The Debate on Assisted Suicide—Redefining Morally Appropriate Care for People with Intractable Suffering

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The recent passage of Oregon Measure 16, which would permit physician-assisted suicide under certain conditions, has forced a reevaluation of the proper role for caregivers of patients who are dying or otherwise intractably suffering from "non-terminal" illness.[1] Even before the recent spate of legislative initiatives, several highly respected ethicists and physicians began to advocate physician-assisted suicide whenever such patients see no further hope of meaningful life.[2] The justification for such a

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[1] American Health Consultants, *Ethicists Strive for Acute Ideological Changes in Care for the Dying*, 11 MEDICAL ETHICS ADVISOR 13 (1995); Martin Gunderson and David J. Mayo, *Altruism and Physician-Assisted Death*, 18 J. MED. & PHIL. 281 (1993); Courtney S. Campbell et al., *Conflicts of Conscience—Hospice and Assisted Suicide*, HASTINGS CENTER REP., May-June 1995, at 36.

[2] Sidney H. Wanzer et al., *The Physician's Responsibility Toward Hopelessly Ill Patients: A Second Look*, 320 N. ENG. J. MED. 844, 848 (1989); Timothy E. Quill et al., *Care of the Hopelessly Ill: Proposed Clinical Criteria for Physician-Assisted Suicide*, 327 N. ENG. J. MED.

role for physicians has continued to evolve in the face of growing ambiguity and uncertainty over whether the capacity of modern technology to prolong life has any real meaning for severely incapacitated or dying patients with intractable suffering.[3]

Modern American Paradigms

The dilemma has been graphically depicted in several high-profile accounts of severely incapacitated or dying patients whose suffering has driven them to seek aid in dying from the courts[4] or from sympathetic physicians.[5] Two cases in particular that exemplify these approaches to aid in dying have attracted much attention and sparked prolonged debate about the legality and morality of actively responding to such appeals: the case of Elizabeth Bouvia and that of Timothy Quill's patient "Diane":

> Elizabeth Bouvia is a woman with severe lifelong neuromuscular impairment from cerebral palsy who at one time was able to control a motorized wheelchair and even completed college. After a series of psychosocial crises in her life she became depressed and entered a hospital in California expressing a desire to commit suicide. Her request to be allowed to starve herself was denied, and a judge permitted the hospital to tube feed her. She then filed a suit three years later at age 28 to have her feeding tube removed and be treated for any discomfort as she starved. The trial court decided against her—since fulfilling such a request was seen as tantamount to 'suicide by starvation'—but the decision was reversed by the Court of Appeals, which refused to label her request suicide and opined that such a life 'has been physically destroyed and its quality, dignity and purpose gone.' She is still alive, years after the decision.[6]

1381 (1992); Howard Brody, *Assisted Death—A Compassionate Response to Medical Failure*, 327 N. ENG. J. MED. 1384 (1992).

[3] *See, e.g.*, the arguments of Michael Kligman, *The Role of Comfort Care and Physician-Assisted Suicide in the Search for a Dignified Death*, 2(4) BIOETHICS MATTERS (University of Virginia Center for Biomedical Ethics newsletter) (1993) (*reprinted* in MID-ATLANTIC ETHICS COMMITTEE NEWSLETTER, Fall 1993, at 1); Timothy E. Quill, *Doctor, I Want to Die. Will You Help Me?* 270 JAMA 870 (1993); Franklin G. Miller & Howard Brody, *Professional Integrity and Physician-Assisted Death*, HASTINGS CENTER REP., May-June 1995, at 8.

[4] *See, e.g.*, *Elizabeth Bouvia and Voluntary Death*, *in* GREGORY E. PENCE, CLASSIC CASES IN MEDICAL ETHICS 25-44 (1990); Stanley S. Herr et al., *No Place to Go: Refusal of Life-Sustaining Treatment by Competent Persons with Physical Disabilities*, 8 ISSUES IN LAW & MED. 3, 7-10 (1992); *Verbatim, Rodriguez* v. *Attorney General of Canada*, 9 ISSUES IN LAW & MED. 303 (1993).

[5] Anonymous, *It's Over, Debbie*, 259 JAMA 272 (1988); Timothy E. Quill, *Death and Dignity: A Case of Individualized Decision Making*, 324 N. ENG. J. MED. 691 (1991).

[6] Bouvia v. Superior Court, 179 Cal. App. 3d 1127; 225 Cal. Rptr. 297 (1986). Synopsis distilled from the discussions in PENCE, *supra* note 4, and Herr, *supra* note 4.

> 'Diane' was a woman with a family history of alcoholism and a past medical history of vaginal carcinoma and depression who was diagnosed as having leukemia by a former hospice physician, Timothy Quill. She was referred to an oncologist but then became enraged at his apparent presumption that she would accept his offer of chemotherapy and proceed with the treatment. She expected the worst and was initially convinced she would die. She repeatedly expressed her need to be 'in control' and her fear of becoming dependent. Initially skeptical, Dr. Quill was eventually convinced of her need to 'maintain dignity and control.' He referred Diane to the Hemlock Society and ultimately prescribed a fatal dose of barbiturates. After several 'tumultuous' months—including a brief period of hope for a miraculous cure—Diane finally said good-bye to Dr. Quill, her closest friends, and her husband and son, then took the pills and died.[7]

Bouvia's case has become a paradigm for the rights of *severely disabled but non-terminally ill individuals* to hasten death by refusing life-prolonging medical treatment. As a result of an increasing number of such cases with similar outcomes in several different states, "it is virtually indisputable that competent patients have a right to refuse treatment whether terminally ill or not."[8] However, even though the *courts* have refrained from labeling such requests suicide, the caregiver who is confronted with a patient asking to hasten death is still faced with the dilemma of whether that request should in fact be treated as a suicide. For the purposes of this discussion "competent" refusals of life support by patients who are not dying—typified by the case of Bouvia—will be considered prima facie suicides.[9]

"Diane" has become a paradigm for the right of *terminal but not imminently dying patients* to hasten their dying through the active assistance of physicians because of the fear of future loss of control and dignity in the dying process. Championing such a position, psychiatrist Michael Kligman asserts that modern medicine must face the challenge "to allow terminally ill and intractably suffering patients to die with as much dignity, control, and comfort as possible."[10] He argues that, despite all efforts, including

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[7] Synopsis distilled from Quill, *supra* note 5. *See also* the discussions in Brody, *supra* note 2; Patricia Wesley, *Dying Safely*, 8 ISSUES IN LAW & MED. 467 (1993).

[8] Alan Meisel, *Legal Myths About Terminating Life Support*, 151 ARCHIVES INTERNAL MED. 1497, 1499 (1991). *See also* Ezekiel J. Emanuel, *A Review of the Ethical and Legal Aspects of Terminating Medical Care*, 84 AM. J. MED. 291 (1988).

[9] There is considerable debate over the proper terminology for acts that should be considered suicide, and whether such acts are morally justifiable. The relevant distinctions to be considered in deciding whether a given act is suicide are eloquently discussed in ROBERT N. WENNBERG, TERMINAL CHOICES: EUTHANASIA, SUICIDE, AND THE RIGHT TO DIE 30-38 (1989); STANLEY HAUERWAS, SUFFERING PRESENCE 100-13 (1985).

[10] Kligman, *supra* note 3, at i.

effective pain relief, some patients will be left with "the prospect of losing control and independence, and dying in what for many seems an undignified, helpless, and ultimately unacceptable condition."[11] The problem may even be aggravated, he points out, by a rigid, unreflective adherence to Hippocratic tradition and "the prior application of high technology medical intervention."[12]

Such concerns underscore the need to reevaluate the existential impact of intractable suffering and the related question of what kind of care can deal most effectively with such suffering. Behind the drive to legalize assistance in the types of cases exemplified by Bouvia and Diane is the powerful urge to relieve suffering, perhaps at any cost. But the currently acceptable "remedy" for intractable suffering of persons who are severely disabled and who happen to require life support, namely, the *withdrawal* of that life support,[13] is *not* legally accessible by the "terminally ill" who are neither imminently dying nor dependent on artificial life support.

Physician-Assisted Suicide and Ethical Individualism

This dilemma has led some activists to justify physician assistance in suicide on the basis of patients' rights and the correlative duties required of the caregiver in order to guarantee the free exercise of those rights. Such reasoning has promulgated the following moral assertions in one form or other to guide the ethical care of intractably suffering, dying patients:[14]

- The highest value for suffering, terminally ill patients is to maintain control and dignity in dying by preserving the right to self-determination.
- When there is no longer any reasonable possibility of otherwise maintaining control or dignity, there is no significant moral distinction between allowing such a patient to die and actually causing death.
- When cure is no longer possible, the most important aspect of the physician's care of the patient is the relief of suffering.

