Notre Dame Law Review

Volume 72 | Issue 1 Article 4

6-1-1999

Sophie's Choices: Medical and Legal Responses to Suffering

Lois Shepherd

Sophie's Choices: Medical and Legal Responses to Suffering

*Lois Shepherd**

I. INTRODUCTION

In William Styron's novel *Sophie's Choice*,[1] Sophie Biegański Zawistowska enters Auschwitz-Birkenau in 1943 and is given the choice of saving only one of her two children; the other will be sent to the gas chamber. The medical doctor in charge of selection requires her to make a decision: Should she sacrifice her firstborn son, Jan, or his younger sister, Eva? She is given no time to think. Readers participate in her distress and the impossibility of her situation. Either choice will result in the death of one of her children. She selects Eva for the chamber.

In this Article I argue that Sophie made the wrong choice.[2] Rather than choose one of her children over the other, Sophie could have rejected such a choice altogether.[3] I argue further that some trends in medicine and law concerning suffering are creating situations in which we might be making the wrong choices, or, as was the case with Sophie, in which we are accepting the power to make choices that we could refuse to make. We have the capacity and are morally compelled to resist such trends.

American society, through its law, is showing a willingness to adopt, without due reflection, medical responses to suffering,[4] and to incorporate the medical solution to suffering into our ethical and legal norms to the exclusion of other approaches. The medical response to suffering is to alleviate individual instances of suffering through medical technology with insufficient regard for the costs this approach may have to other things of value, things valued by the individual patient or by us as a community.

Under the developing ethic of this medical culture I would posit that the phrase "needless suffering," which may once have referred to suffering that could be avoided (as compared to suffering which could not), has

---

* Assistant Professor of Law, Florida State University. B.A. University of North Carolina 1984; J.D. Yale Law School 1987. Research for this article was supported by a grant from Florida State University.

My thanks go to April Cherry, Larry George, Adam Hirsch, Tim Schardl, Jean Sternlight, and especially Paul Shepherd for many helpful criticisms and suggestions. I also owe a great deal of thanks to Jolene Kinney, who assisted in my research with great dedication and enthusiasm. Finally, I thank my parents, Carolyn and Jason Lineberger, for their lifelong support of my efforts.

1 WILLIAM STYRON, SOPHIE'S CHOICE (1979).

2 *See infra* notes 237-42 and accompanying text.

3 As readers of *Sophie's Choice*, we, unlike Sophie, have the time, hindsight, and detachment to make this assessment. The point is not to condemn the character Sophie, but to use her situation to better understand the implications of such choices.

4 I use the term "suffering" rather than "pain" in this article because it is not merely physical "hurting" that we seek to avoid, but also the loss of self-control and dignity that may occur even in the absence of physical pain and that often occurs *as a result of* medication to relieve pain.

come to mean all suffering; suffering *is* needless. In many situations this is certainly true. Often suffering is readily apparent, the technology is available to relieve the suffering, and the use of that technology does not impinge upon other individual or community values.

Yet situations remain where medicine cannot provide a cure or effective palliative care. In these situations, what does the notion that "suffering is needless" mean?[5] Medical diagnosis can often now predict if suffering will occur and to what degree. Using this information, medical professionals can then employ medical technology to avoid or eliminate the suffering by avoiding or eliminating the life of the one who suffers. This, in a number of instances, is the "best" that medicine can now offer us with respect to a number of conditions. For example, through amniocentesis, medical professionals can detect a fetus with a fatal or particularly vicious genetic disease (such as Tay-Sachs[6]) and then abort the fetus (a medical procedure). Likewise, the cancer patient can be diagnosed as terminal[7] within six months or so and then (if legally permitted[8]) seek a prescription of lethal drugs and "die with dignity," as doctors consider taking on an expanded role in the process of dying.

We should perhaps expect nothing different from the medical profession. Relief of suffering is a noble pursuit and an essential part of the profession's calling.[9] The problem is our apparent willingness to concede to the medical approach without considering what may be lost if that approach is given unchallenged primacy. The existence of other approaches from other areas of our society, such as law or public opinion, would tem-

---

5 This use of the phrase "needless suffering" or "unnecessary suffering" can be seen in *Lee v. Oregon*, 891 F. Supp. 1429 (D. Or. 1995), challenging the constitutionality of Oregon's Death with Dignity Act, which permits physicians to assist terminally ill patients in dying. In that case the state listed as one of its interests in the Act "avoiding unnecessary pain and suffering." *Id.* at 1434. Because the pain and suffering could not (presumably) be alleviated through comfort care, social support, or other means, it was "unnecessary" only in the sense that it could be alleviated through termination of life. *See infra* notes 98-99 and accompanying text.

6 Within the first year of life children with Tay-Sachs disease, who at birth appear "normal," "begin to regress and lose contact with their families and environment . . . declining inexorably toward a totally vegetative state." Madeleine J. Goodman & Lenn E. Goodman, *The Overselling of Genetic Anxiety*, HASTINGS CTR. REP., October, 1982, at 20. "[M]ental retardation, . . . convulsions, . . . blindness, . . . gross physical deformit[ies]," and "considerable pain" characterize the remainder of the child's life. Curlender v. Bio-Science Lab., 165 Cal. Rptr. 477, 480-81 (Ct. App. 1980). The life span of children with Tay-Sachs is two to four years. Goodman & Goodman, *supra*; *see also* William G. Johnson, *Lysosomal Diseases and Other Storage Diseases*, *in* MERRITT'S TEXTBOOK OF NEUROLOGY 547, 550-51 (Lewis P. Rowland ed., 9th ed. 1995).

7 It should be noted that determining a patient's prognosis is "fraught with difficulties and uncertainties," as evidenced by the fact that physicians commonly refer patients to hospice when they have only one month to live, rather than the six months that the hospice permits. Ann Alpers & Bernard Lo, *Physician-Assisted Suicide in Oregon: A Bold Experiment*, 274 JAMA 483, 484 (1995) (citations omitted); *see also* DAVID CUNDIFF, EUTHANASIA IS NOT THE ANSWER: A HOSPICE PHYSICIAN'S VIEW 62 (1992). Cundiff argues that determining a patient's diagnosis and prognosis is often difficult:

> Currently, for a cancer patient to elect the Medicare hospice benefit, two physicians must certify a prognosis of less than six months. A significant proportion of the patients who elect the Medicare hospice benefit outlive that prediction.
>
> Predicting how long someone may live with cancer is very difficult at best.

Id.

8 *See infra* notes 90-117 and accompanying text.

9 *See* Martin S. Pernick, *The Calculus of Suffering in Nineteenth-Century Suffering*, HASTINGS CTR. REP., Apr. 1983, at 26.

per the effect of a purely medical response to suffering. However, such approaches appear to be losing their ground, particularly in situations at the edges of life.[10] With respect to birth, we see attempts (and some successes) to fashion a right not to be born where severe genetic anomalies may be detected in a fetus. At the end of life, we see attempts (and again some successes) to assert a right to die. In such instances the basis of the rights espoused is the principle that people should not be required to suffer when the means are available to end or altogether avoid such suffering, even if such means are ending the life or avoiding the life of the one who will suffer.

One purpose of this Article is to demonstrate that unprecedented claims to rights based on the avoidance of suffering are being made and recognized in courts and legislatures. The basis of such appeals is a belief that the suffering imposed by nature need not be tolerated and that such suffering instills in the suffering individual a right to relief.[11] Suffering thus becomes a sufficient condition for a right. There need be no tortfeasor nor any societally-caused harm, nor any inequality for a suffering individual (or such individual's advocate) to claim relief. Oftentimes the claim is not specifically articulated as having its basis in the right to avoid suffering, and indeed the claim may masquerade as something else, such as the claim to autonomy made by advocates of physician-assisted suicide.[12]

Why do we see this trend and what are its implications? I believe the combination of two developments explains the emergence of claims to rights based in suffering: first, our increasing acceptance and *expectation* of technology-based solutions to human problems, and second, the development of a collective conscience—a community empathy for other individuals—in matters of personal well-being.

The implications are potentially far-reaching. Although the alleviation of suffering has been for some time an aspiration in human rights pronouncements,[13] in the United States our jurisprudence has given little def-

10 Ronald Dworkin uses this phrase in his discussion of abortion and euthanasia in his recent book, *Life's Dominion.* RONALD DWORKIN, LIFE'S DOMINION (1993).

11 The developing right to avoid suffering is best understood as a Hohfeldian "claim-right," Wesley N. Hohfeld, *Fundamental Legal Conceptions as Applied in Judicial Reasoning*, 23 YALE L.J. 16, 36-38 (1913), which may indicate a duty on behalf of others to either "let P do X" in the sense of a purely negative duty, or to "do what one can to make it possible for P to do X." Jeremy Waldron, *Introduction, in* THEORIES OF RIGHTS 6 (Jeremy Waldron ed., 1984). According to my thesis, the right to avoid suffering is not merely a right to be let alone and instead entails duties of affirmative action on the part of others; the stronger the right becomes, the more the corresponding duties will require affirmative action. Thus, the right not to be born, *see infra* notes 22-72 and accompanying text, requires that physicians predict and evaluate the risk and degree of suffering of children yet to be born and requires that prospective parents act on that information to avoid the suffering of children. The right to die, *see infra* notes 73-131 and accompanying text, requires that physicians assess the degree of suffering that a patient is experiencing or will experience and prescribe the relief sought if that suffering is adequately severe. *See* Bouvia v. Superior Court, 225 Cal. Rptr. 297 (Ct. App. 1986), discussed *infra* notes 118-27 and accompanying text. Although the right to physician-assisted suicide may not require physicians to give patients a lethal prescription of drugs, the right *does* require that the state alter its traditional understanding of the medical profession to permit physicians to perform such services.

