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The Liberal Neutrality of Living and Dying: Bioethics, Constitutional Law, and Political Theory in the American Right-to-Die Debate

Erratum

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THE LIBERAL NEUTRALITY OF LIVING AND DYING: BIOETHICS, CONSTITUTIONAL LAW, AND POLITICAL THEORY IN THE AMERICAN RIGHT-TO-DIE DEBATE

*Bruce Jennings**

Both medical treatment near the end of life and care of the dying are two important issues confronting medicine as the aging society moves from dawn to high noon. How insightfully, imaginatively, and creatively will moral and legal discourse respond to the fundamental human challenge of accepting our mortality, dependency, and finitude? The answer to this question will determine, in large part, how well or how badly most of us shall die.

A recently developed reading of philosophical and political liberalism holds the key to how well bioethics will respond to this challenge. This reading of liberalism is commonly referred to as the theory of "liberal neutrality." This theory holds that public power should not be used to favor any particular conception of the human good, but must remain impartial among competing and conflicting conceptions. Although compelling and attractive in many ways, liberal neutrality does not meet the needs of the aging society. Instead, liberal neutrality provides an unduly abstract and individualistic public philosophy of death and dying, putting too much weight on individual rights to personal control without refining the concepts of reciprocity, mutuality, and interdependence. These are precisely the concepts that are essential to the language, self-consciousness, and agency of a genuinely multi-generational society of care giving, community, and common respect. Liberal neutrality provides but one way to bring bioethics and the law together. This essay provides a critical account of liberalism's public philosophy of death and dying, and reflects on how society might begin developing a viable alternative to it.

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I. LIBERAL NEUTRALITY

In recent years, some of the most influential philosophers in the western world constructed a remarkable normative paradigm by combining elements from liberal political theory, neo-Kantian ethics, and a constitutional jurisprudence centered on individual rights. These areas of thought and philosophy form the paradigm of liberal neutrality.¹

Liberal neutrality has three basic tenets, roughly drawn from the three aforementioned traditions: (1) the doctrine of the moral primacy of the right over the good; (2) the legal primacy of individual rights over collective considerations of social utility; and (3) the political primacy of non-interference, impartiality, and neutrality on the part of the state in relation to beliefs held by individuals. The first tenet generally fits with a deontological, rather than consequentialist metaethic, drawn not only from Kant, but also from the contractarian tradition. The other two tenets are consistent with the type of constitutional liberalism that has developed in the United States, particularly in the post-World War II period and throughout the modern civil rights era.

Under this view of liberalism, matters of promoting a measure of egalitarian social justice and protecting individual rights are properly the concern of the democratic state acting on behalf of the entire political community. Conversely, matters of a more positive duty and moral aspiration concerning human self-realization and the good life are matters of private belief. When addressing matters of private beliefs in which a liberal society as a whole cannot agree, liberal neutrality dictates that the state must take the role of a neutral intermediary, enforcing only meta-norms of tolerance, diversity, and mutual respect.

II. BIOETHICS AND LAW

Liberal neutrality relates directly to bioethics by offering an account of rights and regulation of medical decision making at the end of life, and relates indirectly to bioethics by propounding a particular view of the relationship between ethics and the law. Understanding how liberal neutrality connects ethics and the law is a prerequisite for understanding the substantive stance it takes on end-of-life issues. One can begin to understand liberal neutrality by considering the basic rela-

1. The literature on liberal neutrality is enormous, with John Rawls as the principal architect of this version of liberalism.

tionships between bioethics and the law; two senses in which a relationship may be identified are through a substantive connection and a discursive connection.

The substantive relationship between bioethics and the law relates to the specific way that any particular work in bioethics understands, either implicitly or explicitly, the proper nature, scope, and legitimacy of the law. Conversely, this relationship, in any particular work of jurisprudence, understands the force and function of moral argument, both in court and in relationship to the legitimacy of the court's authority in the broader political culture. For example, it is possible to conceive of a kind of bioethics that would countenance only the force of moral argument within the medical profession and that would reject any recourse to the courts, or to the state, as proper forums for making and enforcing normative arguments about the practice of medicine or conduct of science. However, it is also possible to imagine forms of jurisprudence or philosophies of law in which there are virtually no roles for moral argumentation at all. While such bioethical and jurisprudential views are imaginable, neither has emerged in the mainstream of either field in the United States during recent years.

American bioethicists consider the law and courts as the great reforming ally in a joint effort to vindicate patients' rights while curbing excessive professional power. American constitutional law, for its part, also gives an enormously influential push away from both legal formalism and legal realism through the work of Ronald Dworkin and others who regard the Constitution as essentially an embodiment of a modern liberal moral consensus. With respect to this view, the proper task of judicial interpretation is to bring out the universal moral content of the law while considering the light of changing social conditions and circumstances. Thus, substantive connections can be forged between bioethics and the law in which the thought of each discipline makes normative room for the other.

A second type of relationship between bioethics and the law is what might be termed a "discursive connection." This relationship is less a compatibility of substantive doctrine between the two fields than an affinity or "mimicry" between the conceptual frameworks and analytic reasoning styles of each mode of discourse. In American bioethics, and in at least some parts of American constitutional jurisprudence, there is a high degree of affinity between the conceptual languages used. Without knowing the author's primary institutional or discipli-

nary identity, it is often impossible to tell if one is reading an article by an academic bioethicist or a professor of constitutional law.

There are two reasons why this discursive mimicry evolved. First, end-of-life cases have drawn upon areas of constitutional law most germane to bioethical questions, such as the Fourteenth Amendment,² or the analogous portions of state constitutions. A second reason for this discursive connection is that judges and constitutional lawyers have gravitated, while handling Fourteenth Amendment issues, toward a set of questions and concepts involving the meaning and limits of individual rights. This discussion calls for use of the conceptual tools and reasoning skills highly developed in the school of analytic philosophy, which spread from Oxford and Cambridge in the 1950s to the major North American universities. Those who study moral philosophy, bioethics, or constitutional law at an advanced university level in the United States are thoroughly trained in that particular style of analysis, while both the history of ethics and the continental styles of philosophical discourse are virtually ignored.

Accordingly, when we speak of the relationship between bioethics and the law, consideration must be given to both the substantive and the discursive dimensions of any problem. On both of these levels, American bioethics and constitutional law are tightly bound together through the paradigm of liberal neutrality, where its substantive accounts of moral philosophy and constitutional interpretation are tailor-made to fit the reform agenda of liberal bioethics. Its working language is an analytic philosophy proven to be convincing and appealing both to the courts and to medical elites as an idiom of analytic logic.

If these principles hold true, then it follows that the relationship between bioethics and the law establishes a relationship that is not a dyadic structure at all, but in effect, is a three-way relationship between bioethics, the law, and politics or political theory. For liberal neutrality is itself a normative ethic, a constitutional vision, and a political theory, and each of these has been enormously influential on the development of bioethics.

This paper, however, does not attempt to trace out this suggestion fully in the intellectual history of American bioethics. Instead, it discusses how this paradigm works in the so-called right-to-die debate. This debate originally began as an attempt to empower patients, their families, or other surrogates, in decision making about the use of life-

2. U.S. CONST. amend. XIV.

sustaining medical technologies in critical care settings. The debate has run its course from the New Jersey State Supreme Court in *In re Quinlan*,³ to the United States Supreme Court in *Cruzan v. Director, Missouri Dep't of Health*.⁴ After an evolution of approximately twenty-five years, this debate culminated in a movement to legalize physician assisted suicide (PAS), moving from a recognition of the individual's right to determine the nature and type of medical treatment received, to a recognition of the right to determine the precise nature, circumstances, and timing of one's own death.