The first of these assertions is based on an individualistic ethical framework in which the preservation of patient rights[15] trumps all other

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[11] *Id.* at i.

[12] *Id.* at ii.

[13] Meisel, *supra* note 8; Emanuel, *supra* note 8.

[14] *See, e.g.*, Kligman, *supra* note 3; Quill, *supra* note 2; Franklin G. Miller et al., *Regulating Physician-Assisted Death*, 331 N. ENG. J. MED. 119 (1994).

[15] The constitutional basis for the "right to die" is hotly debated but will not be addressed here per se. The reader is referred to complementary discussions in Leon R. Kass, *Is There a Right to Die?* HASTINGS CENTER REP., Jan.-Feb. 1993, at 34; Yale Kamisar, *Are Laws Against*

values and is guaranteed by "correlative" duties of the caregiver.[16] The second assertion follows logically from the first, in that maintaining a distinction between allowing to die and causing death fails to provide equal protection for the right of dying individuals like Diane to exercise autonomous choice: If the highest value remains the preservation of control and dignity in dying, then it is discriminatory to deny such patients the same right retained by persons who are severely disabled, simply because they have no similar requirement for artificial life support that could conveniently be withdrawn.[17]

The third assertion logically follows the first two and stems from a contractual model for the patient/doctor relationship—in essence, the caregiver provides those services dictated by the "consumer's" autonomous choice.[18] Consequently, if the physician's ultimate role is viewed as the relief of suffering, then he can in good conscience continue to fulfill his contractual obligation to the patient by providing the autonomously chosen "service" of assisted suicide.[19] As long as the intent of such "therapy" is the

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Assisted Suicide Unconstitutional? HASTINGS CENTER REP., May-June 1993, at 32; Robert A. Destro, *The Scope of the Fourteenth Amendment Liberty Interest: Does the Constitution Encompass a Right to Define Oneself Out of Existence?* 10 ISSUES IN LAW & MED. 183 (1994); J. Daryl Charles, *The "Right to Die" in the Light of Contemporary Rights-Rhetoric, in* BIOETHICS AND THE FUTURE OF MEDICINE: A CHRISTIAN APPRAISAL 263 (John Kilner et al. eds., 1995).

[16] The relatively recent legal development in the doctrines of *informed consent* and *confidentiality* and the proliferation of state and federal *advance directive* legislation stem largely from an increased societal recognition of the duty of caregivers to protect the rights of patients to self-determination and privacy.

[17] This conclusion concerning the false distinction maintained between persons who are severely disabled and those who are dying—but not imminently—is fundamentally *correct* (*infra* note 20). In my view, however, the "discrimination" consists in the legal sanction for people who are severely disabled to receive assisted suicide without it being labeled as such or affording the equal protection of intervention that society otherwise reserves for individuals who express clearly suicidal intent. *See, e.g.*, Allen C. Snyder, *Competency to Refuse Lifesaving Treatment: Valuing the Nonlogical Aspects of a Person's Decisions*, 10 ISSUES IN LAW & MED. 299 (1994); Herr, *supra* note 4, at 31; Carol J. Gill, *Suicide Intervention for People with Disabilities: A Lesson in Inequality*, 8 ISSUES IN LAW & MED. 37 (1992); Diane Coleman, *Withdrawing Life-Sustaining Treatment from People with Severe Disabilities Who Request It: Equal Protection Considerations*, 8 ISSUES IN LAW & MED. 55 (1992).

[18] Baruch Brody provides a good general critique of the contractual model for decisionmaking in LIFE AND DEATH DECISION MAKING 56-64 (1988). For a critique of this model as related to the debate on physician-assisted suicide, *see* B. Andrew Lustig, *Public Policy on Physician-Assisted Suicide: Reasons for Retaining the Ban*, BIOETHICS FORUM, Spring 1994, at 7.

[19] Quill's advocacy of a contractual framework for decisionmaking (Timothy E. Quill, *Partnerships in Patient Care: A Contractual Approach*, 98 ANNALS INTERNAL MED. 228 (1983)) helps to explain his support for physician-assisted suicide (Quill et. al., *supra* note 2), as long as consensus can be reached between patient and physician.

relief of suffering, it would therefore be just as ethical for a physician to withdraw life support from one patient as to prescribe lethal drugs for another.[20]

Callahan, among others, has argued vigorously against the moral justification that underlies these assertions[21] but has been accused of "abstract moralizing" in justifying his own position.[22] In my view Callahan's argument raises some very important questions that have significant bearing on the appropriate role of the physician in dealing with intractable suffering, and these questions must be addressed before we can be confident that any proposed approach is morally sound. Any framework based primarily on considering *rights* and correlative *duties* appears ill-suited to address these questions,[23] which have more to do with existential concerns than individual rights:

Do We Understand the Nature and Causes of Suffering Well Enough to Determine Confidently When a Given Life Is No Longer Worth Living?

What is it about suffering that makes some people like Diane sincerely want to die, while others continue to endure intractable suffering and never express such wishes and still others like Bouvia change their minds? How could we possibly tell the difference before the fact?

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[20] The moral equivalence of allowing to die and causing death under such conditions is discussed in Wennberg, *supra* note 9, at 30-38, 136-42; Snyder, *supra* note 17, at 316; Howard Brody, *Causing, Intending, and Assisting Death*, 4 J. CLINICAL ETHICS 112, 115-17 (1993). The morally relevant issue is not the *means* by which death ensues, but the *intent* to hasten death by *whatever means* may be employed to create an irreversibly dying condition that did not already exist. I would argue that this intent is indeed the same in both cases, regardless of the legality of the means (e.g., withdrawal of life support); nevertheless, serious disagreement persists over whether carrying out such intent—even when the means are legal—can be morally justified.

[21] Daniel Callahan, *When Self-Determination Runs Amok*, HASTINGS CENTER REP., Mar.-Apr. 1992, at 52.

[22] John Lachs, *When Abstract Moralizing Runs Amok*, 5 J. CLINICAL ETHICS 10 (1994).

[23] Callahan, *supra* note 21. Callahan has stated his concerns about the limitations of a rights-oriented approach even more eloquently in his latest book, THE TROUBLED DREAM OF LIFE (1993). This is not to say that rights have *no* place in the debate—a high level of concern for such rights may in fact be quite effective in redressing the disparity in power often manifest between people who are non-dying and non-disabled and those who are dying or severely disabled when competing for increasingly scarce health care and social service resources (*see, e.g.*, the references cited, *supra* note 17); these implications are further drawn out *infra*, "The Effect of Suffering on Rational Decisionmaking," *cf.* "The Critical Role of Community."

What Is the Relative Moral Value of Maintaining "Human Dignity" and Control over Death by Preserving the Right to Self-Determination?

Is the right to self-determination important enough to trump other values such as respect for human potential or the sanctity of life? When a physician chooses to actively assist a suffering patient's choice to hasten death, who is morally accountable for the decision?

How Well Do We Understand the Impact of Varying Degrees of Suffering on Rational Decisionmaking?

How can we be sure that requests for assistance in suicide are *rational*, whether or not they seem *reasonable?* Is there any basis for community attempts to influence such an individual's perspective to make more meaningful choices? Is it possible to avoid coercion—even with the best of intentions—when attempting to influence such choices?

What Is the Ultimate Role of the Physician When Cure Is No Longer Possible Or Meaningful?

Is this role, in fact, to relieve suffering at any cost? What is the physician's proper moral standing among the other individuals within the patient's moral community? How else can a physician provide appropriate and legitimate care without resorting to the hastening of death in order to relieve suffering?

An Alternative Way of Framing the Issue: The Wisdom Model and Intractable Suffering

If the individualistic rights/duties framework for decisionmaking is, as we have suggested, inadequate to address these questions,[24] then where should we seek an ethical framework capable of identifying and addressing these issues whenever suffering prompts a request for assistance in suicide? The alternative I have found to be most useful was discovered serendipitously: Following my experience in seminary—but long before I developed any interest in clinical ethics—I began an in-depth study of the Old Testament wisdom books of Job and Ecclesiastes. I ultimately recognized that these books both dealt with the problem of intractable suffering and addressed the questions raised above, so I decided to test

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[24] *Supra* note 23. *See also* Brody, *supra* note 18, at 56-64; Lustig, *supra* note 18. Another example of the difficulty of applying an ethical framework of rights and correlative duties to clinical ethical concerns is discussed in Andrew F. Shorr, *AIDS, Judaism, and the Limits of the Secular Society*, 20 SECOND OPINION 23 (1995) (Shorr finds that Jewish law and rabbinic tradition offer an alternative framework that can more effectively inform questions of duty to treat and to disclose HIV status in cases of AIDS, even for a secular audience).

whether this wisdom could provide a reliable moral framework to guide the caregiver's response to intractable suffering.