12 *See infra* notes 90-117 and accompanying text.

13 *See* Thomas D. Jones, *A Human Rights Tragedy: The Cuban and Haitian Refugee Crises Revisited*, 9 GEO IMMIGR. L.J. 479, 484-85 (1995) (asserting that "[u]pholding universal human rights promotes the common good of mankind. By championing the human rights of refugees to 'seek

erence to such appeals.[14] One recent court of appeals decision reads, "[c]ompassion cannot be the compass of a federal judge. That compass is the Constitution of the United States."[15] The bulwarks of individual rights under the Constitution are generally rights to freedom from the interference of others (liberty) and rights to equal treatment (equality). In medical ethics, these principles translate into autonomy and the Kantian notion of equal respect for persons. Both of these are potentially threatened by rights based in suffering. Recognizing these rights requires that we make decisions about other people's suffering, their quality of life, and therefore their value in living. Once we decide that the suffering is sufficiently severe and the quality of life substantially diminished, then we are justified in treating the individual sufferer differently; we are justified in making decisions that erode autonomy and equality in the name of providing required relief from suffering.

We must be concerned that we will create our own Sophie's choices where they do not now exist, that we will perceive ourselves as being in situations in which medical ethics compel us to choose between one human life and another, *when we are fundamentally entitled to refuse to recognize and make such choices.* Thus, like Sophie, we will make the wrong choice in allowing societal dictum (as she allowed the doctor in charge of selection at Auschwitz-Birkenau) to compel us to choose one human life over another.

Indeed, the recent opinion of the Council on Ethical and Judicial Affairs of the American Medical Association regarding the use of anencephalic infants as organ donors is indicative of developments on the horizon.[16] Anencephalic infants are born with a functioning brain stem, and therefore do not meet our current standards for determining that death has occurred, but they permanently lack all cognitive function because the rest of the brain has failed to develop.[17] Currently anencephalic infants cannot be used as organ donors because we insist that donors be dead prior to the removal of vital organs.[18] The Council Report proposes an exception to this rule, and while the proposal has been "temporarily suspended" in order to allow time for more research into the condition of anencephaly,[19] its fundamental willingness to choose the life of one per-

---

and enjoy' asylum, we 'alleviate [their] suffering' and reinforce[ ] this nation's own cohesion, its moral purpose and its appreciation of its own domestic liberties." (quoting Jerome Shestack, *An Unsteady Focus: The Vulnerabilities of the Reagan Administration's Human Rights Policy*, 2 HARV. HUM. RTS. Y.B. 25, 49-50 (1989))); Michael J. Mattler, Note, *The Distinction Between Civil Wars and International Wars and its Legal Implications*, 26 N.Y.U. J. INT'L L. & POL. 655, 658 (1994) (asserting that "actors such as the United Nations High Commissioner for Refugees and the United Nations High Commissioner for Human Rights have emerged in response to the international community's desire to alleviate all forms of human suffering, regardless of their sources").

14 *See infra* note 225 and accompanying text.

15 Compassion in Dying v. Washington, 49 F.3d 586, 594 (9th Cir. 1995) (Noonan, J.) (holding Washington ban on physician-assisted suicide does not deprive persons of constitutionally protected liberty interest), *rev'd en banc*, 79 F.3d 790 (9th Cir.), *cert. granted sub nom.* Washington v. Glucksberg, 65 U.S.L.W. 3085 (U.S. Oct. 1, 1996). *See infra* notes 101-17 and accompanying text.

16 Council on Ethical and Judicial Affairs, American Medical Association, *The Use of Anencephalic Neonates as Organ Donors*, 273 JAMA 1614 (1995) [hereinafter Council Report].

17 *Id.* at 1615. *See infra* notes 252-78 and accompanying text.

18 *See* UNIF. ANATOMICAL GIFT ACT (1987) §§ 1-3, 8A U.L.A. 29 (1993) (stating that an anatomical gift takes effect upon or after death).

19 *See infra* note 260 and accompanying text.

son[20] over another has not been retracted. The proposal evidences our increasing willingness to seek medical solutions to the difficult issues of life ethics and our readiness to ascribe rights based on relief or avoidance of suffering. The direction the Council Report points, I will argue, is toward Sophie's Choices of our own making.[21]

In Section II of this Article I will explore the emergence of rights based upon the principle that individuals should not be allowed to suffer when the means are available to end or avoid altogether their suffering. This development is explored at both edges of life: in the practices and legal environment of genetic screening to prevent the births of children with genetic anomalies (the right not to be born), and in the debate over decisions to end the life of a person in ill health, either through physician-assisted suicide or the withdrawal of life-sustaining treatment (the right to die). In Section III, I discuss the reasons for this development. In Section IV, I attempt to place the emergence of the principle of suffering-based rights in the context of other grounds for rights and discuss the broader implications of our recognition of suffering-based rights.

II. Rights Based in Suffering

A. The Right Not to Be Born

There is a growing view that some lives are not worth living at all; that for some people, it may be better never to have been born than to have been born with the genetic legacy assigned them by nature.[22] Because most genetic traits considered disorders or diseases are not currently treatable, the very purpose of most prenatal testing is to determine whether the prospective mother should abort a fetus.[23] If, because of the negligence of medical care providers, a pregnant woman is given an inadequate opportunity to abort the fetus with detectable genetic anomalies, the parents of the child may pursue a wrongful birth claim against the providers. Further, in some jurisdictions, the child herself may have a wrongful life claim against the same defendants. As discussed more fully below, in both the wrongful birth and wrongful life suits the plaintiffs must prove that had the prospective mother been aware of the potential disabilities of the child, she would have chosen to abort the fetus. The essence of the child's claim in wrongful life suits is that the child would have been better off had she not been born; her suffering in life is worse than no life at all.[24]

---

20 *See infra* note 271 (discussing whether the infant with anencephaly is a person).

21 *Cf.* Guido Calabresi & Phillip Bobbitt, Tragic Choices (1978) (discussing the approaches we use to allocate tragically scarce resources).

22 *See* Lois Shepherd, *Protecting Parents' Freedom to Have Children with Genetic Differences*, 1995 U. Ill. L. Rev. 761, 769-84 (1995).

23 *See, e.g.*, Gildiner v. Thomas Jefferson Univ. Hosp., 451 F. Supp. 692, 695 (E.D. Pa. 1978) ("The value of genetic testing programs . . . is based on the opportunity of parents to abort afflicted fetuses, within appropriate time limitations.").

24 In *Gleitman v. Cosgrove*, one of the first cases addressing wrongful life and wrongful birth torts (rejecting both), Chief Justice Weintraub, in concurring on the issue that the child did not present a claim upon which relief could be granted, stated:

> Ultimately, the infant's complaint is that he would be better off not to have been born . . . . We must remember that the choice is not between being born with health or

Can the wrongful life suit, to the extent it is recognized, be brought by the child against the parent(s)? If third parties can be found liable under wrongful life suits for negligence, can parents' prenatal choices also be considered negligent? Consistent with the child's right against negligent third parties is the potential legal claim the child may have against the mother who chose not to abort. Again, the child's claim is that the extent of her suffering in life, as predicted by prenatal testing or other means, is worse than never having been born. Instead of designating a third party medical provider as the tortfeasor, however, the mother's failure to obtain an abortion when one was legally available to her is the proximate cause of the child's life of suffering.[25] The recognition of such a claim has been rejected in at least one case[26] and also by state statute.[27] As discussed later in this Section, however, the possibility of legal recognition of such a claim is neither fanciful nor without its supporters.[28] Even absent legal recognition of such a claim against the mother, prospective parents face growing medical, economic, and moral pressure to avoid the births of such children, primarily because of the extent of suffering that birth will entail. Prospective parents may feel an ethical or moral duty not to continue such pregnancies, to follow the medically indicated and prescribed solution rather than rely upon their own autonomous ethical and moral capacities. The emerging notion that a child has a right to be born healthy—a right essentially based in suffering—requires parents to adopt a medical response to predicted suffering which excludes other equally caring responses.

1. Wrongful Life Claims against Third-Party Tortfeasors

When a medical care provider fails to inform a pregnant woman of a prenatal test appropriate for her condition (be it age or family history of a

---

being born without it; it is not claimed that the defendants failed to do something to prevent or reduce the ravages of rubella. Rather the choice is between a worldly existence and none at all.

227 A.2d 689, 711 (N.J. 1967) (Weintraub, J., concurring). *Gleitman* was overruled on the issue of wrongful birth in *Berman v. Allan*, 404 A.2d 8, 14 (N.J. 1979).

25 *See* Margery W. Shaw, *Conditional Prospective Rights of the Fetus*, 5 J. LEGAL MED. 63, 110-11 (1984) (suggesting that, unlike physicians, parents *do* cause a child's impairments when they knowingly pass along deleterious genes or when the mother fails to abort knowing of fetal impairments).

26 Elliott v. Brown, 361 So. 2d 546, 548 (Ala. 1978) (refusing to recognize wrongful life cause of action against a physician partly out of fear that allowing such action would mean women could be found liable for proceeding with pregnancy knowledgeable of probable fetal impairments).