III. THE DECADE OF DEATH AND DYING

In the early 1990s, bioethics found itself in an interesting lull, a kind of holiday truce between advocates from both sides of the debate. While the patient's right to refuse treatment, even life-sustaining treatment, is legally and morally secured,⁵ the next battle, covering the legalization of physician assisted suicide, appears ready to begin.

The 1990s will be remembered as a decade marked by an increasing social awareness of death and dying.⁶ The decade began with the United States Supreme Court's first landmark ruling on end-of-life care in *Cruzan*,⁷ in which the Court recognized that a right to refuse life-sustaining treatment may exist.⁸ In *Cruzan*, the Court found that under certain circumstances a surrogate may act for the patient in determining end-of-life decisions.⁹ Following this decision, a number of different approaches addressing end-of-life care arose. Congress

3. 355 A.2d 647 (N.J. 1976).

4. 497 U.S. 261 (1990).

5. See Alan Meisel, *Forgoing Life Sustaining Treatment: The Legal Consensus*, KENNEDY INST. OF ETHICS J. (Dec. 1994).

6. See MARILYN WEBB, *THE GOOD DEATH: THE NEW AMERICAN SEARCH TO RESHAPE THE END OF LIFE* 28-53 (1997).

7. 497 U.S. 261 (1990).

8. "The principle that a competent person has a constitutionally protected liberty interest in refusing unwanted medical treatment may be inferred from prior decisions." *Id.* at 278; see also *Washington v. Harper*, 494 U.S. 210, 221-222 (1990) (recognizing that prisoners possess a liberty interest in avoiding unwanted anti-psychotic drugs); *Jacobson v. Massachusetts*, 197 U.S. 11, 24-30 (1905) (balancing an individual's right to refuse smallpox vaccines against the state's interest in combating disease).

9. See *Cruzan*, 497 U.S. at 280 (recognizing that an incompetent's right to refuse unwanted medical treatment must be exercised by a surrogate).

passed the Patient Self-Determination Act, while durable powers of attorney for health care statutes appeared in many states, including New York, along with public education efforts to encourage the use of advance directives. These various approaches all focused on stressing the importance of considering individual preferences about end-of-life care.

In the mid 1990s, the SUPPORT study¹⁰ provided rigorous documentation of the alarming extent to which aggressive life-prolonging measures were used in situations that were either medically futile, were unwanted by the patients, or both. Even concerted efforts to improve communication between physicians and dying patients did not stem the technological momentum of end-of-life care in the country's major medical centers. Moreover, a large proportion of families reported that the patient spent the last two or three days of life in severe, unrelieved pain.¹¹

Public fear of losing control of care at the end of life, becoming dependent on machines, becoming an emotional and financial burden to one's family, and suffering due to inadequate treatment of pain and other symptoms, all led to a growing grassroots movement to legalize PAS. These fears were dramatized by the public defiance of Dr. Jack Kevorkian, the debate over the Oregon referendum that legalized PAS for the first time in the United States, and by the Federal Appeals Court rulings in the Second and Ninth Circuits, *Quill v. Vacco*¹² and *Compassion in Dying v. Washington*¹³ (the PAS cases), that temporarily struck down existing state laws aimed at limiting PAS. The Supreme Court also refused to interfere with the Oregon Death with Dignity Act,¹⁴ leaving the constitutional door open for other states to

10. See SUPPORT Principal Investigators, *A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment*, 274 JAMA 1591 (1995).

11. See *id.* at 1598.

12. 97 F.3d 708 (2d Cir. 1996).

13. 79 F.3d 790 (9th Cir. 1996) *rev'd* *Washington v. Glucksberg et al.*, 521 U.S. 702 (1997).

14. The Oregon Death With Dignity Act, ORE. REV. STAT. §§ 127.800, 127.805 (1996). Under the Act, a capable adult resident who has been determined by the attending physician and consulting physician to be suffering from a terminal disease, and who has voluntarily expressed his or her wish to die, may make a written request for medication for the purpose of ending his life in a hu-

change their laws on PAS. Since that decision, a referendum to legalize PAS failed in Michigan, while Dr. Kevorkian was convicted of murder for ending the life of a man with advanced amyotrophic lateral sclerosis.¹⁵

Over the past decade, several groups mounted a less contentious educational and institutional effort to change and improve end-of-life care. No doubt, the prospect of a movement towards legalized PAS throughout the country quickened these less radical reform efforts. Within the health care professions, attention is being directed towards improving the standard of practice in pain management and palliative care. Specialists in this area have long argued that medical education and the knowledge level within medicine are not sufficient to meet patient needs, and that there is a systematic and persistent undertreatment of pain in the mainstream American health care system. As a result, interest in hospice and utilization of hospice services accelerated in the 1990s, nearly doubling from roughly ten percent of those dying of chronic and terminal disease each year (principally, but not exclusively from various forms of cancer) to about seventeen percent by the end of the decade. Efforts by hospitals and community groups to educate consumers concerning the use of advance directives also increased during this period. In addition, new curricula for medical and nursing education were developed and implemented, and a recent Institute of Medicine study, *Approaching Death*,¹⁶ contains what may now be regarded as a general consensus among experts in the area concerning what needs to be done for future care towards the chronically ill.¹⁷

When the first hospice program in the United States began in Connecticut in 1973, end-of-life care was an orphan field — one of little interest to mainstream medicine which was too busy fighting President Nixon's war on cancer. At that time, end-of-life care was such a socially and culturally taboo subject. Even clergy were uncomfortable discussing it and seminaries offered virtually no training in pastoral

mane and dignified manner in accordance with [the provisions of the Act]

OR. REV. STAT. § 127.805.

15. Kervorkian's conviction was based upon a videotape of the assisted suicide broadcast on the television program *60 Minutes* in November 1998.

16. MARILYN J. FIELD & CHRISTINE K. CASSEL, *APPROACHING DEATH: IMPROVING CARE AT THE END OF LIFE* (1997).

17. *See id.* at 259-271.

counseling for terminally ill persons or bereavement counseling for families. As late as the mid-1980s, magazines such as *Modern Maturity*, read by millions of American Association of Retired Persons (AARP) members, did not carry articles on death and dying, advance directives, or palliative care, because these subjects ran counter to the image of the healthy and active seniors that such publications were trying to project.

These attitudes still exist, but society shows signs that it can no longer afford the luxury of ignoring end-of-life issues and that there must be a wide-spread civic conversation about the values that ought to guide end-of-life care options and choices in America. Presently, approximately two million foreseeable deaths occur each year in the United States, more than half of which take place in a hospital or other health care facility.¹⁸ In those institutions, as many as seventy percent of the deaths come after some deliberate non-treatment decision, including a "do-not-resuscitate order," has been made.¹⁹

The question of what constitutes a "good death" or "good care" near the end of life must not be suppressed. Despite the remarkable attention and energy devoted to this notion in the 1990s, a firm grasp on the issue continues to elude bioethicists, perhaps in part because end-of-life care has been seen as "a personal trouble," rather than a "civic problem."²⁰ A personal trouble resides within the individual's own heart and mind, or at most within the ambit of the individual's own immediate family.²¹ In contrast, a civic problem reveals the connection between what individuals experience in their personal and family lives and the larger structures of social custom, cultural belief, combined with political and economic powers that surround them.²² Dying, one of the most intimate and private of personal experiences, is not *only* a personal experience; dying is socially and culturally shaped. To address the question of "good dying" as a civic question, for example, one that engages the shared values of our community of diverse faiths, backgrounds, and needs, it is necessary to challenge prevailing arguments that render such questions suspect or illegitimate. That is precisely what the paradigm of liberal neutrality does and is precisely

18. *See id.* at 34-39.