The reader is not asked here to debate or accept the theistic world view behind the Old Testament wisdom literature. The real question is whether the framework derived from this wisdom effectively identifies and addresses the moral issues surfaced by the problem of intractable suffering, and whether the conclusions adduced from a wisdom approach make good sense, even in a pluralistic and largely secular society.[25] Callahan has addressed these same issues from a nontheistic perspective[26] and has arrived at virtually the same conclusions, but one wonders indeed about the moral framework upon which Callahan bases his vision.[27]

The book of Ecclesiastes consists of a series of observations and wise reflections on the question "What is the point of continuing to struggle through life when life itself seems so meaningless?" This is precisely the dilemma faced by the person who is suffering intolerably, especially when that person is also dying. The book of Job is a paradigm case of intractable suffering very similar to that of Elizabeth Bouvia or "Diane": Job, like Bouvia and Diane, was desperate to find some meaning in his suffering, yet despaired of continuing his miserable existence in the search for such meaning. Job's response to his "caregivers" legitimates the very real concerns precipitated by intractable suffering and sheds important light on the appropriate role of the caregiver.

Can reasonable guidance be distilled from a study of wisdom that could prove useful for the caregiver confronted with a sincere request for assistance in dying? What follows is an ethical framework—the wisdom model—that proposes guidelines for an *effective and ethical* response to requests to hasten death, by first addressing the four substantive issues we have raised concerning such requests under circumstances of intractable suffering.

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[25] Shorr, *supra* note 24, makes the same practical appeal for his own proposed approach based on Judaistic law and rabbinic tradition.

[26] CALLAHAN, THE TROUBLED DREAM OF LIFE, *supra* note 23.

[27] *Id.* Callahan, *id.* at 13, hints at a wisdom orientation in his introduction when he laments "a society more comfortable with legal than with philosophical or religious discourse, and more at ease with moral language focused on the *making* of decisions than with *the wisdom of those decisions*" (emphasis added). He may also betray communitarian underpinnings, *id.*, at 15, in lamenting the loss of "some shared language and public behavior. We no longer have that, either collectively or even in most of our ethnic and religious subgroups." (Shorr's approach, *supra* note 24, harmonizes with many strains of communitarianism and largely complements the wisdom approach taken herein; the important role of community in this wisdom framework is discussed further below.)

The Nature of Suffering

Recalling the first question we raised concerning requests for assistance in suicide, what guidance would our wisdom model provide?

Do We Understand the Nature and Causes of Suffering Well Enough to Determine Confidently When a Given Life Is No Longer Worth Living?

Suffering and Despair. Consider as a model for profound suffering the plight of the Old Testament patriarch Job, following the swift and decisive annihilation of his children, his wealth, and ultimately his health (Job 1-2). Then consider how logical his words might seem when placed in the mouth of Elizabeth Bouvia, Diane, or anyone in a similar plight:

> Why is light given to him who is in misery,
> And life to the bitter of soul,
> Who long for death, but it does not come . . . ;
> And are glad when they can find the grave?
> . . . For my sighing comes before I eat,
> And my groanings pour out like water.
> For the thing I greatly feared has come upon me,
> And what I dreaded has happened to me.
> I am not at ease, nor am I quiet;
> I have no rest, for trouble comes.[28]

It is clear from accounts of patients such as Dr. Quill's Diane, as well as those who suffer from profound lifelong disabilities,[29] that these patients can experience a level of despair over the perceived disintegration of their existence which is comparable to that expressed by Job in the wake of his own loss. As Eric Cassell describes it,

> [s]uffering occurs when an impending destruction of the person is perceived; it continues until the threat of disintegration has passed or until the integrity of the person can be restored in some other manner. It follows, then, that although it often occurs in the presence of acute pain, shortness of breath or other bodily symptoms, suffering extends beyond the physical. Most generally, suffering can be defined as the state of severe distress associated with events that threaten the intactness of the person.[30]

One gets the impression from Quill's account that Diane was, like Job, almost *expecting* her disaster—such dread could well have contributed to

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[28] THE HOLY BIBLE, NEW KING JAMES VERSION (1982), at *Job 3:20-26*. All subsequent citations will be from the same version of the Bible.

[29] *See* Herr, *supra* note 4; Gill, *supra* note 17; Coleman, *supra* note 17.

[30] ERIC J. CASSELL, THE NATURE OF SUFFERING AND THE GOALS OF MEDICINE 33 (1991).

her attitude of resignation and a corresponding despondency.[31] The question commonly arises, therefore, whether such patients may in fact be suffering from clinical depression, which is clearly associated with suicide. But Kligman, a psychiatrist, makes the excellent point that "[i]t is not necessarily indicative of major depression or other psychiatric illness for incurably ill persons to desire relief from a prolonged, personally intolerable dying process through hastening or otherwise controlling the circumstances of their own death."[32] It is thus critically important to distinguish between the process of *depression*, which clearly should receive treatment as suffering progresses in illnesses of this sort,[33] and the suffering of *existential despair*, which has much to do with the above-described sense of impending personal disintegration and may not be reversible.

The Dilemma of Intractable Suffering. The despair that grips those who face the inevitable prospect of such disintegration can be profound. When an individual's suffering becomes progressively more intolerable over time, especially if accompanied by the inexorable erosion of vitality, it would be a serious mistake merely to attribute the desire to hasten death to a major clinical depression without first exploring the role played by legitimate despair. Considering what Job faced, his response seems very reasonable and quite representative of the responses of Bouvia and Diane. We feel very fortunate that we have not been similarly afflicted—in fact, we may be inclined to agree that life in that condition might not be worth living.

Such a response is exemplified as very natural by the author of Ecclesiastes in the vicarious despair he expresses on contemplating the profound suffering he has observed among the oppressed in life:

> And look! The tears of the oppressed
> But they have no comforter—
> On the side of their oppressors there was power,
> But they have no comforter.
> Therefore, I praised the dead who were already dead,
> More than the living who are still alive.

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[31] Quill, *supra* note 5, at 691-92.

[32] Kligman, *supra* note 3, at i.

[33] *See* the discussions of the role of depression in requests for assisted suicide in Mark D. Sullivan & Stewart J. Youngner, *Depression, Competence, and the Right to Refuse Life Saving Medical Treatment*, 151 AM. J. PSYCHIATRY 971 (1994); Herbert Hendin & Gerald Klerman, *Physician-Assisted Suicide: The Dangers of Legalization*, 150 AM. J. PSYCHIATRY 143 (1993); David C. Clark, *Rational Suicide and People with Terminal Conditions or Disabilities*, 8 ISSUES IN LAW & MED. 147 (1992); Yeates Conwell & Eric D. Caine, *Rational Suicide and the Right to Die: Reality and Myth*, 325 N. ENG. J. MED. 1100 (1991).

> Yet, better than both is he who has never existed,
> Who has not seen the evil work that is done under the sun.[34]

When first confronted by the account of Diane's distress, we might well apply the same reasoning and thus agree with Quill's ultimate acquiescence in the case of Diane.[35] But Quill's description of Diane's repeated expressions of hopelessness and the demand for control suggests the strong possibility that in acceding to her request he so identified with her despair over time that he ultimately succumbed to the contagion of that despair.[36]

The subtle ease with which such contagion can influence clinical decisionmaking is illustrated by the following cases I have recently encountered:

> Case 1. After noting facial grimacing in an otherwise unresponsive and terminally ill patient, the family pressured the intern to treat the patient's 'pain.' The intern, feeling uncomfortable about administering morphine to an unresponsive patient, sought advice from the senior resident, who instructed the intern to 'relieve that suffering.' The patient died promptly after a modest bolus of morphine was finally given.
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> Case 2. An alert and conversant patient with terminal cancer was admitted to a palliative care unit for treatment of gnawing pain and intractable vomiting. She requested that her symptoms be treated without providing artificial hydration or nutrition, as she felt this would only prolong her suffering. The physician was very uncomfortable with the idea of withholding nutrition and hydration but did not hesitate to escalate the morphine infusion rate for 'pain control' until the patient became unresponsive, continued to receive morphine, and finally died a week later without regaining consciousness.

Cases such as these are not at all unusual. I would submit that in both situations the physicians were very likely more concerned about relieving their own vicarious despair over intractable suffering than about relieving the suffering of the patient or family.

In the face of such inescapable personal disintegration, nothing seems more appropriate than to help the sufferer preserve what little control or

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[34] *Eccl.* 4:1b-3.

[35] Quill, *supra* note 5, at 693.