27 *See* CAL. CIV. CODE § 43.6(a) (West 1982) (explicitly granting parents immunity from suits by children based upon claim that the child "should not have been conceived or, if conceived, should not have been allowed to have been born alive").

28 *See infra* notes 68-70 and accompanying text; *see also* John A. Robertson, *Procreative Liberty and the Control of Conception, Pregnancy, and Childbirth*, 69 VA. L. REV. 405, 437-38 (1983) (arguing that once a woman has exercised her right to procreate by conceiving, and "waived her right not to procreate by failing to abort the fetus prior to viability . . . . she assumes obligations to the fetus that limit her freedom over her body"; a woman who has failed to abort a nonviable fetus then has a "legal and moral duty to bring the child into the world as healthy as is reasonably possible"); Shaw, *supra* note 25, at 93 (supporting the recognition of a legal duty on the part of parents "not to conceive under certain circumstances," and arguing on behalf of a child's right to "allege that his or her parents had the duty not to conceive at all," and must therefore be held legally responsible to the child "for causing misery, pain, suffering, and death if it could have been avoided").

particular disorder),[29] or fails to diagnose the hereditary ailment of another sibling in order for the parents to avoid conception,[30] or simply makes a mistake in interpreting or communicating the results of carrier screening or prenatal tests,[31] prospective parents do not have the information necessary to make a decision whether to conceive or, if conception has already taken place, whether to abort. As a result, a number of jurisdictions recognize the resulting parents' cause of action for *wrongful birth.*[32] Without the recognition of wrongful birth suits, the law might provide no deterrent to the negligence of medical care providers in carrier screening, prenatal testing and counseling regarding such matters.[33]

While the wrongful birth suit provides recovery for the parents' injury,[34] it does not address the suffering of the child.[35] The *wrongful life* suit is brought by the child against the health care providers who negligently took away from the child's mother the opportunity to abort by failing adequately to advise about or competently to perform indicated carrier screening or prenatal testing. At least three jurisdictions have recognized the

29 *See, e.g.*, Becker v. Schwartz, 386 N.E.2d 807 (N.Y. 1978) (plaintiffs allege that the defendants never advised them of increased risk of Down's Syndrome in children born to women over 35 years of age or of availability of amniocentesis test).

30 *See, e.g.*, Turpin v. Sortini, 643 P.2d 954 (Cal. 1982) (permitting wrongful birth and wrongful life suits where doctors failed to diagnose the hereditary deafness of the child's sister).

31 *See, e.g.*, Curlender v. Bio-Science Lab., 165 Cal. Rptr. 477 (Ct. App. 1980) (alleging that parents were given "incorrect and inaccurate" information concerning test results for carrier status for Tay-Sachs disease).

32 Wrongful birth suits are now widely recognized. *See generally* Lori B. Andrews, *Torts and the Double Helix: Malpractice Liability for Failure to Warn of Genetic Risks*, 29 HOUS. L. REV. 149 (1992); Gregory G. Sarno, Annotation, *Tort Liability for Wrongfully Causing One to Be Born*, 83 A.L.R.3d 15 (1978). *But see* Atlanta Obstetrics & Gynecology Group v. Abelson, 398 S.E.2d 557, 560 (Ga. 1990) (refusing to recognize "wrongful birth" actions in Georgia absent clear mandate for such recognition from legislature).

33 Gildiner v. Thomas Jefferson Univ. Hosp., 451 F. Supp. 692, 696 (E.D. Pa. 1978) ("The recognition of a cause of action for negligence in the performance of genetic testing would encourage the accurate performance of such testing by penalizing physicians who fail to observe customary standards of good medical practice."); Berman v. Allan, 404 A.2d 8, 14 (N.J. 1979) (ruling otherwise "would in effect immunize from liability those in the medical field providing inadequate guidance").

34 In wrongful birth suits, the permissible award of damages varies. Some jurisdictions permit recovery of the extraordinary expenses necessary to raise the child, *see, e.g.*, Siemieniec v. Lutheran Gen. Hosp., 512 N.E.2d 691 (Ill. 1987), some permit recovery for only emotional distress damages to the parents, *see, e.g.*, Berman v. Allan, 404 A.2d 8, 14 (N.J. 1979), and some jurisdictions permit recovery of both, *see, e.g.*, Harbeson v. Parke Davis, Inc., 656 P.2d 483, 493 (Wash. 1983).

35 While recovery under the parents' cause of action may provide the additional resources necessary to care for the child with a disabling condition that could have been detected and avoided (through abortion), damages awarded will generally only cover the life of the child to its majority. At this time the parents may under state law no longer be responsible for providing care for the child. Disability may extend the parents' responsibility for their children's needs beyond minority, but the prediction of such continued disability and its degree of severity must be made years earlier at the time of the parents' wrongful birth suit. The Supreme Court of California explained that, under state law, "the parents' ability to recover those medical expenses which are reasonably likely to be incurred after the age of majority may depend on whether—at the time of trial—it can be determined if the child will be able to 'maintain himself by work' on reaching adulthood." *Turpin*, 643 P.2d at 965 n.12. Furthermore, absent recognition of wrongful life actions, "the afflicted child's receipt of necessary medical expenses might well depend on the wholly fortuitous circumstance of whether the parents are available to sue and recover such damages." *Id.* at 965.

wrongful life cause of action.[36] Many more have denied its availability to persons born with disabilities that could have been detected *in utero* because of the philosophical implications of such a cause of action.[37] In denying wrongful life suits, courts have cited problems with two primary issues, those of injury and damages.

On the issue of injury, the child must allege that had the health care provider not been negligent, her mother, or parents, would have received adequate information to make a decision regarding abortion, and would have aborted. Thus, the child's injury is in being born, not in being born with disabilities.[38] Because no life was possible without such disabilities, the traits from which the child now suffers were unavoidable, unless avoided by avoiding birth itself. To conclude that the plaintiff child had suffered an injury cognizable in tort, the factfinder would have to compare the relative benefits of nonexistence to a life with disabilities, a task courts have labelled "impossible,"[39] involving "a mystery more properly to be left to the philosophers and the theologians,"[40] and "hing[ing] upon subjective and intensely personal notions as to the intangible value of life."[41]

The question of damages is no less troubling. The compensatory measure of damages required by tort actions would theoretically require a determination of the value of life with disabilities versus the value of no life at all. Many courts have refused to make such calculations of injury and the resulting valuations of life with and without disabilities and thus have denied the availability of wrongful life suits to child plaintiffs.[42]

But other courts have not been so troubled and have permitted actions based upon the allegations of the child that she had a "right to be born as a whole, functional human being."[43] Such a right has its origins in early prenatal tort cases in which courts recognized a duty of care on behalf of third parties toward the fetus who would later be born with an injury caused by negligent conduct prior to birth. While prenatal torts require

36 *See generally Turpin*, 643 P.2d 954; *Curlender*, 165 Cal. Rptr. 477; Procanik v. Cillo, 478 A.2d 755 (N.J. 1984); Harbeson v. Parke-Davis, Inc., 656 P.2d 483 (Wash. 1983), *aff'd*, 746 F.2d 517 (9th Cir. 1984). *But see* Anthony Jackson, *Action for Wrongful Life, Wrongful Pregnancy, and Wrongful Birth in the United States and England*, 17 LOY. L.A. INT'L & COMP. L.J. 535, 612-13 (1995) (arguing *against* recognition of wrongful birth actions and *for* recognition of wrongful life actions; the former suits are "highly denigrating to [the] child and to the handicapped population in general," whereas the latter allows compensation to the child whose suffering outweighs the benefits of life).

37 *See, e.g., Siemieniec*, 512 N.E.2d at 696-702 and cases cited therein; *see also* Lininger v. Eisenbaum, 764 P.2d 1202 (Colo. 1988); Smith v. Cote, 513 A.2d 341 (N.H. 1986); Elliot v. Brown, 361 So. 2d 546 (Ala. 1978).

38 *See, e.g.*, Gleitman v. Cosgrove, 227 A.2d 689, 692 (N.J. 1967).

39 Nelson v. Krusen, 678 S.W.2d 918, 925 (Tex. 1984); *Smith*, 513 A.2d at 352.

40 Becker v. Schwartz, 386 N.E.2d 807, 812 (N.Y. 1978).

41 *Smith*, 513 A.2d at 353.

42 *See, e.g., Elliott*, 361 So. 2d at 547 ("The infant plaintiff would have us measure the difference between his life with defects against the utter void of nonexistence, but it is impossible to make such a determination.") (quoting *Gleitman*, 227 A.2d at 692).

43 *See, e.g.*, Turpin v. Sortini, 643 P.2d 954, 956 (Cal. 1982) (child seeking damages for being "deprived of the fundamental right of a child to be born as a whole, functional human being without total deafness."). *See generally* Elizabeth Collins, *An Overview and Analysis: Prenatal Torts, Preconception Torts, Wrongful Life, Wrongful Death, and Wrongful Birth: Time for a New Framework*, 22 J. FAM. L. 677, 706-07 (1984) (advocating recognition of the "right . . . to be born a whole, functioning human being").

redress—for example, the child who suffers injury as a fetus during a car accident caused by a negligent driver—the language that has been used to justify recovery, the language of rights, lays the theoretical groundwork for rights based on the suffering of an individual that has not been caused by a tortfeasor. In the cases involving redress for torts suffered prenatally, courts have declared that children have a right to be born with sound mind and body.[44] What the courts were trying to justify was simply the child's right to have been free from harmful bodily interference from third parties while *in utero.* But the courts needed to avoid saying that *fetuses* had rights, since the injury complained of, and now suffered by the child born alive, may have occurred at a time and under conditions when the mother may have legally terminated the life of the fetus through abortion. In order to avoid saying that fetuses have rights to freedom from bodily interference, the courts used the more positive language of a right "to begin life with a sound mind and body,"[45] which vests in the child later born alive, not in the fetus at all. There are other ways courts might have gotten around this problem. For example, the tort might have been seen as committed against the mother,[46] as in a wrongful birth suit, and damages adequate to cover the child's extra life expenses stemming from the injury could have been awarded through the mother's cause of action. This seems especially reasonable in the case of negligent prenatal screening since it was the mother who engaged the services of the physician in prenatal care.