19. *See id.*

20. C. WRIGHT MILLS, *THE SOCIOLOGICAL IMAGINATION* 8-9 (1959).

21. *See id.*

22. *See id.*

why the prevailing arguments must be challenged.

IV. APPLYING LIBERAL NEUTRALITY TO ETHICS AND LAW AT THE END OF LIFE

A paradigm's function is to structure our moral perspective and imagination in particular ways so that certain questions come to the foreground, allowing various components of human experience to be seen in one way rather than another. Liberal neutrality does this in subtle and telling ways. The use of liberal neutralism, a lens through which to understand the ethical, political, and the legal issues at stake in the American right-to-die debate, is widespread in bioethics and thus could be explicated by reference to any number of writings in the field. Liberal neutrality finds its most intelligent and uncompromising formulation in the work of Ronald Dworkin, who is generally not considered a bioethicist, but whose work has been highly influential in the field.

In *LIFE'S DOMINION*,²³ Dworkin attempts to show that the culture wars over both abortion and euthanasia can be resolved, and an ethical-legal *modus vivendi* achieved, by recourse to the tenets of liberal neutrality theory.²⁴ He believes that the sanctity of life and the value one places on prolonged life are fundamental components of a conception of the human good.²⁵ Dworkin explains that reasonable persons will disagree about the sanctity of life and the role of law.²⁶ He proffers that the function of public morality is to preserve the space of that disagreement and to remain comfortable living in accordance with one's beliefs.²⁷ He believes that the role of law is not to settle such disagreements nor to bring the coercive power of the state down on one side or another in this dispute.²⁸

Dworkin's argument reiterates that if individuals cannot reasonably agree on when life begins, or on the relative value of fetal life, and if we cannot reasonably agree on when dying begins, or on the relative value of living while dying, then in both cases the law should not be used to interfere with and override the individual's liberty to act. This

23. See RONALD DWORKIN, *LIFE'S DOMINION* 3-29 (1993).

24. See *id.*

25. See *id.*

26. See *id.* at 181-182.

27. See *id.* at 28-29.

28. See Dworkin, *supra* note 23, at 157-159.

is best described as “liberty of conscience,” which makes policy questions concerning abortion and euthanasia analogous to constitutional questions over religious freedom.²⁹ Included under this liberty of conscience are the interests that a person has in controlling the circumstances surrounding his or her own body and fundamental life activities, which Dworkin dubs “critical interests,” akin to constitutional issues of liberty under the Fourteenth Amendment.³⁰

Such reasoning leads Dworkin to the conclusion that the Supreme Court was correct, although not always for the right reasons, in abortion cases. He believes the state should not interfere with a woman’s freedom to continue or to discontinue her pregnancy; to do so coercively imposes a conception of religious beliefs onto non-consenting individuals who do not share those private beliefs.³¹

The same reasoning applies, *mutatis mutandis*, to laws pertaining to the refusal of life-sustaining medical treatment, PAS, or active euthanasia. Dworkin argues that the case law from *Quinlan* to *Cruzan* correctly affirmed the right of the individual to refuse life-sustaining medical treatment, because he believes that use of the law and the power of the state to force unwanted treatment onto a patient would give official sanction to private perceptions of the sanctity of life.³² Finally, Dworkin asserts that since there is no principled difference between the refusal of life-sustaining treatment and assistance with dying via lethal prescription (PAS) or lethal injection (active euthanasia), statutes making it a crime for physicians to aid in dying should be overturned as unconstitutional. Doing so would affirm, he believes, that the substantive political morality enshrined in the constitution is essentially that of liberal neutrality.

*The Philosophers’ Brief*³³ is essentially an extension of the theory of liberal neutrality applied to the specific public policy question of legalizing PAS. Indeed, the Brief follows closely the version of that theory put forward in *LIFE’S DOMINION*. If affirmed and embraced by the Supreme Court the PAS cases would have replayed a scenario like

29. See generally *id.* at 30-101.

30. See *id.* at 201-208.

31. See *id.* at 165-166.

32. See DWORKIN, *supra* note 23, at 196-217.

33. Brief for Ronald Dworkin et al., as Amicus Curiae Supporting Respondent, *Vacco v. Quill*, 521 U.S. 793 (1997) (No. 96-110).

that created by *Roe v. Wade*.³⁴ Few issues have been better positioned to illustrate the principles of liberal neutrality. With the finding of a constitutionally protected right for individuals,³⁵ the court could have swept aside existing statutes in nearly every state, overriding prevailing legislative majorities. If this occurred, the result would create the need for a long series of other rulings to clarify and fine tune what statutory approaches were permissible. This is precisely what liberally neutral courts are supposed to do in a democracy. On the other hand, such an exercise of judicial power would have triggered a bitter social and cultural conflict, akin to that, which has persisted around abortion for nearly thirty years.³⁶

Dworkin left no doubt about the continuity between the *Brief* and the theory of liberal neutrality. In the *Brief*, he writes, "defines a very general moral and constitutional principle that every competent person has the right to make momentous personal decisions that invoke fundamental religious or philosophical convictions about life's value for himself."³⁷ The *Brief* asserts that denying competent, terminally ill patients, who find their continued life intolerable, the freedom to hasten their own death is something improper for the state to do.³⁸ The *Brief* bases this assertion on the fact that "individuals have a constitutionally protected interest in making those grave judgments for themselves, free from the imposition of any religious or philosophical orthodoxy by court or legislature."³⁹ For the state to deny such persons the "opportunity" to hasten their death, with or without assistance, "could only be justified on the basis of a religious or ethical conviction about the value or meaning of life itself. Our Constitution forbids government to impose such convictions on its citizens."⁴⁰

The body of the *Brief* considers other potential justifications for denying this liberty interest and finds them all lacking. It argues that

34. 410 U.S. 113 (1973), *reh'g denied* 410 U.S. 959 (1973). In *Roe*, the Court recognized that a woman's right to choose to have an abortion was part of the fundamental constitutional right to privacy. *Id.* at 153.

35. *See id.*

36. *See* JAMES DAVIDSON HUNTER, BEFORE THE SHOOTING BEGINS 20-42 (1994).

37. DWORKIN, *supra* note 33, at *6-7.

38. *See id.* at *3.

39. *Id.*

40. *Id.*

prior Court rulings in other areas of medical care decision making,⁴¹ reproductive decisions,⁴² and right to privacy⁴³ protect an individual's right to make momentous life choices free from the imposition of any religious, ethical, or philosophical orthodoxy.⁴⁴ Finally, it contends that to decide to hasten one's death, for any personal reason, and with or without assistance, is one of those constitutionally protected areas of our liberty.⁴⁵

Dworkin's premise, in both *The Philosopher's Brief* and LIFE'S DOMINION, rests on the notion that state prohibition on ending the life of one's fetus with medical assistance or ending one's own life with medical assistance is properly understood as an improper imposition of a religious or philosophical orthodoxy on citizens.⁴⁶ Another view is that a valid purpose of the state is to prevent one person from directly and intentionally killing another and that is what laws against abortion and PAS are all about.