[36] Empathic overidentification with a patient's suffering can indeed lead to the contagion of the caregiver by the sufferer's despair. This phenomenon is clearly implied in Wesley's critique of Quill's account (*supra* note 7, at 484-85, as noted in Herbert Hendin, *Seduced by Death: Doctors, Patients, and the Dutch Cure*, 10 ISSUES IN LAW & MED. 123, 127-28 (1994), and is capably discussed by Steven Miles, *Physicians and Their Patients' Suicides*, 271 JAMA 1786 (1994), and by Susan D. Block & J. Andrew Billings, *Patient Requests to Hasten Death*, 154 ARCHIVES INTERNAL MED. 2039, 2043-44 (1994)).

dignity remains for them in life. However, identifying in this way with the prospect of inexorable decline and personal disintegration fails to explain why some individuals who experience this level of suffering persevere. What is it, then, about the response to suffering that determines why some individuals decide to take their own lives, whereas others demonstrate truly heroic levels of perseverance, even in the midst of intractable suffering?

Despair and Meaning. Granted, unavoidable suffering in life often seems to preclude the possibility of any advantage to prolonging one's existence. But as our author continues to explore the circumstances in life that evoke the sense of futility, he is struck by the discovery that even when oppression is absent from the lives of those who seem to have it all, death may *still* seem preferable to life, as long as that life appears devoid of any soul-satisfying meaning:

> If a man begets a hundred children and lives many years, so that the days of his years are many, but his soul is not satisfied with goodness . . . I say that a stillborn child is better than he—for it comes in vanity and departs in darkness, and its name is covered with darkness. Though it has not seen the sun or known anything, this has more rest than that man, even if he lives a thousand years twice over—but has not seen goodness.[37]

Our author ultimately arrives at the realization that, behind the obvious sense of powerlessness to control one's circumstances that is felt by those who are unable to escape the jaws of suffering, there exists an inability to find "goodness" [satisfying meaning] in life; it is this inability rather than the suffering per se that leads one to feel that death might be preferable. We have all heard of persons who have committed suicide in spite of having everything they thought they wanted. Such inwardly oriented despair is therefore independent of—though it may well be precipitated by—the circumstances of intractable suffering.

In this view, then, it is the perception that life is meaningless—whether one is afflicted by intractable suffering or not—that most influences the decision to hasten death. Maybe the question should not be, "How *bad* am I suffering?" but "Where can I seek meaning in life, once caught in the jaws of suffering?" It would certainly be nice if all patients could find such meaning through suffering. But it is clear that some who suffer never seem to respond with any hope for meaning in life, while others with perhaps even greater suffering are still somehow able to find such hope. Callahan elucidates the basis for this distinction as he describes two dichotomous responses to intractable suffering:

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[37] *Eccl. 6:3-6a.*

> When we listen to the voices of those who have endured the worst that life can bring, a life of concentration camps and organized murder, we can hear them say something of great importance: what enables people to endure, and to do so with dignity and grace, is *not their ability to change their circumstances,* but what they make of them. . . . They possess a suppleness, not a rigidity, in the face of a loss of power to manage their lives. . . . They do not accept the evil that brought them their fate; they would be the first to want it changed. But, once it is given, they learn how to . . . *redeem what they cannot change.*
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> We all know people whose lives, day in and day out, are dominated by a desire to be in charge of themselves, to have life fully under control. They are restless, even angry, *when their lives are interrupted by the unexpected event,* by that which *unsettles their self-managed existence.* They cannot readily abide the notion that they must be *forced by circumstances to do something they did not choose,* did not contract for. Surprise is their enemy. The worst enemies of all are those *unexpected demands* that other human beings make upon one's life.[38]

Ironically, then, the process of suffering itself offers an opportunity to discover new meaning in life, even when the suffering continues unabated.

Despair as a Turning Point. The author of Ecclesiastes goes on to describe this opportunity and how it relates to authentic mourning: "*Sorrow is better than laughter,/For by a sad countenance the heart is made better. The heart of the wise is in the house of mourning,/But the heart of fools is in the house of mirth.*"[39] Spending time in the "house of mourning"—whether it be in an ICU, hospice, nursing home, or funeral parlor—is wise because it "does the heart good." The phrase "by a sad countenance" literally means "by external misery"; in other words, *honest mourning* over the circumstances of suffering can lead to a willingness to endure suffering and accept the limitations of mortal existence. This in turn can serve as a *turning point* to new sources of meaning, even in the midst of intractable suffering.[40] Those who work regularly with patients who have terminal diseases are often familiar with the mystery of this kind of turning point in the midst of grief or mourning.[41]

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[38] CALLAHAN, THE TROUBLED DREAM OF LIFE, *supra* note 23, at 131-32 (emphasis added).

[39] *Eccl.* 7:3-4.

[40] C. STEPHEN EVANS, EXISTENTIALISM: THE PHILOSOPHY OF DESPAIR AND THE QUEST FOR HOPE 42 (1984) ("Thus, in our journey through the valley of despair, we encounter evidence . . . that despair is not a dead end to which we are inevitably driven, but is in some cases the prelude to a fuller understanding of human existence . . . that lends hope that here at least is a pathway to hope.").

[41] *See, e.g.,* BERNIE S. SIEGEL, LOVE, MEDICINE, AND MIRACLES: LESSONS LEARNED ABOUT SELF-HEALING FROM A SURGEON'S EXPERIENCE WITH EXCEPTIONAL PATIENTS (1986); LAWRENCE

Therefore, the sufferer apparently has a choice in how she responds to suffering: She can accept her limitations and the uncertainty that attends the search for authentic meaning under circumstances beyond her control; or she can maintain a rigid, self-determined demand for control when her own expectations of life have been thoroughly frustrated.[42] How should we respond to those like Diane or Bouvia, for whom the intense demand for control seems to trump any appeal to continue their existence and redeem some meaning out of their misery? This leads us to consider our second major question raised by the dilemma of intractable suffering.

Preserving Control and Human Dignity in Suffering

What Is the Relative Moral Value of Maintaining "Human Dignity" and Control over Death by Preserving the Right to Self-Determination?

The obvious logic of maintaining control and dignity in the face of such misery is quite compelling in a society like ours that places the right to self-determination among the greatest values in life. Is this logic compelling enough that those with moral standing in the life of the sufferer may *reasonably* accede to a request for assistance in suicide when there appears to be no other hope of further meaning in life?

The Illusion of "Control" in the Search for Meaning. The apparent futility of the lives of those who can find no meaning in life, even when suffering is absent (Eccl. 6:3-6a, *above*), leads the author of Ecclesiastes to question whether maintaining control per se can ultimately convey any benefit, regardless of suffering:

> All the labor of man is for his mouth,
> And yet the soul is not satisfied. . . .
> This is vanity and grasping for the wind.
> Whatever one is, he has been named already,
> For it is known that he is man;
> And he cannot contend with Him who is mightier than he.
> Since there are many things that increase vanity,
> How is man the better?
> For who knows what is good for man in life, all the days of his vain life

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LESHAN, YOU CAN FIGHT FOR YOUR LIFE: EMOTIONAL FACTORS IN THE TREATMENT OF CANCER (1976).

[42] Callahan, *supra* note 38; Herbert Hendin, *supra* note 36, at 126 (pointing out in his discussion of the case of Diane that ". . . characteristically it is suicidal people who are most afflicted by the need to control and to make demands on life that life cannot fulfill. Determining the time, place, and circumstances of death is the most dramatic of such demands.").

> which he passes like a shadow? Who can tell a man what will happen
> after him under the sun?[43]

The image here is that of an individual desperately contending against life's circumstances to eke out some significance: Unable to escape his human limitations, he ends up shaking his fist at God or fate. Thus, the notion that one can *forge* meaning out of one's own existence by controlling circumstances is illusory because one can never be certain before the fact which choices in life will really be good or meaningful for him.[44] This general unpredictability of good choices in life would seem to diminish the propriety of a single-minded focus on the right to self-determination as the paramount value in decisionmaking.[45]

Human Dignity and Living Hope. But even if we buy the author's argument that preserving control can't really provide any lasting meaning, how do we handle the intolerable indignity that so often accompanies the inexorable erosion of vitality in terminal illness or in severe disability, such as that faced by Diane and Elizabeth Bouvia? This appeal to human dignity has often carried great moral weight in court decisions on behalf of seriously disabled petitioners for the right to die with assistance.[46] Why wouldn't we be equally justified in hastening the death of terminally ill patients[47] who will soon face the indignity of progressively helpless dependence on others?

As if on cue, our author proceeds to address this concern for human dignity in his ongoing quest for meaning while life remains. In the face of the inevitable limitations of mortality and uncertainty the appeal of preserving dignity in death is weighed against the elusive hope of finding any meaning in continuing a miserable, subjectively demeaning existence

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[43] *Eccl. 6:7, 9b-12.*

[44] Interestingly, this unpredictability of the good for a given individual is increasingly recognized by noted ethicists in the arena of medical decisionmaking. *See, e.g.*, Robert M. Veatch, *Abandoning Informed Consent*, 25 HASTINGS CENTER REP., Mar.-Apr. 1995, at 5, 7 ("Axiology—the study of theories of the good or valuable—is a field of . . . ethics that is in considerable turmoil. . . . There is no reason to believe that a physician or any other expert in only one component of well-being should be able to determine what constitutes the good for another being.