Instead of choosing this course, however, courts recognizing prenatal torts selected the dangerously expansive, positive language of rights to a sound mind and body. With this characterization, the prenatal tort appears based upon a right to have reasonably avoidable suffering avoided. The wrongful life suit is a form of that right. While attempting to deny

---

44 *See, e.g.*, Smith v. Brennan, 157 A.2d 497, 503 (N.J. 1960) (holding that infant child was entitled to recover for prenatal injury because "justice requires . . . that a child has a legal right to begin life with a sound mind and body"); Womack v. Buckhorn, 187 N.W.2d 218 (Mich. 1971) (holding that a child may recover for damages for harm caused by wrongful conduct that interferes with a child's "legal right to begin life with a sound mind and body") (quoting *Smith*, 157 A.2d at 503). For an example of the use of this language of rights to scrutinize prenatal conduct on the part of the pregnant woman, see *In re* Baby X, 293 N.W.2d 736, 739 (Mich. Ct. App. 1980) (In case involving prenatal maternal drug addiction, the court states that "[s]ince a child has a legal right to begin life with a sound mind and body . . . we believe it is within this best interest to examine *all prenatal conduct bearing on that right.*" (emphasis added)).

45 *See Smith*, 157 A.2d at 503. In *Womack v. Buckhorn*, the Michigan Supreme Court held that an eight year old child could sue for injuries suffered in an automobile accident when he was a four month old fetus:

> [A] child has a legal right to begin life with a sound mind and body. If the wrongful conduct of another interferes with that right, and it can be established by competent proof that there is a causal connection between the wrongful interference and the harm suffered by the child when born, damages for such harm should be recoverable by the child.

Womack v. Buckhorn, 187 N.W.2d at 219, 222 (Mich. 1971) (quoting *Smith*, 157 A.2d 497 at 503).

46 *See* Dawn E. Johnsen, Note, *The Creation of Fetal Rights: Conflicts with Women's Constitutional Rights to Liberty, Privacy, and Equal Protection*, 95 YALE L.J. 599, 611 (1986) ("In their attempt to protect pregnant women from violent criminal or tortious acts, . . . lawmakers should structure the laws so that they retain their focus on the primary subject of protection—the pregnant woman.").

this,[47] courts recognizing the wrongful life suit choose essentially to credit the plaintiffs' claims that their suffering is so grave as to exceed the benefits of life.[48] Because the suffering of many of these children could only have been avoided by avoiding their births, the "right to sound mind and body" becomes a "right not to be born," and we begin to look to parents to avoid the children's suffering through prenatal testing and abortion.

2. Restrictions on Parental Choices

The very purpose of prenatal testing at this stage in medical science is to permit pregnant women to abort fetuses with genetic anomalies.[49] This decision has generally been considered one for the mother to make without interference. Thus, early attempts by amniocentesis laboratories to make availability of the technology contingent upon the pregnant woman's agreement beforehand that she would abort the fetus if the suspected anomaly were detected, were criticized, and apparently abandoned.[50] Likewise, suggestions that health maintenance organizations may be currently engaging in similar coercive methods are met with disbelief and protest.[51] In the same vein, genetic counseling as a profession has long embraced ethics that encourage women, or parents jointly, to make their own decisions, and the genetic counselor to remain neutral.[52]

The appropriateness of neutrality in genetic counseling has, however, come under recent attack.[53] Also, genetic counseling may never have been neutral in practice, even though counselors not only subscribed to an ethic of neutrality but honestly sought to follow it.[54] One scholar, Barbara Katz Rothman, offers a number of examples of counselling interviews conducted by genetic counselors that reveal their biases toward abortion when the perceived genetic anomaly may be severe, and their biases in the other

47 Curlender v. Bio-Science Lab., 165 Cal. Rptr. 477, 489 (Ct. App. 1980) ("[W]e reject the notion that a 'wrongful-life' cause of action involves any attempted evaluation of a claimed right not to be born.").

48 Damages, however, have been limited by these courts to special damages, that amount necessary to cover the extraordinary expenses such children will face in their lifetime because of their disability. They refuse to grant general damages on the theory that to do so would involve a determination of the extent to which nonlife was preferable to the life of the child with disabilities. *See, e.g.*, Turpin v. Sortini, 643 P.2d 954 (Cal. 1982).

49 *See supra* text accompanying note 23. Arthur Caplan points out that California's mandate that physicians offer alpha-fetoprotein screening to all pregnant woman is done "in the hope that some of those who are found to have children with neural tube defects will choose not to bring them to term; thereby, preventing the state from having to bear the burden of their care." Arthur L. Caplan, *Neutrality is Not Morality: The Ethics of Genetic Counseling, in* PRESCRIBING OUR FUTURE: ETHICAL CHALLENGES IN GENETIC COUNSELING 149, 158-59 (Dianne M. Bartels et al. eds., 1993).

50 Mark I. Evans et al., *Prenatal Diagnosis of Chromosomal and Mendelian Disorders in* FETAL DIAGNOSIS AND THERAPY: SCIENCE, ETHICS AND THE LAW 41 (Mark I. Evans et al. eds., 1989).

51 David T. Morris, *Cost Containment and Reproductive Autonomy: Prenatal Genetic Screening and the American Health Security Act of 1993*, 20 AM. J.L. & MED. 295, 308 (1994).

52 *See generally* James R. Sorenson, *Genetic Counseling: Values that Have Mattered, in* PRESCRIBING OUR FUTURE: ETHICAL CHALLENGES IN GENETIC COUNSELING, *supra* note 49, at 3.

53 *See* Caplan, *supra* note 49 at 149 (challenging idea that genetic counseling is value neutral in practice and also suggesting that it is time for genetic counselors to abandon "the ethic of neutrality").

54 BARBARA KATZ ROTHMAN, THE TENTATIVE PREGNANCY: PRENATAL DIAGNOSIS AND THE FUTURE OF MOTHERHOOD 40-48 (1986).

direction when the genetic difference is thought to be only slight.[55] Biases toward aborting fetuses that will have significant genetic differences are also apparent in the preference of many genetic counselors that prospective parents not face the abortion decision until after the amniocentesis. As Rothman points out, the decision not to abort is more difficult once parents are faced with actual knowledge of the fetus' potential difficulties.[56] Elias and Annas, writers of some authority in this field, recognize that parents will be subjected to pressure to abort once the amniocentesis has revealed a serious genetic anomaly.[57]

The "seriousness" of any genetic anomaly is largely determined by the judgments of medical professionals. Usually seeing only those persons with disabilities who are having medical problems, such professionals' perceptions about the quality of life of persons with disabilities may be excessively negative.[58] The medical profession also appears to have a more conservative perception of what is an acceptable degree of risk[59] than the lay community has, and those perceptions appear to be growing even more conservative. Since the introduction of prenatal testing, genetic counselors have undergone a substantial change of heart about what odds are high risks and what odds are low risks.[60] In Rothman's study of genetic counsel-

55 *Id.*

56 *Id.* at 44. Parents may be forced to obtain knowledge as to whether or not their offspring carries a "congenital defect" because, as Robertson argues, once a woman chooses to conceive and carry the child to term, certain obligations attach, including a duty to undergo prenatal testing "where there is a reason to believe that this screening may identify congenital defects correctable with available therapies." Robertson, *supra* note 28, at 450.

57 Sherman Elias & George J. Annas, *Generic Consent for Genetic Screening*, 330 NEW ENG. J. MED. 1611, 1612 (1994) (recognizing that such pressure will be imposed, and emphasizing that the abortion question should be discussed prior to prenatal testing).

58 Marsha Saxton, *Prenatal Screening and Discriminatory Attitudes About Disability*, 13 WOMEN & HEALTH 217, 223 (1988) ("By working in hospitals, with sick people, doctors generally see only those cases of disability where there are complications, where patients are poorly managed, or patients in terminal stages. Many physicians never have the opportunity to see disabled individuals living independently, productively, enjoyably.").

59 Often, prenatal testing can result only in a finding of probability of a particular condition, rather than outright discovery of it. For example, in members of the same family, different genes found on different chromosomes can independently result in identical clinical symptoms, as occurs in the inherited form of blindness, retinitis pigmentosa. In addition, a single gene may have the potential to undergo hundreds of different mutations, all resulting in one type of disease, and it is difficult to test for every possible mutation. Further, some mutations may be expressed clinically in certain people, and silent in others, or if the mutation does present itself clinically, the condition may vary widely in symptomatology or severity. COMMITTEE ON ASSESSING GENETIC RISKS, DIVISION OF HEALTH SCIENCES POLICY, INSTITUTE OF MEDICINE, ASSESSING GENETIC RISKS: IMPLICATIONS FOR HEALTH AND SOCIAL POLICY 62 (Lori B. Andrews et al. eds., 1994). The Committee on Assessing Genetic Risks (Committee) notes that:

> Many diseases do not manifest clinically until adulthood and may become apparent only in middle age or later. *Predictive* or *presymptomatic* testing and screening can provide clues to which people may later develop one or more of these disorders. Often such tests will give information regarding a genetic susceptibility or predisposition, rather than providing definitive prediction.

