without embarrassment and humiliation. The illness gradually restricts his mobility, and he is unable to venture far from his bedroom, where he experiences an ever-increasing isolation. Other persons become intruders and painful reminders of active life and Ilyich's complete dependency. Communication ceases for Ilyich, either because he cannot find the voice or language to express the intensity of his pain and suffering, or because he concludes that others will not be capable of comprehending his experience. He is finally reduced to a pre-linguistic screaming of "O" during the last three days of tortuous pain prior to death.²⁰ Diminished in body to the point of confinement to a sofa in his bedroom, the world of Ivan Ilyich ultimately becomes only memories and the anguish of soul over the false meaning of his life.

Tolstoy's masterpiece of meaning offers an instructive account of the patterns of existential suffering. Existential and mortal suffering are both unified under the more general concept of "suffering" in that they reflect a person's experience, actual or perceived loss of control, or a feeling of powerlessness in the face of overwhelming forces beyond personal control. The difference between these forms of suffering concerns the place and continuity of the self. Mortal suffering presumes self-control and a resiliency of character in the face of loss of control over the individual's world. The experience of existential suffering, by contrast, involves a serious challenge to the capacity to sustain a self over time. Indeed, existential suffering is characterized by an actual or perceived threat of *dissolution* to the identity and integrity of the self. It calls into profound question the continuity of the "I" by which individuals refer to themselves.

^{19.} LEO TOLSTOY, THE DEATH OF IVAN ILVICH (1987).

^{20.} See ELAINE SCARRY, THE BODY IN PAIN: THE MAKING AND UNMAKING OF THE WORLD (1985) for a compelling account of how pain and suffering can fragment our linguistic capabilities.

It should be clear simply on this initial sketch why taking existential suffering seriously, as a non-medical phenomenon distinct from pain, is most problematic for advocates of physician-assisted suicide. The disruption of the self is so significant that the concept of the autonomous person, upon which the principle of self-determination rests, is substantially undermined. The individual that suffers existentially seeks understanding first rather than exemplifying patience, because he or she is experiencing some ordeal or catastrophe that erodes coherence, meaning and purpose to his or her place and being in the world. As one author describes it, the ordeal of existential suffering involves "universe altering events . . . [that] call into question both the individual's very capacity to maintain itself as a whole and the idea of the whole according to which that organization takes place."²¹

It is through acknowledging existential suffering that society can make some sense of the lament, "my world is coming apart." This form of suffering seems to deprive the sufferer of all that is most humanly meaningful in life: relationships, memory, creativity, communication, a responsive body, autonomy; in short, precisely those characteristics that might well constitute an individual's sense of "dignity." If there is a realm of suffering that is "too intimate and personal" to be subject to intervention. whether from the state or from medicine, it is to be found in this threat of dissolution of the self. This is a private, particularized and subjective threat; the catastrophe, be it in the form of the onset of terminal illness, the death of a loved one, or a relational rupturing such as a divorce, diminishes and challenges the sufferer's identity, loyalties and sense of self. Since the prospect of threat strikes to the very core of who an individual is, the challenge for patients posed by mortal suffering to display patience, self-control and endurance must give way to a more formidable task of self-reconstitution.

Existential suffering represents not only a threat to the autonomous self but also implicates the claimed liberty interest of terminally ill persons in a right to die. The Ninth Circuit explicates the core of the liberty interest via the following passage from *Casey*: "At the heart of liberty is the right to define one's own concept of existence, of meaning, of the universe, and of the mystery of human life."²² In the ordeal of existential suffering, however, it is precisely an individual's concept of existence and

^{21.} Mary C. Rawlinson, The Sense of Suffering, 11 J. of Med. and Phil. 39, 47-8 (1986).

^{22.} Compassion in Dying, 79 F.3d at 813 (quoting Casey, 505 U.S. at 851).

understanding of meaning that is under siege. The individual's universe and world is conceptually "coming apart," and he or she has no answers for the mystery of his or her own life, let alone human life in general. The sufferer winds up asking, as Tolstoy does, "why these torments," and finding an answer equivalent to, "for no reason—they just are."²³ Confronting this abyss of meaninglessness can be almost too intimate and personal for the patient to bear.