"Determining what it means to say that something is in someone's best interest turns out to be a very difficult task. Establishing the proper criteria for determining that one course or another maximizes the good for an individual is even harder.").

[45] Veatch, *id.* at 10-11 (implying the same in his opinion that allowing the patient to decide is inadequate to solve the problem of informed consent); Callahan, *supra* note 21.

[46] Herr, *supra* note 4; Gill, *supra* note 17.

[47] *See, e.g.*, the argument, *supra* note 20, for treating both the same.

like that experienced by Diane and Bouvia: "*But for him who is joined to all the living there is hope, for a living dog is better than a dead lion.*"[48]

The text makes no apology in placing the value of hope in remaining alive—even in a degraded condition—above the prerogatives of "death with dignity," and thus it challenges the core justification of the death with dignity movement. The option of actively hastening death would thus appear to be foreclosed, even when life seems to have lost all dignity, irrespective of the constitutionality of the right to die.[49]

What Constitutes a "Living Dog"? The question must then be asked, Can any reasonable person really consider the kind of existence that characterizes the lives of people who are severely disabled—or of those terminal patients who face severe suffering for the short time they have left before death—to be "living" in any meaningful sense? In other words, where could such "hope" possibly lie when facing the prospect of continued intolerable suffering, especially in the setting of impending death and/or total dependence on others?[50] This is immediately clarified in the following verses, where the author predicates such hope on the continued exercise of certain existential capacities that the living retain:

> For the living know that they will die;
> But the dead know nothing.
> And they have no more reward,
> For the memory of them is forgotten.
> Also their love, their hatred, and their envy have now perished;
> Nevermore will they have a share
> In anything done under the sun.[51]

According to this model, then, life is worth supporting as long as there remain the capacities for cognition, rewarding relationship, emotional expression, or volition. It would appear that there is especially little room for debate in the cases of patients like Diane and Elizabeth Bouvia, who retain full cognitive function and the capacity for relationship and choice in life. While this wisdom should never be invoked to *force* such patients to continue living, the strong implication is that neither should a choice to die be facilitated by the active assistance of caregivers (or the courts[52]).

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[48] *Eccl. 9:4.*

[49] *Supra* note 15.

[50] *See supra* text accompanying note 11.

[51] *Eccl. 9:5-6.*

[52] *Supra* note 17 (noting especially the bold advice that the relevant decisions should be "overturned" because "court rulings authorizing assisted suicide for people with disabilities cannot withstand a genuine application of equal protection review" (Coleman, *supra* note 17, at 79), a view that is complemented by the wisdom model we have been discussing).

To maintain this position in response to a steadfast request to hasten death might well invite the rejoinder, How can you claim to respect her autonomy if you refuse to help her when she has made up her mind to die? Perhaps a better way to frame the question would be to ask, What would really show the most respect for her as a person?[53] Would we respect her as a person by acceding to her request and thereby foreclosing forever any possibility of turning despair into hope? Perhaps the best question would be, How can we creatively support the hope that remains[54] in those existential capacities that she retains, even as a "living dog"?

Maintaining Control and Preserving Moral Accountability. It is clear that there are many—particularly those who embrace an individualistic, rights-oriented ethical framework—who would not accept the "living dog" criteria for hope in the face of a settled and determined decision to hasten death. What then would be the implications from the wisdom perspective for those caregivers who respond by acceding to such a request in the interests of "maintaining control and dignity"? Who then would be morally accountable for her decision to kill herself? Our text actually addresses this question of moral accountability in just the kind of situation where the need to maintain control is expressed as a demand to dictate the circumstances and timing of one's death in the face of intractable suffering:

> [F]or every matter there is time and judgment,
> Though the misery of man increases greatly.
> For he does not know what will happen;
> So who can tell him when it will occur?
> No one has power over the spirit to retain the spirit,
> And no one has power in the day of death.[55]

Although the text indicates that there is an appropriate time for every matter, including the day of death,[56] no one can know when it will occur, thus strongly indicting any who would presume to judge when life should end. It would seem equally presumptuous, then, for a *physician* to judge the appropriate time for such a patient to die, as long as the "living dog" criteria are met. Moreover, in asserting that "for every matter there is . . . judgment,

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[53] Baruch Brody, *supra* note 18, at 32-35, 87-89 (emphasizing the moral appeal of respect for persons as quite different from respect for autonomy and a primary criterion for consideration in matters of life and death in his pluralistic theory of decisionmaking).

[54] *See supra* note 17 (concerning the cogent suggestions made by the authors cited for such support in cases of severely disabled persons; this is further discussed *infra*, "The Effect of Suffering on Rational Decisionmaking," *cf.* "The Critical Role of Community").

[55] *Eccl. 8:6-8.*

[56] Note also the more familiar expression of this same assertion in Eccl 3:1-2, which is cited in connection with the commonly encountered difficulty of determining the appropriate time of death in ROBERT D. ORR et al., LIFE & DEATH DECISIONS 146-50 (1990).

though the misery of man increases greatly," the author strongly implies the retention of moral accountability for one's autonomous choices, even under circumstances of intractable suffering. Thus, according to the wisdom model, the physician who helped to carry out an "autonomous" choice to hasten death would appear to share in the moral culpability of that choice.

The text seems to be suggesting that even when the propriety of continued existence remains ambiguous in the face of intractable suffering and the loss of control and dignity, the suffering patient is to remain accountable for her "stewardship" of life as long as it remains. Margaret Walker eloquently articulates the importance of preserving such accountability in any worthwhile system of moral deliberation and clarifies how this also preserves respect for personhood on the part of the patient's community:

> There are usually multiple parties and multiple values to be acknowledged and (ideally) reconciled in cases that require any serious deliberation at all . . . But whether uniquely compelling and universally satisfying resolutions are possible—and especially where they are not—fuller consideration serves the larger end of keeping us morally accountable to each other, renewing common moral life itself.
>
> By accounting to each other through a moral medium, parties to a common life (or the hope of one) recognize each other as agents of value, capable of considered choices, responsive to value, and so responsible for themselves and to others for the moral sense and impact of what they do. They invoke their shared moral resources not only to achieve solutions, but to achieve solutions that at the same time protect, refine, and extend those very moral resources themselves—ones that keep the moral medium alive and available, that keep the moral community itself going.[57]

Framing the moral dilemma of the patient who prefers to hasten death as one of individual rights (to maintain "control" and "dignity" in death) only forecloses such deliberation over the substance and direction of moral accountability. If the kind of collective stewardship described by Walker should be the norm for suffering patients, then Quill's acquiescence to Diane's demand for control—to the point of *helping* to hasten her death—illustrates a failure of stewardship: I would argue that Quill effectively *narrowed* her range of options by validating her death wish, in essence robbing her of autonomy and sharing in her moral culpability;[58] wisdom was forfeited by an inordinate focus on her demand to control her death.

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[57] Margaret U. Walker, *Keeping Moral Space Open: New Images of Ethics Consulting*, HASTINGS CENTER REP., Mar.-Apr. 1993, at 33, 36-37 (emphasis in original).

[58] Herbert Hendin, *Selling Death and Dignity*, HASTINGS CENTER REP., May-June 1995, at 19, examines two other accounts of assisted suicide and incisively illustrates the subtle but

Control Versus Meaning: The Need for Wisdom. If the caregiver who is confronted by a request for assistance in suicide is persuaded by Walker's reasoning, then preserving stewardship in decisionmaking is to be pursued in the interest of promoting the most meaningful choices possible. But Wesley appropriately questions the scope of accountability for such stewardship in the midst of intractable suffering when she asks, "[D]id Diane's view that she must be independent and in control, no matter what the cost, impair her ability to fully assess her options as she faced a life-threatening illness?"[59] The implication of Wesley's question is that the reasoning capacity of *any* patient who requests assistance in dying may well be adversely affected, thus potentially compromising such stewardship in the pursuit of meaning.

If we recall our previous text on the value of mourning, we find that the meaningful benefit of mourning requires wise reflection through the despair of suffering: "*Sorrow is better than laughter,/For by a sad countenance the heart is made better. The heart of the wise is in the house of mourning,/But the heart of fools is in the house of mirth.*"[60] The text clearly justifies paying *some* attention to the soundness of the reasoning process of the intractably suffering patient before we can confidently hold that patient accountable for her choice to die. This leads to our third major issue raised by intractable suffering.

The Effect of Suffering on Rational Decisionmaking

How Well Do We Understand the Impact of Varying Degrees of Suffering on Rational Decisionmaking?