Id. at 86. The Committee also notes that many diseases are multi-factorial in causation, meaning that environmental factors may interact with one family's set of genes but not with another's. Additionally, the various genes themselves may interact with each other, and this "multiple gene action" is impossible to predict using a separate analysis of each single gene. "In such cases, definitive predictions will rarely, if ever, be possible, and it will be impossible to group individuals into two distinct categories—those at no (or very low) risk and those at high risk." *Id.* (citations omitted).

60 ROTHMAN, *supra* note 54, at 43-44.

ing, twice as many counselors in 1983 as in 1973 called a risk of one-in-100 "high" or "very high,"[61] and one-fourth did not consider a risk of one-in-400 to be low.[62] By contrast, one study of women's attitudes toward abortion of fetuses with neural tube defects revealed a sharp increase in the number of women who said they would abort a fetus when the probability of the fetus being affected with a neural tube defect rose from 95% to 100%, causing the researchers to conclude that "although 95 per cent accuracy in diagnosis is very acceptable to many professionals, to parents, the psychological difference between any chance and certainty may be tremendous and may make the difference between deciding to abort the fetus or to bear the child."[63]

In addition, whether counselors characterize a potential disability to be a high risk or a low risk depends substantially upon their assessment of the severity of the disability; the possibility of the presence of Tay-Sachs, for example, would be considered a "high risk" at lower actual percentages of probability of occurrence than a less debilitating condition.[64] Rothman reports one genetic counselor as explaining that one-in-a-million is a high risk for Tay-Sachs.[65] Thus, the assessment prospective parents receive from genetic counselors and physicians regarding the *extent* of risk for a condition reflects not only statistical probabilities but also the professional counselor's feelings about certain conditions.

Alongside an increasing willingness to exert pressure on women to abort fetuses with detectable genetic anomalies stands legal precedent that makes possible the recognition of a cause of action in tort by a child against a parent for having been born. In the 1980 California case of *Curlender v. Bioscience Laboratories*, the California Appeals Court stated that there was no reason why suit could not be brought against parents who proceeded with the pregnancy of a fetus they knew to be carrying a "genetic defect."[66] Although the legislature of California passed a statute prohibiting such lawsuits,[67] the California court was not as far afield of legal precedent as some may think.[68] While as a practical matter prenatal injury cases still appear mainly to involve a traditional tort actor (such as the third party who negligently crashes into the car of a pregnant woman), such recovery is permitted from the party whose "wrongful conduct" "interferes" with the child's "legal right to begin life with a sound mind and body."[69] While initially

61 *Id.* at 43.

62 *Id.*

63 Ruth R. Faden et al., *Prenatal Screening and Pregnant Women's Attitudes Toward the Abortion of Defective Fetuses*, 77 AM. J. PUB. HEALTH, 288, 289-90 (1987).

64 ROTHMAN, *supra* note 54, at 43-44.

65 *Id.*

66 165 Cal. Rptr. 477, 488 (Ct. App. 1980) ("Under such circumstances, we see no sound public policy which should protect those parents from being answerable for the pain, suffering and misery which they have wrought upon their offspring.").

67 CAL. CIV. CODE § 43.6(a) (West 1982).

68 George Schedler, *Women's Reproductive Rights: Is There a Conflict with a Child's Right to Be Born free From Defects?* 7 J. LEGAL MED. 357, 366 (1986) ("It seems logically odd, if not inconsistent, to claim that the physician's failure to inform the mother causes the fetus's defective birth and thereby wrongs the fetus, when the mother would have done no legal wrong to the fetus had she brought it to term knowing it was defective.").

69 Womack v. Buckhorn, 187 N.W.2d 218, 222 (Mich. 1971).

such wrongful conduct came from traditional third parties, recently courts have shown a willingness to find the pregnant woman herself to blame, making her potentially liable under criminal or tort law as the party engaging in the wrongful conduct—for example, as an ingestor of illegal drugs or even inappropriate prescription drugs.[70] Even those cases, however, bear at least some resemblance to tort or criminal precepts about noxious conduct.

Moving from tort or criminal precepts, where one can identify an agent of harm, to the bare language of rights, however, suggests that we recognize responsibility not only to avoid harming an individual, but affirmatively to "rescue" an individual from more naturally occurring harm. Combined with the availability of prenatal testing and legal abortion, the right to sound mind and body suggests—as the California court in *Curlender* suggested—that the mother of a child who will suffer because of congenital impairments has an *affirmative* obligation to step in and alleviate (through abortion) that potential child's fated suffering.

In such a view, prenatal testing and its acceptance, or welcome, as a tool in the management of pregnancy, increases not parental choice but parental obligation. The parent who does carry to term a child with anomalies detectable *in utero* is, in the minds of many, a responsible party.[71] As Ruth Hubbard explains, the mother of such a child is now potentially at fault according to the moral if not yet the legal censure of society.[72] The child's right not to be born to suffering requires the prospective parents to choose the medical solution of abortion over other, more individualized responses to their family's suffering.

B. The Right to Die

In Nietzsche's *The Birth of Tragedy from the Spirit of Music,* Midas asks Silenus what fate is best for a man, and Silenus answers,

> Oh wretched ephemeral race, children of chance and misery, why do ye compel me to tell you what it were most expedient for you not to hear?

---

70 *See In re* Baby X, 293 N.W.2d 736, 739 (Mich. Ct. App. 1980) (holding that a newborn suffering drug withdrawal symptoms because of prenatal drug addiction may be considered a neglected child; "[s]ince a child has a legal right to begin life with a sound mind and body, . . . we believe it is within this best interest to examine all prenatal conduct bearing on that right"); Stephen Goldsmith, *Prosecution to Enhance Treatment,* 19 U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES CHILDREN TODAY 13 (1990) (describing various prosecutions for women giving birth to drug-addicted babies); Grodin v. Grodin, 301 N.W.2d 869, 870 (Mich. Ct. App. 1980) (finding that because a child has a "legal right to begin life with a sound mind and body," a child could maintain an action against his mother on grounds that his mother negligently failed to seek proper prenatal care, failed to ask her doctor to test her for pregnancy, and failed to tell her doctors she was taking the drug tetracycline which caused the child's teeth to be discolored); *see also* Bonte v. Bonte, 616 A.2d 464, 466 (N.H. 1992) (holding that a child could maintain action against his mother for her negligence in failing to use reasonable care in crossing street).

71 In *The Tentative Pregnancy,* Barbara Katz Rothman notes the societal pressure on women "not to bring into the world" a child who is disabled. "Blame begins to insinuate itself. The birth of a severely disabled child, when the disability could have been prenatally diagnosed and the pregnancy terminated, begins to be seen as an act of irresponsibility. The standards of production rise, and we are to be held accountable by those standards." ROTHMAN, *supra* note 54, at 227.

72 Ruth Hubbard, *Eugenics: New Tools, Old Ideas,* 13 WOMEN & HEALTH 225, 232 (1987).

> What is best of all is beyond your reach forever: not to be born, not to *be*, to be *nothing*. But the second best for you—is quickly to die.[73]

While Silenus's statement may not reflect our attitude toward a healthy life, it does seem much like our developing understanding of what one should do about a severely "unhealthy" life when there is little or no possibility of medical cure or effective treatment. The life predicted to come into being without good health should be avoided, if possible, through prenatal testing and abortion. At the other edge of life, the dying process of a suffering patient should be capable, at the behest of the patient (or her surrogate decision maker), of acceleration.

In the early days of modern medical science, suffering did not merit such deference. At the beginning of the nineteenth century, physicians generally would not consider reducing the suffering of a patient if doing so increased the risk of death; rather, "saving life held absolute priority over avoiding suffering."[74] During the 1800s, however, the discovery of anesthesia required surgeons to begin developing a more "utilitarian professionalism"[75] that permitted a weighing of the risks of injury from anesthesia or pain-killing drugs against the benefits to the patient of less pain and suffering. The prolonging of life or improvement of health and the reduction of suffering are now dual goals in medicine,[76] although life and health still appear more important than the reduction of suffering when medicine can provide potential solutions toward these ends. Aggressive treatments are still often pursued on slim chances of success because of the physician's belief in the priority of preserving life. For example, physicians do not hesitate to prescribe chemotherapy and radiation treatments for cancer where there is a great possibility of suffering induced by the treatments against a disproportionately small chance of cure. The presumption in hospitals is that an individual, no matter how ill, desires resuscitation unless she has consented to a "do not resuscitate" (DNR) order.[77] Despite these longstanding assumptions in favor of life, however, the culture of medicine is undergoing a change in its understanding of the relationship between life prolongation and suffering. Where medicine *cannot* provide a means for prolonging life and *cannot* significantly improve the quality of life of the very ill, medicine is increasingly open to the idea of *relief from suffering through death*, which is a shift from the mere acceptance of an increased risk of death occasioned by the use of painkillers (the doctrine of "double effect"). Is the excessive morphine prescribed for the cancer patient designed to relieve her pain at an increased risk to her life (an application of the doctrine of double effect, which even the Catholic Church

73 FRIEDRICH WILHELM NIETZSCHE, *The Birth of Tragedy from the Spirit of Music, in* THE PHILOSOPHY OF NIETZSCHE 951, 926 (Clifton Fadiman trans., 1954).