One may argue that this legitimate state purpose⁴⁷ is misdirected or misapplied in the case of particular laws against abortion or PAS, or that other rights or social interests outweigh this state interest in discouraging intentional killing. Yet, these are not the arguments that

41. See *Roe*, 410 U.S. at 153.

42. See *Planned Parenthood v. Casey*, 505 U.S. 883 (1992) (examining state regulations aimed to limit abortions); *Webster v. Reproductive Health Services*, 492 U.S. 490 (1989) (examining whether a state's refusal to subsidize abortions limited a woman's right to privacy).

43. See *Griswold v. Connecticut*, 381 U.S. 479 (1965) (striking down a Connecticut law that barred the use of contraceptives by married persons); see also *Eisenstadt v. Baird*, 405 U.S. 438 (1972) (striking down a statute that prohibited distribution of contraceptives to unmarried persons as a violation of the equal protection clause).

44. See JOHN NOWAK & RONALD ROTUNDA, *CONSTITUTIONAL LAW*, §§ 14.28, 14.29 (1995); "Matters involving the most intimate and personal choices a person may make in a lifetime, choices central to a person's dignity and autonomy, are central to the liberty protected by the Fourteenth Amendment." *Casey*, 505 U.S. at 851.

45. See DWORKIN, *supra* note 33, at *9. The purpose of this essay is not to engage in a thorough critical analysis of these arguments, instead, the focus is on the general language and conceptual framework they offer for our understanding of the moral situation in end-of-life care.

46. See *id.*

47. See *Roe*, 410 U.S. at 155-156 (holding that the Court will only strike down abortion laws that are not supported by a compelling state interest).

Dworkin or the theory of liberal neutrality generally intend to pursue. Nor do these arguments constitute the radical and compelling paradigm shift in our moral understanding of individual rights that Dworkin hopes to accomplish. While one may follow and accept this approach, Dworkin fails to supply independent reasons or arguments about why one should do so.

Another aspect of Dworkin's argument is he tends to transform ideas that many people regard as reasonable and objective moral truth into matters of quasi-rational or irrational belief.⁴⁸ This argument transforms a good deal of the content of what is regarded as public morality into the realm of private religion, and he seems to do this sorting in an arbitrary or ideologically motivated way.⁴⁹ Drawing the line between public morals and private religion is crucial in a liberal society, but Dworkin again does not provide much in the way of theoretical or procedural justification for doing so. This is all the more troubling because Dworkin focuses so much of his work on the policy making role of judges and the courts, and seems to give little place for democratic politics or politically accountable legislators in the realm of social policy that touches on fundamental individual rights. This is a shortcoming of the theory of liberal neutrality generally: it relies far too heavily on affecting progressive social change through judicial authority and betrays an orientation toward politics that generally is elitist and anti-democratic.⁵⁰

Given this view of liberal neutrality, some of the following concerns emerge from the *Brief's* argument. First, do past court decisions actually require finding a constitutionally protected right to assistance in controlling the timing of one's death? Second, even though the cases under review focused on provisions in state law that penalized physicians for assisting in suicide, the *Brief* argues grounds for establishing that an individual has a right to obtain the assistance of anyone he chooses (and who agrees), not only a physician. It is actually an argument for assisted suicide, not PAS.

Moreover, liberal neutrality is not merely an argument for assisted suicide but also one for direct euthanasia. The *Brief* supplies no reason why the dying patient must take her life with her own hand. Emotional or aesthetic responses to scenarios where the doctor may prescribe the

48. See ROBERT P. GEORGE, MAKING MEN MORTAL 190 (1993).

49. See *id.* at 190-191.

50. See CASS SUNSTEIN, BEYOND NEUTRALITY 1123-1163 (1997).

pills a patient takes, or the situation where a family member pulls the trigger do not factor into the analysis at all. Interestingly enough, sympathy for the plight of the dying, especially the moving cases represented by the plaintiffs in the cases, does figure in the *Brief*, but not directly in its conceptual or argumentative structure. What the majority opinion by Justice Rehnquist ultimately relied on and embraced in *Glucksberg* was the distinction between the right to be free from unwanted bodily invasion versus the right to obtain assistance in directly and deliberately ending one's life.⁵¹ Using rhetoric and phraseology that erases that distinction, *The Philosophers' Brief* does not address this distinction adequately.

V. THE FRAMEWORK OF LIBERAL NEUTRALITY

Viewing the right-to-die and abortion issues through the lens of liberal neutrality affects our understanding in several important respects. First, it links a seemingly localized question "how should we regulate medical practice and the use of medical technology in given areas of practice?" with a societal issue questioning the very nature of our constitutional regime. Whether morally right or wrong, restriction of abortion would not simply restrict the freedom of women, it would threaten civil and religious liberties across the board. Liberal neutrality would have us believe the same thing about laws governing both the termination of life-sustaining treatment, PAS, and active euthanasia.

Second, in a related gesture, this perspective sets up a linear narrative for the development of the right-to-die debate. According to this narrative, individual autonomy at the end of life is a logical extension of the entire civil rights movement of the post-war years. These questions do not arise primarily because people are living longer or because advances of medical technology are permitting physicians to prolong biological life beyond the capacity to restore function or cognitive capacity. In many patients, the use of improved medical technology may prolong their dying in a burdensome way. However, on the liberal neutrality account, these questions arise for an altogether different reason: they represent the next frontier in sweeping away the

51. See *Glucksberg*, 521 U.S. at 710-711. "The States' assisted-suicide bans are not innovations. Rather, they are longstanding expressions of the States' commitment to the protection and preservation of all human life." *Id.* (citing *Cruzan*, 497 U.S. at 280).

legal residue of a past era when individuals were subject to conceptions of how they should live their lives without any sufficient public protection.

Another significant aspect of the liberal neutrality perspective is that it erases the distinction between the right to refuse life-sustaining treatment and the right to obtain medical assistance with one's death. Yet, this precise distinction has emerged over the past twenty-five years as a linchpin of bioethics and the law at the end of life when only foregoing life-supports, and not PAS, was the center of attention.

This is important for the sake of ethical and jurisprudential consistency. If there is no principled distinction made between foregoing treatment and PAS, and if the courts have decided against a prohibition on the practice of foregoing treatment, then the courts cannot consistently allow a prohibition on the practice of PAS. If there is a common law right or liberty interest at work, it is the person's right to choose death, or the autonomy to control the timing and circumstances of one's own death. In both foregoing treatment and PAS, the patient exercises the same right, not two different rights, and the patient and the physician have the same intention or goal, namely, the early death of the patient to relieve the burden or suffering caused by prolonged living.

The question is also important from a substantive constitutional analysis. If there is no principled distinction to be made between the two approaches, and the courts permit decisions to forgo life-sustaining treatment but prohibit PAS, a violation of the equal protection clause of the Fourteenth Amendment may arise. The law may ban or permit both, but it cannot split the difference. This, in essence, is what the Federal Court of Appeals for the Second Circuit held in *Quill v. Vacco*.⁵²

Finally, this approach is important both within the Supreme Court and in the broader political arena. Within the framework of the Supreme Court, it is important for the sake of the rule of *stare decisis*. Many of those arguing in favor of PAS in the Supreme Court cases of 1997, *Glucksberg* and *Vacco*, warned the Court that upholding the existing prohibition against PAS in state laws would undermine important earlier precedents in both the abortion and the right-to-refuse

52. 80 F.3d 716 (2d. Cir. 1996). "The right to suicide finds no cognizable basis in the Constitution." *Id.* at 724-25.

treatment areas.⁵³ In particular, a ruling against PAS could not be reconciled with either *Casey* or *Cruzan*.⁵⁴ Naturally, those favoring the legal *status quo* were at pains to deny this, including an additional amicus brief on behalf of a group of bioethics professors.