It should now come as little surprise why proponents of physician-assisted suicide and sympathetic judges should seek to portray dignity and suffering as antithetical and mutually exclusive. Dignity, it appears, seems to be rooted in an autonomous self, a self able to address the ultimate questions of meaning and purpose and to formulate a coherent view of the world and an individual's place in it in response to these questions. This includes assuming a stance toward death and the dying process, and the extent to which, if any, death should be hastened or assisted as a means to achieving dignity. Suffering, by contrast, is an ordeal that erodes each of these foundations of dignity. The self may well be fragmented rather than autonomous, and incoherence and loss of meaning appear to be the ruling forces of existence. The "self" experiences a hostile world characterized by arbitrariness, abuse and alienation, and a hostile body that frustrates life plans and aspirations rather than facilitating their achievement.

If such suffering could be relieved by medicine, of course, then all would be conducive to a peaceful and dignified death. What drug or medication is there, though, that can alleviate this rupture of an individual's self and world? Society needs to understand that while medicine certainly can prevent or remedy the occasions out of which suffering arises, the experiences of suffering, mortal or existential, are not so medically malleable. What is needed in these circumstances is a different kind of response, a human response that can be given professional direction; the response of compassion.

V. COMPASSION FOR THE SUFFERER

In this world, people suffer. This is a fact of the human condition about which neither society, medicine nor the law can do anything. How people respond to suffering, their own and that of others, is, however, a contingent feature of an individual's experience over which the individual does have control. Individuals may find themselves experiencing revulsion at the physical man-

^{23.} TOLSTOY, supra note 19, at 121.

ifestation of suffering; expressing criticism of the sufferer ("others have it worse than you"); engaging in victim-blaming ("you brought this on yourself") as in the paradigmatic biblical account of both mortal and existential suffering, the story of Job; or leaving the suffering individual to his or her own fate. Religious traditions may offer global explanations of "the" purpose of suffering, which deprive individuals of finding personal validation or meaning. These are all common human responses to suffering, but they do not display the way of compassion.

It is perhaps not surprising that at roughly the same time in our cultural history when suffering assumed in medicine the status of the greatest evil, society's concept of compassion became confused. As Marvin Olasky has observed, the roots of the term "compassion" are the same as those for the term "suffering": the Latin term pati, the original definition of which means, "suffering together with another, participation in suffering."24 A different understanding emerged in the twentieth century, however, such that the most recent edition of Webster's dictionary defines compassion as a "deep feeling for and understanding of misery or suffering and the concomitant desire to promote its alleviation." An action of community, of participating with another in enduring an ordeal, has now become a feeling and a desire to end the ordeal. The Ninth Circuit can refer to physicians who support professional assistance in suicide as "honorable, dedicated, and [even] compassionate individuals"²⁵ on the contemporary understanding, but not on the historical understanding. In such a perspective, the compassion of physician-assisted suicide constitutes abandonment of the patient.

Compassion is integrally related to the suffering of another individual. Beyond this, it is a virtue that involves assuming the burden of another's suffering as one's own. Compassion thus requires that caregivers suffer with patients rather than express moral or theological judgment, and also requires that caregivers offer personal presence to patients rather than abandonment. A necessary starting point of compassion is the recognition and appreciation of the particularity of suffering, especially existential suffering. Each individual will make of suffering what he or she will or suffering will make the individual a different person. It thus involves minimal empathy and only a great deal of pretension to console the sufferer with, "I know how you feel." Such cruel words isolate the suffering individual, who is rightly skeptical about such an arrogant claim to personal, intimate knowl-

^{24.} MARVIN OLASKY, THE TRAGEDY OF AMERICAN COMPASSION 196-99 (1992).

^{25.} Compassion in Dying, 79 F.3d at 827.

edge. Even if a professional and patient have undergone a similar ordeal of suffering, the significance of each experience will be very particularized and personalized, for the ordeal will have tested the very identity and integrity of the individual.

Compassion requires a bond between individuals that cannot be conveved by the offer of a technological fix for terminal illness. Such an approach reinforces the conventional power relationships in medicine in which knowledge, power and authority reside in the professional. Suffering, as has been seen, involves a subverting of an individual's self and world-order; this entails that a compassionate response will no less subvert the power relationships within medicine. The professional assumes a position of limited knowledge and dependency on the patient. As Dr. Howard Brody explains, the compassionate physician must be willing "to adopt a position of relative powerlessness" and "acknowledge that the patient's suffering has incredible power over him and that he cannot remain unchanged in the face of it."26 The community-creating bond of compassion is reinforced by an affective, emotional bond, for at a basic level the experience of compassion must involve "passion," an intensity of deep emotion to the very ground of an individual's being. This no less subverts the detached and objective aspirations of medicine.