Although guidelines have been proposed for the careful evaluation of requests for physician assistance in suicide,[61] *can we ever be sure that such a request is truly rational?* What can be done to ensure that wisdom prevails in deliberations over whatever options might remain in the pursuit of meaning whenever suffering patients request assistance in suicide?

Suffering and Reasoning Capacity. Immediately following the passage affirming the importance of wisdom for a meaningful response to suffering,[62] the author directly addresses the question of reasoning capacity under the circumstances of suffering: "*It is better to hear the rebuke of the*

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potent coercive effect that such "validation" can have, actually encroaching on genuine autonomy.

[59] Wesley, *supra* note 7, at 469.

[60] *Eccl.* 7:3-4, *supra* note 39.

[61] *See*, for example, Quill, *supra* note 2.

[62] *Supra* notes 39, 60.

wise/Than for a man to hear the song of fools. . . . Surely oppression destroys a wise man's reason,/And a bribe debases the heart."[63]

The text clearly implies that suffering generally has a deleterious effect on reasoning capacity. Wesley appropriately cautions that "[a]ll human willing and acting is imbued with complexities and ambiguities that can baffle our best efforts to sort them out."[64] This appears to justify the previously voiced doubt as to whether profoundly suffering patients are truly capable of rational end-of-life decisions, irrespective of the presence or absence of depression.[65] Callahan goes on to make the point that "if it is difficult to measure suffering, how much more difficult to determine the value of a patient's statement that her life is not worth living."[66]

Such impairment in reasoning may therefore necessitate what our author calls "the rebuke of the wise," implying that it may benefit the sufferer to *challenge* his/her choices. So the rebuke of the wise amounts to a kind of "wise advocacy" for the sufferer who may not be reasoning clearly. By contrast, the reference to the song of fools suggests the appeasement of suffering by false reassurance: Instead of allowing sorrow to pursue its natural course and make the "heart better,"[67] such appeasement only "debases the heart"—in other words, bribing the sufferer with the promise of relief only *subverts* the potential benefit of genuine mourning in response to despair.

The contrast implies that the wise advocacy of another may well be required to balance the impairment of rational decisionmaking observed in suffering and thereby keep the sufferer accountable for his decisions.[68] One could well argue that such advocacy—even when it opposes the expressed preferences of the sufferer—may well enhance autonomous decisionmaking by broadening the range of choices available when reasoning is impaired by suffering. By contrast the ill-advised song of fools is like a bribe, only appeasing suffering by accommodating the request to hasten death.

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[63] *Eccl. 7:5, 7.*

[64] Wesley, *supra* note 7, at 473. Along similar lines of reasoning, *see also* Donald A. Redelmeier et al., *Understanding Patients' Decisions: Cognitive and Emotional Perspectives*, 270 JAMA 72 (1993); Edmund D. Pellegrino, *Compassion Needs Reason Too*, 270 JAMA 874 (1993); and Eric D. Caine & Yeates C. Conwell, *Self-Determined Death, the Physician, and Medical Priorities: Is There Time to Talk?* 270 JAMA 875 (1993).

[65] Wesley, *supra* note 7, at 469; Clark, *supra* note 33; Conwell & Caine, *supra* note 33; Hendin & Klerman, *supra* note 33; Gill, *supra* note 17, at 45-46.

[66] Callahan, *supra* note 21, at 53.

[67] *Supra* note 60.

[68] *See supra* text accompanying notes 55, 57; contrast with the result, *supra* note 58.

The Foolishness of Demanding Control. Again, the hypothetical sufferer presented in this passage has two choices:[69] She can respond to the wise advocacy provided by others who are willing to challenge her and thereby gain the benefits of authentic mourning we have discussed, or she can listen to the reasoning of fools and remain entrenched in her disposition of radical self-determination. Our author proceeds to describe the result of adopting the latter disposition in the sufferer who chooses, like Diane, to listen to the siren song of relief:

> The end of a thing is better than its beginning,
> And the patient in spirit is better than the proud in spirit.
> Do not hasten in your spirit to be angry,
> For anger rests in the bosom of fools.
> Do not say, 'Why were the former days better than these?'
> For you do not inquire wisely concerning this.[70]

This passage exemplifies how wise decisionmaking is jeopardized when the sufferer refuses to give up control over life, and it appears to confirm Wesley's previously quoted suspicion about Diane's reasoning capacity:[71] Responding in anger to frustrated expectations in life is unwise ("For anger rests in the bosom of fools"), as it only aggravates the adverse effect of suffering on reasoning. Moreover, the last two lines affirm the foolishness of maintaining an attitude of entitlement[72]—one that might only be further entrenched by an approach to decisionmaking that emphasizes the right to self-determination and the preservation of autonomous choice.

Wesley hints that a similar frustration of prior expectations of control may have fueled the rage Diane displayed when she was confronted with the option of treating her illness.[73] We should not therefore be surprised when Diane—or anyone else who exemplifies her radically self-determined disposition—prefers in the face of intractable suffering to emulate the "dead lion" rather than the "living dog."[74] Considering that such anger can so adversely affect the sufferer's decisions, we should be cautious of fanning the flames of entitlement by adopting a rights-oriented approach to demands for control over the circumstances of death. This admonition highlights the subtle life-giving opportunities—but also the risks—that exist for members of the sufferer's community to mediate the kind of challenge counseled by our author.

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[69] See *supra* text accompanying note 42.

[70] *Eccl. 7:8-10.*

[71] *Supra* note 59.

[72] *See* text quoted from CALLAHAN, *supra* note 38 (describing this attitude of entitlement in response to suffering).

[73] Wesley, *supra* note 7, at 473-75.

[74] *Supra* note 48.

The Critical Role of Community. Wesley's assertion of a failure to perceive the adverse effect of suffering on reasoning in the case of Diane leads her to the caution that "at times we must surrender some control and tolerate a certain degree of dependence on others. Serious illness is such an occasion."[75] The author of Ecclesiastes presents a compelling case for the importance of depending on community in the context of an individual disposition of radical self-determination:

> There is one alone, without companion:
> He has neither son nor brother.
> Yet there is no end to all his labors . . .
> "For whom do I toil and deprive myself of good?"
> This is also vanity and a grave misfortune.
>
> Two are better than one,
> Because they have a good reward for their labor.
> For if they fall, one will lift up his companion.
> But woe to him who is alone when he falls,
> For he has no one to help him up.[76]

The text makes the poignant observation that those who demand absolute control over their lives will ultimately find that it is only to their own detriment (i.e., "vanity"): When faced with adversity, the man who is utterly determined to control life only alienates himself from community and its advantages.

Assuming that such adversity would reasonably include the kind of intractable suffering we have been addressing, one could draw the inference that sharing decisions with the members of one's community would offer the sufferer similar protection against self-destructive decisions. By insisting on her own way, a radically self-determined sufferer like Diane or Elizabeth Bouvia seriously risks alienating others—even close relatives—who could provide the wise advocacy she really needs. How can those with moral standing in the community of the sufferer offer this kind of "protection" when the sufferer is so intent on hastening death?

A contractual model of moral accountability between patient and physician would only foster the radical individualism that serves to isolate a self-determined individual[77] like Diane or Elizabeth Bouvia from the benefits of community; nevertheless, the primacy of the right to self-determination in our culture helps explain the widespread acceptance of the ultimate outcome in each of those cases.[78] Ironically, Quill admits to still being

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[75] Wesley, *supra* note 7, at 475.
[76] *Eccl. 4:8-10.*
[77] *Supra* note 19. *See* again Brody, *supra* note 18, at 56-64; Lustig, *supra* note 18, at 7.
[78] *Supra* notes 6, 7, 17.

"haunted" by Diane's isolation in her suicide.[79] How, then, can those within the sufferer's community have confidence when confronted with a request to hasten death that they are expending the appropriate effort to help such individuals realize meaning in life?

We can only wonder how often a request for assistance in dying by sufferers like Diane or Elizabeth Bouvia constitutes their final "test"—like a bizarre version of Russian roulette—of whether they can command the sustained interest of others in their less powerful, less competitive condition in life: "If someone cares enough when they see how serious I am, maybe they will challenge me to keep on living; if not, maybe they will help me die—at least I'll be out of my misery." As noted by Block and Billings:

> Ambivalence is a nearly universal feature of a patient's request for accelerated death. . . . While actively seeking a quick and painless end to living, a patient may simultaneously be hoping for a cure of the underlying medical disorder, remission of symptoms, lifting of a depression, or alleviation of the social and economic burdens of illness. In expressing a wish to separate from the living, a patient may be searching for a relationship that counters loneliness. In arguing that life has become meaningless, the patient may be seeking a reason to live.[80]

Bouvia's choice ultimately not to die may indicate that the attention lavished upon her as a result of her court action provided—at least in part—the kind of care she required from her extended community.[81] This dynamic became explicit in the case of Larry McAfee,[82] a quadriplegic who petitioned the court in the state of Georgia to unhook his ventilator after three months in an ICU. The court granted his request, and the decision was upheld by the Georgia Supreme Court. But when McAfee was challenged to join a disability program that allowed him to be employed in computerized design and drafting, he changed his mind and now lives a productive life—he had a community that was willing to "help him up."[83]

This underscores the need to reexamine the pivotal role of the individual caregiver within a morally accountable community: When the sufferer is determined to hasten death, how far should a caregiver go to challenge her choice and risk being accused of coercion? In particular, how are physicians to be viewed in the context of others with moral standing in

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[79] Timothy E. Quill, *The Ambiguity of Clinical Intentions*, 329 N. ENG. J. MED. 1039, 1040 (1993).