74 Pernick, *supra* note 9, at 26-27. Pernick further writes, "[I]n the half-century prior to the discovery of anesthesia, American physicians and surgeons generally defined professional duty as demanding the unhesitating infliction of extreme suffering in order to save lives." *Id.* at 28.

75 *Id.* at 26.

76 *Id.*

77 Kathleen M. Boozang, *Death Wish: Resuscitating Self-Determination for the Critically Ill*, 35 ARIZ. L. REV. 23 (1993). Some states, by statute, require this presumption. *See, e.g.*, N.Y. PUB. HEALTH LAW § 2962.1 (McKinney 1996).

accepts),[78] or is it instead intended to relieve her pain by taking her life? Jack Kevorkian was acquitted by Michigan juries in 1994 and 1996 of charges that he illegally assisted the suicides of individuals suffering from terminal diseases, because jury members determined that he had not intended the *deaths* of the individuals but that he intended instead to relieve their pain and suffering.[79] Kevorkian continues to crusade for what he has called "a fundamental human right—*the right not to suffer*—that cannot be taken away by any law."[80]

Physician-assisted suicide and withdrawal of life support are two situations in which patients look for, and doctors may be willing to provide, relief from suffering through death. These are situations where not only are physicians asked to and often willing to participate in the dying process by providing medical assistance to that end,[81] but where individuals have asserted with some success that they are entitled to such assistance, that they have a *right* to die.

The debate surrounding both of these situations—physician-assisted suicide and withdrawal of life support—focuses predominantly upon the extent to which we should recognize an individual patient's right to autonomy. And no wonder. The principle of autonomy has emerged in this century as preeminent among the other traditional *a priori* or universal principles of biomedical ethics—beneficence, nonmaleficence and distrib-

78 *See* CHARLES E. RICE, 50 QUESTIONS ON THE NATURAL LAW: WHAT IT IS AND WHY WE NEED IT 290-91 (1993) (observing that Catholic teaching accepts the principle of the double effect to justify the morality of "indirect abortions . . . [when] the death of the child is an unintended effect of an operation independently justified by the necessity of saving the mother's life").

79 David Margolick, *Kevorkian's Trial Has Come to End But Debate on Assisted Suicide Hasn't*, N.Y. TIMES, May 4, 1994, at A16; Kelly A. Anderson, *Kevorkian Acquitted for the Second Time*, ASSOCIATED PRESS, March 8, 1996, *available in* 1996 WL 4415582. In both cases Kevorkian was charged under a 15-month ban on assisted suicide passed by the state legislature in 1992 to stop him. He is also being prosecuted for assisting in the deaths of two women in 1991 in violation of a common law prohibition against assisted suicide. *Id.* Kevorkian insisted in both trials in which he was acquitted that "his primary intent was to relieve suffering, and death was the only option available." *Id.* This characterization of his actions was designed to exempt them from the Michigan statute banning assisted suicide, which excepts the administration of "medications or procedures if the intent is to relieve pain or discomfort and not to cause death, even if the medication or procedure may hasten or increase the risk of death." MICH. COMP. LAWS ANN. § 752.1027(3) (West Supp. 1996-97). Yale Kamisar explains that in the 1994 prosecution jurors were confused about the distinction between Kevorkian's motive (to relieve Hyde of his suffering) and his intent (to bring about Hyde's death). Yale Kamisar, *Physician-Assisted Suicide: The Last Bridge to Active Voluntary Euthanasia, in* EUTHANASIA EXAMINED 225, 257 n.116 (John Keown ed., 1995). "The exception applies when death is *a byproduct* of attempts to relieve suffering by increasing the dose of narcotics; it does not apply when death is *the result intended*—when the defendant means to bring about death as a way to end the patient's suffering." *Id.* A similar confusion plagued the 1996 jury. Anderson, *supra.*

80 *Kevorkian Vows to Keep Fighting Laws Barring Assisted Suicide*, N.Y. TIMES, Dec. 18, 1994, § 1, at 43 (emphasis added). Regarding the 1996 acquittal, Kevorkian's lawyer Geoffrey Fieger said the verdict showed that "the people of America are not going to allow certain government officials to tell us at the end of our life how much we have to suffer. This is not about the right to die. It is about the right not to suffer." Anderson, *supra* note 79.

81 A recent study revealed that 26% of 828 physicians questioned had been asked at some point in their career to assist a patient in dying. *Physicians Admit They Aid Suicides*, DES MOINES REGISTER, March 27, 1996, at 3. Twenty-four percent of patients who requested such aid received it. *Id.* In another recent study, seven percent of Oregon physicians said they had prescribed a lethal dose of medicine to a patient who had asked for it. Melinda A. Lee, et al., *Legalizing Assisted Suicide—Views of Physicians in Oregon*, 334 NEW ENG. J. MED. 313 (1996).

utive justice.[82] Autonomy is firmly grounded in our Constitution's protection of individual liberty; accordingly, liberty interests have been relied upon to support a Constitutional right to physician-assisted suicide and withdrawal of life support.[83]

To be sure, notions of autonomy have had undeniably positive, humanitarian effects upon the medical profession's treatment of patients. The law has promoted physician respect for patient autonomy in its requirements concerning informed consent,[84] in permitting an individual through an executed gift document to determine whether to donate organs upon death,[85] and in allowing individuals through advance directives to direct physicians regarding whether to initiate and continue life-sustaining medical procedures in the event of the patient's later incompetency.[86] In each of these instances, however, there remains substantial physician discretion, autonomy being compromised by a number of forces, some avoidable, such as physicians' difficulty in adequately communicating the risks and benefits of treatment to patients in a way that they can understand,[87] as well as their apparent failings in discerning and following pa-

82 TOM L. BEUCHAMP & JAMES F. CHILDRESS, PRINCIPLES OF BIOMEDICAL ETHICS 38 (1994) (noting that nonmaleficence and beneficence in medical ethics, historically prominent, have been eclipsed by concerns about autonomy and justice).

83 *See, e.g.*, Compassion in Dying v. Washington, 79 F.3d 790, 793, 798 (9th Cir.) (holding that the Constitution encompasses a due process liberty interest in controlling the time and manner of one's death, which includes a right of terminally ill, competent adults to physician-assisted suicide), *cert. granted sub nom.* Washington v. Glucksberg, 65 U.S.L.W. 3085 (U.S. Oct. 1, 1996); Cruzan v. Director, Mo. Dep't of Health, 497 U.S. 261, 287 (1990) (O'Connor, J., concurring) ("[a] protected liberty interest in refusing unwanted medical treatment may be inferred from our prior decisions . . . and . . . the refusal of artificially delivered food and water is encompassed within that liberty interest"). A right to physician-assisted suicide has also been successfully brought on equal protection grounds. *See* Quill v. Vacco, 80 F.3d 716 (2d Cir.), *cert. granted*, 64 U.S.L.W. 3795 (U.S. Oct. 1, 1996) (declining to recognize a fundamental due process right to physician-assisted suicide, but declaring New York statutes in violation of Equal Protection Clause because they treated terminally ill patients differently; those on life-support systems could require their removal, while those not on life-support could receive no physician assistance in ending their lives); Compassion in Dying v. Washington, 850 F. Supp. 1454 (W.D. Wash. 1994) (holding that a Washington statute proscribing physician-assisted suicide violates the Equal Protection Clause because it impermissibly treats similarly situated groups of terminally ill patients differently; the Ninth Circuit on appeal did not resolve the question of equal protection violation), *aff'd en banc*, 79 F.3d 790 (9th Cir.), *cert. granted sub nom.* Washington v. Glucksberg, 65 U.S.L.W. 3085 (U.S. Oct. 1, 1996).

84 The doctrine of informed consent grows out of the principle that, "[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body . . . ." Schloendorff v. Society of N.Y. Hosp., 105 N.E. 92, 93 (N.Y. 1914) (Cardozo, J.). *See generally* BARRY R. FURROW ET AL., HEALTH LAW 265-88 (1995) (explaining doctrine of informed consent); JAY KATZ, THE SILENT WORLD OF DOCTOR AND PATIENT (1984) (describing historical development of the doctrine and the failure of physician practices to provide meaningful content to doctrine of informed consent).

85 Unif. Anatomical Gift Act 8A U.L.A. 29 (1993). But note that doctors have long ignored the written gift documents of potential organ donors, even when executed with all the formal requisites of the Uniform Anatomical Gift Act, when the family of the potential donor does not wish to donate the decedent's organs. Lois L. Shepherd, *Organ Procurement and Transplantation*, *in* HEALTHCARE FACILITIES LAW 711, 788 (Anne M. Dellinger ed., 1991).

86 *See* FURROW ET AL., *supra* note 84, at 708-15. The Federal Patient Self-Determination Act requires that as a condition of receiving Medicaid or Medicare funding, hospitals and other health care facilities provide written information to each of their patients concerning an individual's rights under state law regarding advance directives and the health care facility's policies respecting the implementation of such rights. 42 U.S.C. § 1395cc(f)(1)(A) (1994).

87 For example, studies and commentary on informed consent in practice have demonstrated significant communication problems between patient and physician: "Many physicians

tient preferences regarding end of life decisions;[88] and some that may be unavoidable, such as physician discretion regarding when a patient is terminally ill or incompetent.[89]

Notions of autonomy become intertwined with concerns about suffering in end of life decisions in particular, and practices that go on under the name of autonomy, and rights that are invoked to permit or require such practices, are often really practices and rights driven by compassionate concerns to relieve suffering.