For the liberal neutrality perspective to deny the moral force of the distinction between foregoing treatment and PAS or active euthanasia is also ironic. In the late 1970s and early 1980s, vitalists and others associated with the right-to-life movement opposed decisions to forgo life-sustaining treatment on two grounds. One reason was that this was no different from murder, or at least mercy killing.⁵⁵ The second was a slippery slope argument that there would be no way to stem the movement toward; (1) foregoing medically provided nutrition and hydration, (2) giving high doses of narcotics, and (3) allowing active, intentional killing of the patient.⁵⁶

In the American right-to-die debate we have come full circle. After two decades, foregoing treatment has gained legal, ethical, and medical legitimacy. The right-to-die movement has now turned its attention to active, intentional, medically assisted dying. Both PAS advocates and vitalistic right-to-lifers share a linear historical narrative; for the latter it is a downward spiral and for the former, an ascent toward moral progress and liberation. Now, as in the past, erasing the moral distinction between foregoing treatment and aid in dying is a mistake, with the linear view of history more problematic than it would first appear.

VI. IN SEARCH OF A LANGUAGE OF MORAL UNDERSTANDING

As an ethical and legal consensus emerged from *Quinlan* to *Cruzan*, with over 100 appellate level cases covering virtually every state in between, the distinction between foregoing treatment⁵⁷ and suicide or

53. See DWORKIN, *supra* note 33, at *3-5.

54. See *id.*

55. See Brief for the United States Catholic Conference et al. as Amicus Curiae Supporting Petitioner at *7, *Washington v. Glucksberg*, 521 U.S. 702 (1997) (No. 96-110).

56. See *id.* at *23-24.

57. See DWORKIN, *supra* note 33, at *11. For example, although *Cruzan* is often described as a "right to die" case, see *Compassion in Dying*, 79 F.3d. at 799; *Glucksburg*, 521 U.S. 702 (Stevens, J., concurring) (*Cruzan* recognized "the more specific interest in making decisions about how to confront an imminent death"), in fact, the more precise conclusion is that: "we assumed that

assisting suicide⁵⁸ was fundamental.⁵⁹ In the right-to-die cases, as in all civil rights cases that involve a state restriction on individual rights, the burden of proof lies with the state to show a compelling state or societal interest that justifies the restriction of liberty.

In analyzing cases involving patient or family requests to terminate life-sustaining treatment, various courts have asked if allowing treatment to be discontinued would violate any important state interests, including the state's interest in preventing suicide. The courts consistently held that suicide was not implicated in these cases and that this prevented no obstacle to the right to refuse treatment. This is a prime example earlier referred to as the discursive mimicry that relates ethics and the law.

This is a familiar pattern in bioethics: medical technologies create new possibilities for human choice and action, new kinds of decisions have to be made, and a new vocabulary must be devised with which to articulate what these actions are and what intentions and consequences they involve. Ordinary dictionary definitions are not helpful, and loose-limbed, casual talk about "wanting to die," the "right-to-die," and "passive and active euthanasia" must give way to more precise, if sometimes stilted and pedantic formulations.

Over time, those who were deliberate and careful in talking about foregoing treatment abandoned all language of suicide, choosing death, or intending that the patient die. They began to talk instead about the patient's right to be free of unduly burdensome and invasive

the Constitution granted competent persons a 'constitutionally protected right' to refuse lifesaving hydration and nutrition." *Id.* at 723; *Cruzan*, 497 U.S. at 279 (O'Connor, J., concurring) ("[A] liberty interest in refusing unwanted medical treatment may be inferred from our prior decisions.").

58. "That being the case, our decisions lead us to conclude that the asserted 'right' to assistance in committing suicide is not a fundamental liberty interest protected by the Due Process Clause." *Glucksberg*, 521 U.S. at 728.

59. "We assume that the United States Constitution would grant a competent person a constitutionally protected right to refuse lifesaving hydration and nutrition." *Cruzan*, 497 U.S. at 279. The American Medical Association emphasizes the "fundamental difference between refusing life-sustaining treatment and demanding a life-ending treatment." American Medical Association, Council on Ethical and Judicial Affairs, *Physician-Assisted Suicide*, 10 ISSUES IN LAW & MEDICINE 91, 93 (1994); see also Meisel, *supra* note 5, at 326-328; NATIONAL CENTER FOR STATE COURTS, GUIDELINES FOR STATE COURT DECISION MAKING IN LIFE-SUSTAINING MEDICAL TREATMENT CASES 54-71 (2d ed. 1992).

medical interventions, or the right not to have one's life prolonged by unwanted medical treatment. However, the proper focus is not on death, but on how one lives during the course of dying. It is not death that is being chosen, but a certain form of living. Therefore, the term "right-to-die" is a grave misnomer. In the foregoing treatment cases, the focus should not be about the right-to-die at all, but about the right to live in a certain way while dying. The PAS and active euthanasia arguments, on the other hand, are indeed about the right-to-die.

These distinctions mark something real in the experience of dying patients, their families, and in the reality of clinical care. Great caution must be exercised in order to give due recognition to the various expressions used for PAS. Thus, it seems both cavalier and uncharacteristically unsophisticated for Dworkin to assert that the relevant issue is to distinguish "acts and omissions that are designed to cause death and those that are not,"⁶⁰ and then to combine foregoing life-sustaining treatment and PAS under the heading of acts clearly designed to cause death.

In a similar vein, *The Philosophers' Brief* states that if and when it is permissible for [a doctor] to act with death in view, it does not matter which of . . . two means he and his patient choose. If it is permissible for a doctor deliberately to withdraw medical treatment in order to allow death to result from a natural process, then it is equally permissible for him to help his patient hasten his own death more actively, if that is the patient's express wish.⁶¹

We should be wary of assimilating the moral significance of foregoing treatment and PAS under headings "designed to cause death," or "with death in view," and then using that re-description of the acts to conclude that they are morally equivalent and that the law should treat them as being so.

This search for an appropriate ethical and legal idiom to use in talking about medical decision making near the end of life was not completed overnight, of course, and it has had its share of missteps and false starts. The campaign to legalize PAS continues at the level of state politics with the encouragement of the Supreme Court, which found no constitutional basis for a right to PAS, but also found no constitutional bar for creating a statutory right via a democratic legis-

60. DWORKIN, *supra* note 33, at 42.

61. *Id.* at 45.

lative process. In that campaign and in the forthcoming politics of PAS, we will see a concerted attempt to rewrite the lexicon of end-of-life bioethics. Advocates on both sides understand that what practices society eventually embraces will depend on how we describe what it is we seek to justify.

Among the dead ends that have come up during the search for the right vocabulary have been distinctions such as killing versus letting die, acts versus omissions, and active euthanasia versus passive euthanasia. There has also been a voluminous discussion about what causes the patient's death and about various kinds of intentions that patients and physicians might have, such as intending the patient's death versus merely foreseeing it.⁶²

Most of these discussions boil down to questions of causation. The act versus omission distinction, preposterous on its face when applied to something like terminal and intensive medical care, seems promising because common sense suggests that one cannot really cause something to happen by omitting to act. Therefore, one cannot be directly responsible for an outcome based on omission. The justification is doctors do not kill when they only stand aside and watch. Similarly, the killing versus letting die slogan seems attractive because the underlying disease process, not the act of foregoing life-sustaining treatment, is what really causes the patient's death.⁶³

The trouble with much of these arguments is that there are no such things as "omissions" in the care of the dying, and if there are, they fall under the heading of abuse and neglect, not foregoing treatment. Something, whether aggressive or palliative care, is always being done to, and for, a dying patient. So there are only actions here, actions of intervention and actions of non-intervention, but actions nonetheless. Any of these actions potentially bear moral and legal responsibility. No one human action is *the* cause of death. Human actions and biological processes are both involved in a person's dying and death, and thus, rather than discovering a single cause we find multiple causal

62. See DANIEL CALLAHAN, *THE TROUBLED DREAM OF LIFE* 76-82 (1993); F.M. Kamm, *Physician Assisted Suicide, The Doctrine of Double Effect, and the Ground of Value*, *ETHICS* 586, 586-591 (April 1999).