[80] Block & Billings, *supra* note 36, at 2044.

[81] *See supra* text accompanying notes 54, 57. *See* also Pence, *supra* note 4; Herr, *supra* note 4, at 7-10; 34-36 (discussing this dynamic in Bouvia's case).

[82] The following synopsis is also distilled from Herr, *supra* note 4, at 15-18; 34-36.

[83] *Supra* note 76.

the sufferer's community? This leads to our last major question concerning the appropriate response to intractable suffering.

The Physician's Role in Intractable Suffering

What Is the Ultimate Role of the Physician When Cure Is No Longer Possible or Meaningful?

Wouldn't a physician or nurse be better advised to leave the challenge of wise advocacy to others with "greater" moral standing in the sufferer's community and stick instead to the relief of suffering?

Confronted by the Face of Despair. At this point it is helpful to return to the paradigm of Job, who found himself in need of just this kind of advocacy. Job looked to his friends for this kind of support in the midst of despair but encountered instead his own version of a bribe when they were suddenly faced with the challenge of responding to his agonized expression of intolerable suffering.[84] As a result, the book of Job provides us with some of the best teaching available on the proper response of a caregiver to a patient who demonstrates impaired decisionmaking in the midst of suffering and despair.

In the dialogue with his friend after seven days of silent grief over his disastrous calamities, Job uses the same imagery of stillbirth employed by the author of Ecclesiastes[85] to give some dimension to the depth of his despair: "*Why did I not die at birth? Why did I not perish when I came from the womb? . . . For now I would have lain still and been quiet,/I would have been asleep;/Then I would have been at rest.*"[86] There is little doubt that Job views death as preferable to a continued existence of intolerable suffering—he sounds frankly suicidal, perhaps even irrational. Such rumination over the anticipated blessing of non-existence is profoundly disturbing to Job's friends—just as disturbing as a patient's request for assistance in suicide must be to the physician entrusted with his or her care. As we saw in Ecclesiastes, the appeal of relief is very potent, and we tend to retreat to such relief at all costs.[87] In the last sentence of his book Cassell even proclaims the relief of suffering to be "the fundamental goal of medicine."[88]

Compassion Held Hostage—The Fear of Contagion. Understandably, then, Job's friends cannot remain silent in the face of this suicidal ideation, and they quickly try to reassure Job with the promise of prompt relief of

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[84] *Job* 3-6.

[85] *Supra* note 37.

[86] *Job* 3:11, 13.

[87] *See supra* text accompanying notes 34-36.

[88] CASSELL, *supra* note 30, at 249.

suffering if he will only repent of some imagined sin,[89] for that is the only way they can conceive that God would rescind his "punishment." Job shows no evidence of the reassurance his friends were hoping for—rather, he chides his friends for their lack of compassion: *"To him who is afflicted, kindness should be shown by his friend, . . . My brothers have dealt deceitfully."*[90]

Why did Job label his friends as "deceitful"? He immediately recognized their fear of contagion when they faced his despair[91] and showed remarkable diagnostic skill in tracing this fear within them to its roots:

> They are disappointed because they were confident;
> They come there and are confused.
> For now you are nothing, you see terror and are afraid.
> Did I ever say, 'Bring something to me'?
> Or 'Offer a bribe for me from your wealth'?
> Or 'Deliver me from the enemy's hand'?
> Or, 'Redeem me from the hand of the oppressors'?[92]

The attempt to *appease* the victim of intractable suffering with whatever it takes to relieve the suffering amounts to a bribe—an understandable impulse, but one which only corrupts the sufferer's decisionmaking by neglecting the wise advocacy he really needs in his profound suffering.[93]

Block and Billings accurately describe the dangers of this pressure to reassure the suffering patient with the promise of relief of suffering:

> When the clinician takes a request to hasten death simply at face value without recognizing ambivalence, he or she runs the risk of colluding with the patient's feelings of hopelessness and helplessness. . . . When patients acknowledge demoralization or wishes for early death, exploration rather than reassurance should be the initial response. . . . The physician's willingness to speak openly about the wish to die and to hear and bear the burden of the patient's distress counters feelings of isolation and is often sufficient to allow the patient to want to continue living.[94]

This is precisely the thrust of Wesley's analysis of Quill's narrative—she identifies multiple instances when Quill appears to have avoided looking more deeply into the factors that predisposed Diane to her "firm" decision

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[89] *Job 5.*
[90] *Job 6:14a, 15a.*
[91] *Supra* note 36.
[92] *Job 6:20-22.*
[93] *See supra* text accompanying note 67.
[94] Block & Billings, *supra* note 36, at 2044.

to decline medical therapy and thereby facilitated her decision to eliminate her suffering by suicide.[95]

The Courage of Sustained Presence and Wise Advocacy. In fairness to Quill, at least Job perceived his need for wise advocacy—an insight Diane did *not* seem to possess at a similar point of despair. In order to see his options more clearly, Job then went on to challenge his friends to provide him with the wisdom that he so desperately needed in the throes of his deep despair:

> Teach me, and I will hold my tongue;
> Cause me to understand wherein I have erred.
> How forceful are right words!
> But what does your arguing prove?
> Do you intend to reprove my words,
> And the speeches of a desperate one, which are as wind?
> . . . [Y]ou undermine your friend.
> Now therefore, be pleased to look at me;
> For I would never lie to your face.
> Turn now, let there be no injustice.[96]

Here Job clarifies how his friends' misguided attempt to relieve his intractable suffering (by squelching his death wish) caused them to miss his genuine need for wisdom. The sufferer's expressions of deep despair in the midst of intolerable suffering should not be assumed to represent the settled conclusions of rational deliberation—as if such expressions were subject to the kind of reproof or counterargument that has been offered by Job's friends. Rather, they should be taken as the emotional outbursts of a despairing man ("the speeches of a desperate one"), which seem for the time the only adequate means of communicating the profound depth of his suffering.

Job's plea thus underscores the need for courage among members of the sufferer's community to be willing to sustain their presence and face the emotional challenge of wise advocacy. When no one else with moral standing in the life of the sufferer is willing to do so, this might entail the physician himself assuming the role of this kind of advocacy, even at the risk of evoking a determined sufferer's rage.[97] The challenge is especially daunting in a climate that virtually worships autonomous choice, particularly with patients like Diane and Bouvia, who strongly and repeatedly express the conviction that life is no longer worth living.

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[95] Wesley, *supra* note 7, at 473-85.

[96] *Job 6:24-26, 27b-29.*

[97] *See supra* text accompanying note 70.

Nevertheless, as Steven Miles points out, a taboo on assisted suicide may provide the incentive to

> foster a therapeutic intimacy by creating a 'landmark' for a physician in an emotionally disorienting relationship with a dying patient. If I know that I may not project my disquiet back on a patient by improperly leading him or her to choose suicide, perhaps I will then dare to create a more intimate clinical relationship in which I can face more of my discomfort with her suffering. Openness to my distress at a patient's suffering improves therapeutic insight into a patient's pain, demoralization, and depression.[98]

Views such as these, which virtually proscribe any role for the physician that might involve acceding to a request to hasten death, predictably raise fears of moralistic paternalism among physicians.[99] Job's plea here also warns of these dangers, which dictate special vigilance on the part of the caregiver under the circumstances of intractable suffering and the desire to hasten death. As pointed out by Block and Billings,

> the implications of a physician's refusal to help the patient to die have not been adequately scrutinized. When the patient's desire to die cannot be reconciled with the physician's values and view of the physician role, a crisis in the doctor-patient relationship ensues. . . . The physician's refusal to help may be experienced by the patient as an abandonment, a rejection, or an expression of inappropriate paternalistic authority. . . . The patient's feelings of alienation become yet another source of suffering, and may lead the patient and physician to further distance themselves from one another.[100]

The Comfort of "Suffering Presence." Such alienation is exactly what developed between Job and his supposed friends, who continued to find ways to circumvent the clear need for advocacy and support, and Job finally resorted to the most stinging rebuke he could conceive, calling them "worthless physicians"[101] and "miserable comforters."[102] Job's words couldn't have been more auspicious for physicians today, thousands of years later.