1. Suffering or Autonomy? The Case of Physician-Assisted Suicide

Proponents of physician-assisted suicide frame the argument for legalization in a way that emphasizes the autonomy of the individual: a person has a right to do with her body as she likes, a person thus has a right to die with dignity, in a planned and painless death.[90] But what is also clear is that individual patients seek recognition of a right to avoid suffering the physical pain and mental ignominy connected to the end stages of a terminal illness.[91]

In Timothy Quill's well-known letter to the *New England Journal of Medicine* describing a patient's decision to take a lethal dose of barbiturates that he prescribed,[92] Dr. Quill describes his patient's decision to commit suicide as a rational one—we must respect her decision because she is a competent individual; we know she is competent because she is making a rational decision. Why is the decision to kill herself rational? Because, from Quill's viewpoint, she will suffer less for it. So it is her *suffering*, not her *autonomy* that is critical;[93] for if she were not to suffer, her decision

---

discuss risk in a more or less perfunctory manner and without much regard to how well the patient comprehends the information. Many patients appear to understand little of the risk information and, shortly after the discussion, to recall even less." Peter H. Schuck, *Rethinking Informed Consent*, 103 YALE L.J. 899, 948 (1994). *See generally* Martha Minow, *Telling Medical Stories: Sharing Information Among Doctors, Patients, and Families*, 1992 UTAH L. REV. 903 (1992) (inquiring into the difficulties of communication between physicians and patients).

88 *See generally* Alfred F. Conners et al., *A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients: The Study to Understand Prognoses and Preference for Outcomes and Risks of Treatment (SUPPORT)*, 274 JAMA 1591 (1995); Bernard Lo, *Improving Care Near the End of Life; Why Is It So Hard?* 274 JAMA 1634, 1635 (1995) (revealing only 41% of patients in SUPPORT study reported discussing CPR or their prognosis with their physicians; physicians misunderstood patients' preference with respect to CPR in 80% of cases).

89 *See* Alpers & Lo, *supra* note 7, at 484.

90 Marcus Aurelius, a Roman emperor and stoic philosopher, wrote: "It is a shame for the soul to be first to give way in this life, when thy body does not give way." MARCUS AURELIUS, MEDITATIONS 55 (George Long trans., 1991). The Ninth Circuit Court of Appeals, in its opinion recognizing a constitutional right to physician-assisted suicide for the terminally ill, notes that many terminally ill patients would probably identify with Marcus Aurelius. Compassion in Dying v. Washington, 79 F.3d 790, 821, n.85 (9th Cir.), *cert. granted sub nom.* Washington v. Glucksberg, 65 U.S.L.W. 3085 (U.S. Oct. 1, 1996).

91 *See generally* DEREK HUMPHREY, FINAL EXIT (1991) (bestseller advocating the right to die and outlining methods of suicide for the terminally ill).

92 Timothy E. Quill, *Death and Dignity: A Case of Individualized Decision Making*, 324 NEW ENG. J. MED. 691 (1991).

93 Autonomy might be the predominant concern in these situations if in practice a more individualized rationality were recognized; in other words, if the individual's right to choose values, including a choice to regard suffering as more evil than the expiration of life, were respected. However, in practice we appear to be looking at the question as one of normative

would not be rational and, therefore, would be a sign of incompetence, an inability to make such a decision.[94]

The relief of suffering is the stated purpose of Oregon's Death with Dignity Act (Measure 16),[95] which permits physicians to prescribe lethal doses of medication to patients suffering from a "terminal disease."[96] Upon passage of the Act, Oregon became the first and only jurisdiction in the world to legalize physician-assisted suicide.[97] In August of 1995, the statute was declared unconstitutional and enjoined by the United States District Court in Oregon because the Act denied terminally ill patients the equal protection of the laws regarding suicide and physician malpractice as are granted to persons who are not terminally ill.[98]

---

rationality, respecting the decision of the individual or not according to our own notions of the extent to which one must bear suffering. *See infra* note 94.

94 *See* Carol J. Gill, *Suicide Intervention for Persons with Disabilities: A Lesson in Inequality*, 8 ISSUES IN L. & MED. 37, 38-39 (1992) (asserting that when persons with disabilities say they want to die, it is treated as "natural" or "reasonable," while persons without disabilities expressing the same wish are labeled "suicidal").

Quill and two other physicians recently brought suit in federal district court in New York challenging the constitutionality of New York statutes making it a crime to aid the commission of suicide by a mentally competent terminally ill adult "wishing to avoid continued severe suffering." Quill v. Koppell, 870 F. Supp. 78, 79 (S.D.N.Y. 1994). While the district court granted summary judgment for the defendants, the United States Court of Appeals for the Second Circuit held that New York's statutes criminalizing assisted suicide violated the Equal Protection Clause in their dissimilar treatment of patients dependent on life-support systems and patients not dependent on life-support systems. Quill v. Vacco, 80 F.3d 716 (2d Cir.), *cert. granted*, 64 U.S.L.W. 3795 (U.S. Oct. 1, 1996). This unequal treatment of similarly situated individuals was not rationally related to some legitimate state interest. *Id.* at 729-31. "And what business is it of the state," asked the Court, "to require the continuation of agony when the result is imminent and inevitable?" *Id.* at 730.

95 Lee v. Oregon, 869 F. Supp. 1491, 1497 (D. Or. 1994) ("The state has identified its interests in Measure 16 as preventing continued pain and suffering of competent terminally ill patients and support of Oregon voters' rights to participate in the democratic process."); Lee v. Oregon, 891 F. Supp. 1429, 1434 (D. Or. 1995) (listing "avoiding unnecessary pain and suffering" as one of five interests claimed by the state). The statute was borne of an initiative passed by referendum in November 1994.

96 Meaning an incurable and irreversible disease that will, within reasonable medical judgment, produce death within six months. 1995 Or. Laws ch. 3, § 1.01(12). The Act has a number of procedural safeguards, such as the requirement of a second physician's opinion regarding the terminal condition of the patient, and requirements of both written and oral requests made over time. The patient must also be considered by the two physicians certifying to the terminal prognosis to be capable of acting voluntarily and to have made an informed decision. *Id.* at § 3.02, 3.06. *See generally* Alpers & Lo, *supra* note 7.

97 In the Netherlands, physician-assisted suicide is illegal, although physicians who participate in acts of suicide according to certain standards are not prosecuted. Richard Fenigsen, *Euthanasia in the Netherlands*, 6 ISSUES IN L. & MED. 229, 231-32 (1990). In 1991 and 1992, Washington and California also considered similar initiatives, but these were defeated. Cheryl K. Smith, *What About Legalized Assisted Suicide?*, 8 ISSUES IN L. & MED. 503 (1993).

98 Lee v. Oregon, 891 F. Supp. 1429 (D. Or. 1995) (granting plaintiffs' motion for summary judgment as to Equal Protection Clause claim); Lee v. Oregon, 891 F. Supp. 1439 (D. Or. 1995) (granting permanent injunction against recognition of Measure 16).

The court noted the following deficiencies in the Act: physicians not trained in psychiatry or psychology could make the evaluation whether a condition of the patient was causing impaired judgment; there was no requirement that the person seeking assistance in dying consult a specialist to explore social services that might aid in the individual's comfort; the term "terminal disease" was imprecise; the consulting physician required to confirm that the person seeking assistance in dying is capable and acting voluntarily was not independent, but was referred by the attending physician; the waiting period between an initial oral request for assistance and the written prescription was too short; there was no protection for ensuring that at the time the lethal prescription was taken the decision was rationally and voluntarily made.

What is important for purposes of this discussion is the Act's treatment of concerns about suffering and autonomy. While the request of the patient is required and some safeguards were placed in the Act to guard against coercion of the patient, if the initiative were about respecting the autonomy of persons, it would permit anyone who was capable of making an informed decision to get a prescription for lethal doses of medication. Why does the Act insist that individuals be terminally ill? Because the terminally ill are thought to suffer without cause; they are not in a situation where the suffering should be borne because of the brighter outcome on the other side of the suffering. Medicine cannot provide the bridge to the healthy life. Medicine can provide relief from the suffering only through assistance in ending the life of the one who suffers. The prevention of pain and suffering of terminally ill patients was explicitly identified by the State of Oregon as the interest it was promoting by the Death with Dignity Act in the litigation challenging the constitutionality of the statute.[99]

The justification of suffering and the connection between rights and suffering are most apparent in the litigation challenging the constitutionality of laws banning physician-assisted suicide.[100] In *Compassion in Dying v. Washington*,[101] the Ninth Circuit Court of Appeals declared that Washington's statutory ban on physician-assisted suicide violated the constitutionally protected liberty interests of terminally ill patients under the Due Process Clause of the Fourteenth Amendment.[102] While the court declared that it is the terminally ill patient's liberty interest in controlling "the time and manner of death" that is unconstitutionally burdened by the prohibition against physician-assisted suicide, the decision is driven by concerns about suffering.[103] The opinion describes in some detail the pain

---

With respect to the equal protection claim regarding malpractice, the court determined that Measure 16 unconstitutionally adopted a "good faith" standard of care for a physician's participation under the Act instead of the generally applicable objective medical community standard of care for medical malpractice actions. *Lee*, 891 F. Supp. at 1435-37.

99 Another interest it cited was "support of Oregon voters' right to participate in the democratic process." Lee v. Oregon, 869 F. Supp. 1491, 1497 (D. Or. 1994).