63. "[W]hen a patient refuses life-sustaining medical treatment, he dies from an underlying fatal disease or pathology; but if a patient ingests lethal medication prescribed by a physician, he is killed by that medication." *Vacco*, 521 U.S. at 801; see also *People v. Kevorkian*, 527 N.W.2d 714, 728 (1994), *cert. denied*, 514 U.S. 1083 (1995).

chains.

Some still cling to the hope that these causes can be fit into a pattern like deductive explanations in the natural sciences, and that an assignment of moral and legal responsibility can be inferred from that pattern of causal antecedence. On the contrary, these multiple causal chains should be fit together in a pattern that has the properties of a narrative rather than a scientific explanation. A narrative is an explanation or interpretation of meaning that assigns moral responsibility to human agents in varying degrees. In other words, we do not logically infer moral responsibility from causal explanations; instead, we construct causal accounts at least partly on the basis of pre-established moral sensibilities and interpretations.⁶⁴ Moral interpretation and assignment of responsibility precedes causal knowledge, not the other way around.

VII. THE INTEGRITY OF THE PERSON AND MORAL TRESPASS

Liberal neutrality offers one way in which to transform medical responses to dying and to the deliberate ending of a human life from a personal trouble into a civic problem. Yet, liberal neutrality may not offer the best way to frame end-of-life decisions as a civic problem. The blind spots in its perspective are too large, and the way it leaves us to articulate the life world and care of the dying is finally inadequate.

Like all work in ethics and the law, the frame of liberal neutrality is an abstraction, a figurative construction of moral reality that shapes the experience, and hence the nature, of that reality in particular ways. This is not a fault of liberal neutrality, because all theoretical frameworks (even realist, positivist, or naturalistic ones that purport not to be) are figurative constructions of reality. The problem with any theory lies with what it leaves out, erases, or obscures.

In the case of liberal neutrality, its conceptual framework obscures or erases the surrounding interpersonal context of the dying process. It flattens an otherwise multidimensional reality, substitutes abstractions like "power," "control," and "interests," for entangled relationships and intertwined feelings, memories, fears, hopes, regrets, and reconciliations that admit of no such tidy characterizations.

While this realm of thought resists capture in the individualistic language of liberalism, the experiences are neither incorrigibly idio-

64. See MARTHA NUSSBAUM, *LOVE'S KNOWLEDGE* 84 (1990).

syncratic nor wholly subjective. Without a shared culture and sustaining relationships, we could not feel at all. Yet, liberal neutrality internalizes everything that is most social, cultural, and inter-subjective about the experience of life; it treats all of this as cognitive “beliefs.”⁶⁵ This type of psychology is particularly debilitating when talking about life at the end of life. One wonders whether this account really sustains the notion of what it is to have a belief at all, or how a dying person could tell the difference between a momentous decision and a trivial one. Respecting autonomy gives private choice value only because beyond autonomy there is a public, subjective realm of shared meaning and mutual activity that gives each of us things of value to choose.⁶⁶

In short, liberal neutrality obscures crucial aspects of the human experience of dying and care-giving that other theoretical frameworks can better accommodate and articulate. Two new concepts are introduced in this section which illustrate how we can go beyond the language of liberal neutrality, “relational integrity of the person” and the need to protect dying persons from “moral trespass.”

Returning to the line of cases concerning the right to forgo life-sustaining treatment, over time two basic grounds for recognizing this right emerged. One approach is recognition of a constitutional right of the individual to control the most important aspects of her life and conduct.⁶⁷ In the aftermath of the Supreme Court rulings on contraception and abortion, initially this right was associated with the concept of privacy.⁶⁸ Later, especially in *Cruzan*, the Court referred to this right as a “liberty interest” located within the Fourteenth Amendment.⁶⁹ Bioethics emphasizes this same notion, calling it individual autonomy or the right to self-determination.

The second ground for the right to refuse treatment is a right that resides in the tradition of the common law as the right to be protected from non-consensual touching (battery) or unwanted bodily invasion.

65. IRIS MURDOCH, *THE SOVEREIGNTY OF GOOD* 17 (1959).

66. See WILLARD GAYLIN & BRUCE JENNINGS, *THE PERVERSION OF AUTONOMY* 228-246 (1996).

67. See DWORKIN, *supra* note 33, at *3-4.

68. See *id.*

69. See *id.* at *10-11, *but cf.* *Schmerber v. California*, 384 U.S. 757 (1966) (holding that extraction of blood from an individual suspected of driving while intoxicated does not violate the privilege against self-incrimination or other constitutional rights).

The development of the law of informed consent extends this common law protection to physicians and medical care settings. Throughout the period culminating in the *Cruzan* ruling, these two grounds were connected together in arguments favoring policies and practices, such as advance directives, to facilitate the patient's right to refuse treatment. The movement and arguments to legalize PAS, however, drove a wedge between the autonomy and the bodily integrity notions. This occurred because the autonomy notion seems to support the contention that there is no principled distinction drawn between foregoing treatment and PAS, while the bodily integrity notion clearly applies to foregoing treatment but not to PAS. For in the latter case, it is not medical treatment or technology that is violating bodily integrity, but the disease process itself.

In the many *amici* briefs filed in support of the respondents in the PAS cases, groups that for many years defended patient autonomy suddenly back-paddled with some vigor. Although he does not often use the term explicitly in this connection, Dworkin clearly allies himself with those in bioethics who ground the right to refuse treatment on autonomy. However, this issue must be handled with care by proponents of liberal neutrality because protecting and promoting individual autonomy is itself a substantive conception of the human good, or a philosophy of life.⁷⁰ If this is the case, liberal neutrality would have to exclude it from public morality and make it a matter of private belief. Then, it could hardly be said to be a constitutional principle or protected right governing state action at the end of life. Despite this potential complication, autonomy-based bioethics and the theory of liberal neutrality have joined forces in the PAS debate, at least in the philosophical wing of the field.

Why not ground the right to refuse treatment on the right to bodily integrity and leave it at that? Because, if autonomy tends to justify too much, bodily integrity justifies too little. For one thing, common law traditions can be superseded by democratic statutes and do not have the same significance as constitutional rights. In an aging society, it will probably be necessary to have closure on these rights at the constitutional level. This presents an interesting dilemma, however, where important questions of morality always develop into constitutional ones. Utilization of this approach gives undue power to the courts and

70. See JOSEPH RAZ, *THE MORALITY OF FREEDOM* 369-79 (1986).

bespeaks a lack of faith in democracy.⁷¹

Moreover, the concept of bodily integrity is too narrow and physically defined to capture all that we want to protect and preserve for the dying person.⁷² It invites distracting questions covering what medical procedures are really "invasive" and which are not, as seen in the case of artificial feeding tubes.⁷³

The proper approach should incorporate a metaphorical extension of the notion of bodily integrity, one that is more focused on the surrounding relationships, the ecology of dying, and not just with the boundary of the skin. Thus, it is not simply the physical integrity of the body that we should care about, but the integrity of the person as well. This approach recognizes both the physical confines of one's own body and the extended social space making up most of one's personhood and moral identity. This is always important, but never more so than near the end of life, when the scope of one's activities and active relationships focuses on family, intimate friends, and professional caregivers. For each person, the exact diameter of this social space will differ, however, it is this extended skin that exhibits certain qualities and characteristics.