What kind of approach by the caregiver in this setting could engender enough trust to provide the wise advocacy that Job or anyone in his circumstances needs, without resorting to assisted suicide? Miles clearly recognizes the dangers of moralistic paternalism in proscribing assisted

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[98] Miles, *supra* note 36, at 1787.

[99] Christine K. Cassel & Diane E. Meier, *Morals and Moralism in the Debate over Euthanasia and Assisted Suicide*, 323 N. ENG. J. MED. 750 (1990).

[100] Block & Billings, *supra* note 36, at 2045.

[101] *Job 13:4.*

[102] *Job 16:2.*

suicide, yet he also sees a need for some kind of empathic identification with the patient who desires to hasten death. He thus responds to the above caveat with the balanced statement that

> [t]o be constructive, the taboo on physician-assisted suicide cannot be a moralistic last word, especially one pronounced in cool distance from a dying patient and accompanied by judgmental attitudes. . . . Rather, the taboo on physician-assisted suicide should be understood as enabling and pointing to the necessity of an honest painful intimacy to better understand and treat suffering patients.[103]

Job proceeds to illustrate and confirm this priority of empathic identification for the patient in intractable suffering: *"I also could speak as you do,/If your soul were in my soul's place. . . . But I would strengthen you with my mouth/And the comfort of my lips would relieve your grief."*[104] The word translated "comfort" here is literally *quivering;* the image of "quivering lips" unmistakably displays a deep empathy in response to the observation of intractable suffering in another. By demonstrating true empathy in this way, Job's friends might have earned the moral standing to be truly wise advocates who could legitimately challenge his choices. The text thus strongly suggests that the establishment of some empathic connection with an intractably suffering patient is indeed necessary to develop the kind of advocacy that Job invited his friends to provide him; such advocacy mediates the best kind of care that can be shown for the patient who is in intractable suffering and wants to hasten death.

The Standard of Care? Does this imply that the proper role of the physician necessarily involves that much care for the suffering patient? How can the committed caregiver—with no natural incentive to remain exposed to the sufferer's grief and pain—stay faithfully and intimately engaged in this way under the continued circumstances of intractable suffering? What about all the caregivers who are incapable of relating in such a deeply empathic fashion?

Curzer has expressed considerable pessimism over whether it is expedient for *any* physician to adopt an ethic of care and has offered a list of caveats detailing the potential adverse consequences—including emotional burnout—of caring for the patient in the truly empathic fashion suggested by Job.[105] The substance of Curzer's concern is to seriously question whether that is something we can or even should encourage physicians to provide—i.e., going beyond respectful and caring behavior to actually

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[103] Miles, *supra* note 36, at 1787.

[104] *Job 16:4-5.*

[105] Howard J. Curzer, *Is Care a Virtue for Health Care Professionals?* 18 J. MED. & PHIL. 51 (1993).

feeling their pain. Unfortunately, Curzer seems to project into his definition of caring for the patient the sense of overidentification and even countertransference we previously warned against,[106] and that is certainly *not* what is being advocated in the excellent commentaries by Block and Billings[107] and Miles.[108]

Nevertheless, the dangers of such emotional enmeshment under circumstances of intractable suffering are real and palpable. Moreover, many (if not most) physicians clearly lack training in the psychodynamic skills and patience required to look objectively behind the suffering of the demanding patient,[109] while also realizing the potential to be a sustained empathic presence in the patient's life context.[110] It is therefore unrealistic to expect that in every case of request for assisted death the physician will be capable of providing the kind of care advocated herein, even if he/she is the appropriate individual to do so within the patient's community. Do any other alternatives exist when it becomes clear for one reason or another that the physician is not in a position to render the kind of empathic care and advocacy we have been discussing?

The Potential Contribution of Hospice and Ethics Consultation. Walker makes an excellent case for the superiority of narrative methodology in decisionmaking when differing views conflict among the parties with moral standing in the life of the sufferer as to how the potential for meaning in that life should be construed.[111] The narrative paradigm carries with it the implication that we would be well advised to reevaluate which practical approaches, including improved utilization of hospice[112] and the newer models for ethics consultation,[113] might have the greatest potential to

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[106] *Supra* note 36.

[107] *Id.*

[108] *Id.*

[109] Miles, *id.* at 1786-87.

[110] STANLEY HAUERWAS, SUFFERING PRESENCE 21-83 (1985); William Zinn, *The Empathic Physician*, 153 ARCHIVES INTERNAL MED. 306 (1993); HOWARD BRODY, THE HEALER'S POWER (1992); Richard M. Zaner, *Medicine and Dialogue*, 15 J. MED. & PHIL. 303 (1990); Leon R. Kass, *Ethical Dilemmas in the Care of the Ill: I. What Is the Physician's Service? II. What Is the Patient's Good?* 244 JAMA 1811, 1946 (1980).

[111] Walker, *supra* note 57.

[112] Campbell, *supra* note 1. The hospice movement has come a long way toward facilitating this kind of care with a philosophy quite compatible with the wisdom model, but it may well be compromised if legal developments allow freer access to medical assistance in suicide (*id.*).

[113] Walker, *supra* note 57. *See also* RICHARD M. ZANER, TROUBLED VOICES (1993) (an anthology of case consultations eloquently illustrating the advantages of narrative methodology in facilitating the resolution of clinical ethical dilemmas); ETHICS AND THE CLINICAL ENCOUNTER (1988) (describing Zaner's model for ethics consultation); *Voices and Time*, 18 J. MED. & PHIL. 9 (1993) (analyzing competing models of ethics consultation); and

enhance the process of moral deliberation for such patients within a caring community. The wisdom model provides a viable framework to ethically and effectively address the needs of people with intractable suffering through such forums for moral deliberation.

Conclusion

The contractual model for decisionmaking is ill suited to identify or effectively address the unique problems that are presented by patients in intractable suffering who desire to hasten death and request assistance in doing so. Such requests are fraught with ambiguity and surface several issues that surround the dilemma of intractable suffering. An ethical framework adduced from the books of Job and Ecclesiastes—the wisdom model—directly addresses these moral issues evoked by intractable suffering. By warning the caregiver of the pitfalls of (1) the contagion of despair, (2) an inflexible disposition of radical self-determination, and (3) the adverse influence of suffering on reasoning capacity, the wisdom model equips the caregiver to more effectively address the needs of the sufferer.

The ethical framework adduced from the wisdom model supports the notion that those with moral standing within the sufferer's community are accountable for mediating a positive impact on the suffering patient. This may require the courage of wise advocacy, whereby the caregiver earns the sufferer's trust by becoming a comforting presence[114] and then challenges the sufferer to enter into moral deliberation over the options for preserving meaning in life, which is often ambiguous and uncertain. When received by the sufferer, this kind of advocacy confers great benefit—even in the midst of intractable suffering—*without resorting to assisted suicide;* when rejected, it need not at all imply that the caregiver has either failed to demonstrate genuine care or done coercive violence to autonomous choice.

However, as Kilner warns, "[C]aregiving . . . can be a heavy burden, particularly if it involves efforts to help the patient bear the burdens of suffering. As in the case of all suffering, the personal and vicarious suffering of the caregiver may prove valuable only after an extended period of uncertainty or even despair."[115] Many physicians, like Job's friends, have demonstrated their inability to meet these high standards of wise advocacy and empathic comfort under conditions of intractable suffering. Yet there

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Timothy J. Keay, *Ethics Committees and Family Ghosts: Case Studies*, 5 J. CLINICAL ETHICS 19 (1994).

[114] Callahan, *supra* note 21, at 55 ("It is not medicine's place to determine when lives are not worth living or when the burden of life is too great to be borne . . . [Doctors] should relieve pain, do what they can to allay anxiety and uncertainty, and be a comforting presence.").

[115] JOHN F. KILNER, LIFE ON THE LINE 105 (1992).

are clear occasions when the physician is indeed the most appropriate member of the "moral community" to provide this kind of care.

When Job—like many of today's victims of intractable suffering—despaired of ever finding an advocate like this who could sustain a comforting presence and help bear his suffering, he cried out, "There is no mediator. . . ."[116] Even when *physicians* are unable to provide such advocacy, however, the wisdom model supplies a moral framework for hospice and/or the ethics consultant working within the patient's community to mediate the comfort and advocacy so desperately needed by the suffering patient. The wisdom model promises reliable guidance that is capable of avoiding both the precarious Scylla of "colluding with the patient's feelings of hopelessness and helplessness"[117] and the treacherous Charybdis of cool distance and moralistic paternalism.[118] Let us hope that we may become such a moral community, fully equal to the task of caring for persons with intractable suffering.

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[116] *Job* 9:33.

[117] *Supra* note 94.

[118] *Supra* note 103.