The intricacy of the relationship between compassion and suffering has been thoughtfully developed by Warren T. Reich, who delineates a process dialectic called "mute suffering" between the suffering patient and the caregiver who suffers with the patient.²⁷ Mute suffering is a dialect in which the sufferer, who is rendered literally incapable of expressing his or her experience, or as with Tolstoy's Ilyich, reverts to a pre-linguistic form of utterance, invokes the response of silent compassion, a respectful quiet but personal presence in the midst of the other's suffering. In a transitional phase of "expressive" suffering, the sufferer places his or her experience in a narrative context that is met with a response of expressive compassion that seeks to connect the patient's story to "a wider spectrum of meaning and value." The sufferer's discovery of a voice to share the suffering initiates a third phase, the finding or discovery of a new identity through the ordeal, and the caregiver who has suffered with the patient likewise gains a new awareness of his or her own self as compassionate. The presence of the compassionate individual thus involves a commitment of solidarity with the patient to suffer

^{26.} HOWARD BRODY, THE HEALERS' POWER 259 (1992).

^{27.} WARREN T. REICH, Speaking of Suffering: A Moral Account of Compassion, SOUNDINGS 72, 83-108 (Spring 1989).

together. It is an arduous and time-consuming commitment, illsuited to a "hastened" medicine. It is also what transforms a distanced professional into a personalized caregiver, however, for the gift of compassion to the suffering patient is not only time or empathetic presence, but the gift of self.

It is a legitimate question to ask why a terminally ill patient should be required to endure the ordeal of suffering out of which his or her identity is re-constituted when the point of a physician-assisted suicide request is to bring an end to the patient's life. A response to this point, however, comes at three levels. The foregoing analysis suggests that the integral connection between suffering and compassion means that the personal and moral character of caregivers, professional and familial, can be renewed through suffering with the patient. An intolerance for suffering, no matter how well-intended, necessarily limits the occasions for the expression and moral capacity for compassion.

The same point holds at the societal level. People do not and should not want to see others experience suffering. Yet, when suffering does occur, the compassionate individual and the compassionate culture should offer presence to the suffering patient rather than abandonment. In this respect, cultural attitudes toward suffering reveal the depth (or lack thereof) of society's commitment to caring and compassion. If the source of patient suffering is pain, then a compassionate society should devote more of its research and clinical resources to pain control. If the source of suffering is what this author designates as mortal or existential suffering, then society should not seek to transform a question of meaning into a challenge to medical efficacy. These are human questions, not questions of professional proficiency, and the appropriate response is that of compassion and human presence to the sufferer.

This author's conviction is that individuals whose suffering cannot be relieved through attention to pain are very few in number. They constitute the "hard cases" that are presented as the normative paradigm of the terminally ill individual by advocates of physician-assisted suicide legalization and by relevant court decisions. The question that must be asked is whether these "hard cases" illuminate or distort social understandings of the terminal phase of life. It is instructive in this regard to consider the observations of Derek Humphry, founder of The Hemlock Society and current president of the Euthanasia Research and Guidance Organization (ERGO). In the midst of the 1994 debate in Oregon over the "death with dignity" ballot initiative, Humphry suggested the number of Oregon citizens who would opt for physician-assisted suicide would be comparable to the number of persons in the Netherlands, 0.3%.²⁸ Given the number of people that die in Oregon on an annual basis (approximately 27,000), Humphry's comparison implied that voters were contemplating an unprecedented change in the law and in medical practice that would directly affect the manner of death of, at most, eighty-one individuals. How many of those eighty-one individuals could truly be classified as "hard cases" is unclear, but it seems to this author insufficient to warrant such a substantial change in public policy toward dying individuals. The compassionate society should, then, resist the temptation to make these "hard cases" prescriptive for policy.

The third level addresses the suffering endured by the terminally ill patient. According to physician-assisted suicide advocates and the Compassion in Dying decision, the underlying objective of physician-assisted suicide is not death, but a certain type of death characterized by "dignity." It is mistaken, however, to isolate dignity from the totality of a person's life story as though dignity in death were a secularized form of deathbed salvation. The dignity of an individual's death is integrally connected with the character of the individual's entire life; a life in which finitude, frustration and suffering are part of the lot of mortality. An individual does not seek out suffering in life, but, through the ordeals of suffering that are endured, there is growth in depth and breadth of character, identity and integrity. If dignity involves consistency in character and continuity in values over an entire lifespan, the suffering undergone in terminal illness is the culmination of dignity, a dignity with which individuals can both live and die.

^{28.} Derek Humphry, Dutch statistics show 0.3 percent opt to hasten death, OREGONIAN, Aug. 14, 1994, at B2.

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Pages 125-158

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