A dying person has a right to a certain quality of living while dying: a right to a decent, competent, respectful, and nurturing social ecology. Among those things that undermine a good social ecology near the end of life are uncontrolled pain, incompetent caregivers, isolation or abandonment, intrusive medical technology, unwanted institutional settings, and physical invasion of the body. Anything that violates and undermines the social ecology of personhood and caring constitutes a moral trespass, and it is an appropriate task of bioethics, the law, and public policy to protect the individual. While not yet explored, this next section suggests that answers to these notions can be found in an undeveloped and unexplored thread of the *Quinlan* case.

VIII. *QUINLAN*: THE ROAD NOT TAKEN

When one goes back and rereads the text of the New Jersey Supreme Court decision in *Quinlan* utilizing the linear narrative approach, the textual argument becomes virtually incomprehensible.

71. See SUNSTEIN, *supra* note 50, at 1123.

72. See Dan Brock, *A Critique of Three Objections to Physician Assisted Suicide*, ETHICS 519, 526-31 (1999).

73. See *id.*

From the perspective of liberal neutrality, the opinion spends an inordinate amount of time on seemingly irrelevant issues; for example, the lengthy discussion on "a way to free physicians, in the pursuit of their healing vocation, from possible contamination by self-interest or self-protection concerns."⁷⁴ Furthermore, when the opinion mentions an "ethics committee,"⁷⁵ the panel appears to accept the belief that a medical prognosis committee could override the patient's autonomous choice to forgo life-sustaining treatment.⁷⁶ The opinion appears hopelessly inconsistent as it moves back and forth between what we would now call the principle of respect for persons and the principle of beneficence or best interests.⁷⁷ It does not have a notion of substituted judgment such that it is really Karen, the patient, who will make the decision through Mr. Quinlan; the court appears to think that the family must be trusted and Mr. Quinlan will make the ultimate decision.⁷⁸

Also implicit in *Quinlan* is a very different way of looking at the moral reality, the moral life world of the dying and care giving processes. Given this view, the lessons of *Quinlan* remain evolving and unsettled in law and bioethics. *Quinlan* supplied the line of reasoning about decisions near the end of life by supplying both respect for autonomy and respect for relational integrity in the terminology used by the New Jersey Supreme Court, namely the notion of "privacy."⁷⁹ Of these two views, only the autonomy side of privacy has been recognized and built upon in any systematic way by bioethics subsequent to *Quinlan*.

The other idea of privacy in *Quinlan* is the idea that the rights and fundamental interests of the dying are compromised when the moral space of the person and the physical space of the body is trespassed upon.⁸⁰ This idea is the road not yet taken.

74. 355 A.2d at 668.

75. *Id.*

76. *See id.* at 668-69. The court observed the statements of Dr. Karen Teel, who wrote that "[p]hysicians, by virtue of their responsibility for medical judgments are, partly by choice and partly by default, charged with the responsibility of making ethical judgments which we are sometimes ill-equipped to make. We are not always morally and legally authorized to make them." *Id.* at 668.

77. *See id.* at 663-664.

78. *See id.* at 653.

79. *See Quinlan*, 335 A.2d at 662-663.

80. *See id.* at 664.

The idea of privacy as personal integrity involves the notion that the human good requires a defense against moral trespass and protection of the security and integrity of one's person. Privacy as moral security is an ecological or relational notion, not a notion of independence of solitude often conveyed by the notions of privacy or property in other contexts, which involve cutting the self off from others behind protective fences. One reason why the idea of relational integrity did not emerge from the language of *Quinlan* is that the semantic register of the notion of the right to privacy was simply too powerfully individualistic.⁸¹

One of the motifs of *Quinlan* is the intrusive presence of machines at or near the bedside of the patient. Not only were these machines prolonging Karen's dying process, they interfered with the kind of caring, vigilant relationship that the family wished to have with her. This intrusive presence forms the fatal flaw in end-of-life care. The nursing routine and the functions of the intensive care unit were in service to the machine, not Karen, and they took precedence over the needs and proper performance of the family.⁸² While the staff expressed no ill will or malice towards Karen's condition,⁸³ the result was an ecological reality in the situation, a fact of the care giving and grieving experience. The court had no real way to express this paradigm, but recognized its existence and expressed a desire to acknowledge and ameliorate it.

The decision is also interesting for the absence of rhetoric of suspicion or questions of conflict of interest. The court's focus is almost personal and friendly toward the Quinlan family.⁸⁴ The court quickly dispatched such notions by establishing the character of both the guardian and the family. That seems odd in light of the main issues in later cases, but understandable as a means of grounding the decision in the quality of the relationships that might surround the patient if the medical interventions did not prevent those relationships. This made

81. Compare the continuing argument about abortion rights in which any entangling or encumbering relationships, to use Michael Sandel's apt phrase, such as parental notification, notification of the biological father, waiting periods for counseling, and the like, are strenuously opposed as violations of the woman's rights or autonomy, because it is said, there is no way from keeping these relationships from becoming coercive.

82. See Interview with Mrs. Joseph Quinlan (1995).

83. See *id.*

84. See *Quinlan*, 335 A.2d at 671.

the central issue not whether "Do I want to die?" nor even, "Do I want these machines?" but rather, "How do I want to be cared for?"⁸⁵

Another interesting aspect of the *Quinlan* decision is the serious attention the court pays to the teachings of the Quinlan family's religion, Roman Catholicism.⁸⁶ Karen's family relied heavily, and quoted extensively an *amicus* brief submitted by the New Jersey Catholic Conference.⁸⁷ After closely considering the implications of the Quinlans' religion, the court failed to establish that allowing the ventilator to be removed would not violate those religious beliefs.⁸⁸

A later attitude, and certainly the one offered by liberal neutrality, would be that the entire subject of religion is irrelevant to the court's business. The *Quinlan* court did not interpret this as a violation of the separation of church and state, nor did it focus on the danger of imposing some orthodox beliefs on Karen. In an uncanny configuration of liberal neutrality, Mr. Quinlan asserted his right to decide his daughter's medical treatment based on his right to exercise his religion, among other grounds.⁸⁹ The court rejected that argument, but channeled the religious question into his fitness as the guardian and how his faith would affect his relation to his daughter. Hence, the court took this question to be a vital factor in understanding the social and moral ecology of Karen's personhood, both before her brain injury and during her period of persistent vegetative state.

To be sure, the *Quinlan* court did not have the language, the metaphors, or the background in phenomenological social science to formulate the question in terms like "integrity of the person" or "moral trespass." There is no reason to think that the judges would have embraced such language if it had been suggested to them at the time. However, the concepts and intuitions that make for the most plausible and coherent reading of the court's decision require the language of social personhood and an ecology of care giving relationships to express the court's meaning. For example, near the legal heart of the text the court makes the following statement:

We think that the State's interest [in preserving life] weakens and the individual's right to privacy grows as

85. See Interview with Mrs. Joseph Quinlan, *supra* note 82. (1995).

86. See *Quinlan*, 335 A.2d at 658-59.

87. See *id.*

88. See *id.* at 661-662.

89. See *id.* at 660-661.

the degree of bodily invasion increases and the prognosis dims. Ultimately there comes a point at which the individual's right overcomes the State interest. It is for that reason that we believe Karen's choice [to turn off the respirator], if she were competent to make it, would be vindicated.⁹⁰

The first thing to notice about this formulation is that privacy is distinct from autonomy. Karen's wishes do not drive the decision, the right to privacy does. It is because the court recognized Karen's wishes coincided with what the right to privacy requires, thus vindicating her wish to terminate the extraordinary treatment.⁹¹

The second point to notice is that the constitutional evaluation of this situation is two-pronged: it involves medical prognosis and the "degree of bodily invasion." However, interpreting the notion of bodily invasion narrowly and physically, the position taken by the court is morally untenable. Assume there are two patients, each of whom has a grave medical prognosis and is imminently dying. Holding that variable constant, the court essentially says that patient A has a greater privacy right in refusing major surgery (which is very invasive) than patient B has in refusing intravenous fluids (which are minimally invasive). Surely this cannot be correct. If there is no reasonable medical purpose served by an intervention, both patients have an equally strong right to refuse it regardless of how invasive. Surely the state has no greater interest in protecting the rights of one of these patients than it has in the rights of the other.

This objection is avoided, or at least alleviated, by employing the principle of interpretive charity and reading the concept of "bodily integrity" in a broader and more social way. Then it can be said patients with equally grim prognoses may have different rights to the extent that a proposed medical treatment or some other intervention substantially affects their surrounding relationships and care giving. Under this reasoning, the patient has a right to refuse entry to whatever would trespass on that relational and care giving space, without the state having an interest in sustaining that right.

If medical services do not disrupt the relational integrity surrounding the person, and if there is a very low degree invasion of (social) bodily integrity, then it may be that the patient has a weaker right to

90. *Quinlan*, 335 A.2d at 664.

91. *See id.* at 665.

resist the intrusion of that service or procedure. For that entity is not an invader or a trespasser; it is just passing through. Examples of such entities might be some administrative or organizational rules of the facility that are designed for safety, efficiency, interests of other residents, or periodic visits by supervisors or state inspectors in home care settings. In these particular cases it may be hard to draw the line between a trespasser and a benign visitor, but that is the relevant question. In sum, those things that break the patient's moral community of caring, witness, and vigil can be much worse than things that break the patient's skin.

Another peculiar thing about *Quinlan* is the way it moves back and forth between considerations that have to do with Karen's autonomy.⁹² The court moved from the question of what Karen would want and whether this accords with what her father was proposing to do towards considerations of a seemingly more categorical and objective nature.⁹³

In the moral universe constructed by that text, respecting an individual's rights was not set in opposition to promoting the individual's good, and honoring human dignity was not simply a matter of doing whatever the patient wants or would have wanted. Honoring the integrity of the person means that certain things, under certain circumstances, ought not be thrust upon someone. In this case, it means that medical technology, such as a ventilator, should not be used on a person for whom it provides no substantive benefit — someone whose human good or flourishing it does not promote, for example, someone in a permanent unconscious state such as Karen Ann Quinlan. To impose a treatment that promotes no flourishing extension of life is a wrongful imposition, a violation of boundaries, a breaching of the zone around a person's body that breaks the moral skin, so to speak. It compromises something that should remain intact, that ought to have its integrity preserved. To initiate or continue life-sustaining medical treatment that imposes and compromises integrity in this way is to violate privacy. This is wrong not because there is an autonomous right-to-die, but because it is the proper approach to keep one's moral skin intact until the very end.

92. *See id.* at 662-663.

93. *See id.*

IX. CONCLUSION: TALKING A NEW TALK, AND WALKING THE RAZOR'S EDGE

Privacy's prohibition of moral trespassing is neither subjective nor procedural; it is not about a patient's preferences or desires, and it is not about who has the power and authority to make the decision. It is about what is right and what is wrong in terms of the human good and the patient's flourishing human body. For Karen Ann Quinlan, the time when the ventilator could promote her human flourishing, sadly, had passed.⁹⁴ Of course, that had to be confirmed, and thus the topic of medical prognosis loomed large in the case.⁹⁵ But once medical tests determined impending death, continued medical life-support became a trespass, a violation. The wrongness of this trespass has little or nothing to do with what Karen (or any patient) thought or said before her accident. The moral goal is not primarily to act in accordance with the patient's wishes or values. Rather, the moral goal is to protect the person who exists (even without consciousness) as an embodied self still entangled in relationships of care and memory.

Privacy understood as personal autonomy stands in sharp contrast to the notion of privacy as protecting moral boundaries against trespass. For autonomy, the questions are about the patient's prior beliefs and values, and whether those wishes have been recorded in advance directives, not about what medicine can really do and what furthers the human good. For privacy as protection against moral trespass, some care-giving relationships are respectful, sustaining meaning and integrity, while some do not. It matters less who makes the decision if the decision is a morally proper one. With autonomy, it always must be the patient's own voice, either directly or indirectly heard, that matters. What that voice says doesn't matter — whether it is Mrs. Helga Wanglie's voice saying, "Keep me alive," or that of Paul Brophy, Nancy Jobes, or Nancy Beth Cruzan saying, "Remove me from these unwanted treatments," — as long as it is the voice of the patient and no other.

Autonomy has no body, only mind, and it is mind with no surrounding moral and social space filled with relationships that can be either distorted or undermined by medicine. It was this on which the Quinlan family focused, filling moral/social space with their ongoing

94. *See id.* at 656.

95. *See id.* at 656-657.

relationship with their daughter, not on the isolated will, hypothetically reconstructed, of their daughter. It would be a mistake to say that the court only focused on that dimension of the case, but it would be equally wrong to say that it focused, like later courts, solely on the patient's autonomy. It focused on both, or did not see the difference or possess the appropriate language to express the difference.

In any case, one gets the feeling that the *Quinlan* court sensed, as some later courts and ethicists have seen, that it was in that relational space where Karen, severely diminished though she was, still resided as a moral entity. That relational space was worthy of protection, even at the price of shortening Karen's life, because it was constitutive of Karen's human good.

Americans today are divided by two competing moral images of the dying. One image is drawn from our great tradition of liberalism and civil rights. It is the image of the autonomous individual (or her surrogate) wielding fundamental moral and legal rights against the coercive, paternalistic, and restrictive power of the state. The other image is drawn from more domestic sources in our moral imaginations, what we might call, paraphrasing Michael Oakeshott, the voice of caring in the conversation of mankind.⁹⁶ This is the image of protecting the integrity of the dying person and the surrounding care giving community against moral trespass and disruption. Medical technology, its discourse and its organizational requirements, have tremendous power to invade, colonize, and distort the life world of a caring community. And so do government policies motivated by ideology or by financial and market goals.

It is not yet clear which of these images will ultimately prevail. Is medical care at the end of life fundamentally—and morally—about power and the struggle for control between the dying person and the state? Or is it fundamentally about organizing our care giving and support systems in such a way that our mortality will be accepted and that the quality of the last chapter of our lives will be humane, respectful, and dignified? To die well is to be loved, comforted, mourned, missed, and remembered. This is not a private conception of the good from which we need liberal neutrality to protect us. It is a tenet of public reason and moral sense.

96. See Michael Oakeshott, *The Voice of Poetry in the Conversation of Mankind in Rationalism* in *POLITICS AND OTHER ESSAYS* 488-541 (1991).