100 Several courts have denied the existence of a constitutionally protected right to physician-assisted suicide. *See, e.g.*, People v. Kevorkian, 527 N.W.2d 714, 733 (Mich. 1994), *cert. denied*, 115 S. Ct. 1795 (1995) (holding Due Process Clause of federal constitution does not encompass fundamental right to commit suicide, with or without the assistance of a physician); Donaldson v. Lungren, 4 Cal. Rptr. 2d 59 (Ct. App. 1992) (holding patient suffering from brain tumor does not have a constitutional right to assisted premortem cryogenic suspension of his body). *But see* Quill v. Vacco, 80 F.3d 716 (2d Cir.), *cert. granted*, 64 U.S.L.W. 3795 (U.S. Oct. 1, 1996) (declining to recognize a fundamental due process right to physician-assisted suicide, but holding the New York statutes prohibiting assistance in dying violated the Equal Protection Clause by impermissibly treating similarly situated people differently in that they prohibited terminally ill patients from seeking physician-assisted suicide, but allowed patients to require removal of life-support systems).

101 79 F.3d 790 (9th Cir.) (en banc), *cert. granted sub nom.* Washington v. Glucksberg, 65 U.S.L.W. 3085 (U.S. Oct. 1, 1996), *rev'g* 49 F.3d 586 (9th Cir. 1995) (three-judge panel).

102 *Id.* at 838. The district court whose decision is affirmed by the Ninth Circuit Court of Appeals also determined that the statute in question violated the Equal Protection Clause in that it impermissibly treated similarly situated people differently by prohibiting terminally ill patients from seeking physician-assisted suicide but allowing patients to require removal of life-support systems. Compassion in Dying v. Washington, 850 F. Supp. 1454 (W.D. Wash. 1994), *aff'd en banc*, 79 F.3d 790 (9th Cir.), *cert. granted sub nom.* Washington v. Glucksberg, 65 U.S.L.W. 3085 (U.S. Oct. 1, 1996).

103 The court acknowledges that its conclusion that the Constitution provides a due process liberty interest in controlling the time and manner of one's death is "strongly influenced by, but

and suffering of the three terminally ill plaintiffs, one dying of cancer, one of AIDS, and one of emphysema and heart failure. The descriptions provided are heartrending:

> James Poe is a 69-year-old retired sales representative who suffers from emphysema, which causes him a constant sensation of suffocating. He is connected to an oxygen tank at all times, and takes morphine regularly to calm the panic reaction associated with his feeling of suffocation. Mr. Poe also suffers from heart failure related to his pulmonary disease which obstructs the flow of blood to his extremities and causes severe leg pain.[104]

The court's descriptions of the suffering of some terminally ill patients leads into and supports its analysis that the state's interests in preventing physician-assisted suicide do not outweigh the liberty interests of terminally ill patients in seeking such assistance. The degree of suffering of terminally ill patients determines both the strength of their liberty interest in pursuing physician-assisted suicide and the relative weakness of the state's interests in prohibiting such practices. According to the court:

> [A]n individual's liberty interest in hastening his death is at its low point when that person is young and healthy, because forcing a robust individual to continue living does not, at least absent extraordinary circumstances, subject him to "pain . . . [and] suffering that is too intimate and personal for the State to insist on . . . ."[105]

Drawing from *Casey*, the court analogizes the intimate and personal choice of a woman to abort a fetus to the intimate and personal choice of a terminally ill patient to commit suicide.[106] Indeed, it finds *Casey* "almost pre-

---

not limited to, the plight of mentally competent, terminally ill adults. We are influenced as well by the plight of others, such as those whose existence is reduced to a vegetative state or a permanent and irreversible state of unconsciousness." *Compassion in Dying*, 79 F.3d at 816. Because persons who are incompetent share the same constitutional rights as those who are competent, decisions to seek physician aid in dying would have to be made on the basis of perceptions of suffering and indignity, rather than individual definitions of "one's own concept of existence, of meaning, of the universe, and of the mystery of human life." *Id.* at 813 (citing Planned Parenthood v. Casey, 505 U.S. 833, 851 (1992) (plurality opinion)); *see also infra* notes 116-17 and accompanying text.

104 *Compassion in Dying*, 79 F.3d at 795 (quoting from the district court opinion, *Compassion in Dying*, 850 F. Supp. at 1456-57). The district court opinion also includes declarations submitted by the physician plaintiffs as to the suffering of their patients interested in assisted suicide:

> The cancer patient is fully aware of his or her present suffering and anticipates certain future suffering. The terminal cancer patient faces a future that can be terrifying. Near the end, the cancer patient is usually bedridden, rapidly losing mental and physical functions, often in excruciating, unrelenting pain. Pain management at this stage often requires the patient to choose between enduring unrelenting pain or surrendering an alert mental state because the dose of drugs adequate to alleviate the pain will impair consciousness.

Compassion in Dying, 850 F. Supp. at 1457.

105 *Compassion in Dying*, 79 F.3d at 833 (citing *Casey*, 505 U.S. at 852). The *Compassion in Dying* decision recognizes the *Casey* Court's statement that pregnancy involves "suffering [that] is too intimate and personal for the State to insist, without more, upon its own vision of the woman's role, however dominant that vision has been in the course of our history and culture." *Compassion in Dying*, 79 F.3d at 804 (citing *Casey*, 505 U.S. at 852).

106 *Compassion in Dying*, 79 F.3d at 813.

scriptive" on the issue.[107] *Casey*, as the opinion of the Ninth Circuit points out, "spoke of the suffering of the pregnant woman, which 'is too intimate and personal for the State to insist, without more, upon its own vision of the woman's role . . . .'"[108] The court here concluded that the suffering of a terminally ill person who cannot hasten his own death was no less deserving of "a most vital liberty interest."[109] The strength of the liberty interest in controlling the time and manner of one's death is dependent on the individual's physical condition, and that interest is at its height when "his remaining days are an unmitigated torture."[110]

The *Compassion in Dying* court also considered the suffering of terminally ill patients in determining the relative weakness of the state's interest in prohibiting physician-assisted suicide. Just as the liberty interest is strongest when suffering may thereby be avoided, so too the state's interest in legislation that burdens such liberty interest is weakest when the legislation serves to perpetuate suffering. The state's interests in preserving life and preventing suicide[111] are both "substantially diminished" when a terminally ill adult wishes to end his life in "the final stages of an incurable and painful degenerative disease, in order to avoid debilitating pain and a humiliating death."[112] The Court writes: "Not only is that state's interest in preventing such individuals from hastening their deaths of comparatively little weight, but its insistence on frustrating their wishes seems cruel indeed."[113]

Suffering, real or projected, as understood in terms of pain or indignity, defines the right to physician-assisted suicide under the analysis of the Ninth Circuit in *Compassion in Dying*. If states may continue to prohibit physician-assisted suicide in cases in which the individual is *not* terminally ill (i.e., in the Court's analysis, suffering without cause), because the liberty interest is weaker in such cases and the related state interests stronger, then the content of this liberty interest has less to do with "defin[ing] one's own concept of existence, of meaning, of the universe, and of the mystery of human life," as the *Casey* opinion describes the heart of liberty,[114] and more to do with suffering.[115] Indeed, it has everything to do with suffering.

---

107 *Id.* (agreeing with district judge in finding Supreme Court's reasoning in *Casey* "highly instructive" and "almost prescriptive" on issue of the liberty interests of terminally ill persons) (citing *Compassion in Dying*, 850 F. Supp. at 1459).

108 *Compassion in Dying*, 79 F.3d at 804 (citing *Casey*, 505 U.S. at 852).

109 *Compassion in Dying*, 79 F.3d at 814.

110 *Id.* at 834. Earlier in the opinion the Court describes the suffering of the terminally ill not in terms of pain, but in terms of their loss of dignity: "A competent terminally ill adult, having lived nearly the full measure of his life, has a strong liberty interest in choosing a dignified and humane death rather than being reduced at the end of his existence to a childlike state of helplessness, diapered, sedated, incontinent." *Id.* at 813.

111 These are two of the six related state interests identified in *Compassion in Dying*. The others are: the state's interest in avoiding the involvement of third parties and in precluding the use of arbitrary, unfair, or undue influence; the state's interest in protecting family members and loved ones; the state's interest in protecting the integrity of the medical profession; and the state's interest in avoiding adverse consequences that might ensue if the statutory provision at issue is declared unconstitutional. *Id.* at 816-17.

112 *Id.* at 820.

113 *Id.*

114 *Casey*, 505 U.S. at 851 (1992) (plurality opinion).

115 As the three-member panel of the Ninth Circuit Court of Appeals wrote in its decision reversing the District Court: "If at the heart of the liberty protected by the Fourteenth Amend-

This is made even clearer by the *Compassion in Dying* Court's intimation that an incompetent, terminally ill patient may be entitled to seek physician assistance in suicide through a surrogate decisionmaker because "a decision of a duly appointed surrogate decision maker is for all legal purposes the decision of the patient himself."[116] In addition, the Court refused to "intimate any view as to the constitutional or legal implications" of the practice of involuntary euthanasia.[117] The availment of physician-assisted suicide by incompetent individuals through surrogate decisionmakers would clearly have to draw its support from concerns about suffering, not autonomy, as would involuntary euthanasia.

2. Withdrawal of Life Support

The willingness of medical care providers and courts to follow the wishes of the patient to discontinue life-sustaining treatments is likewise bound up in their perception of the patient's suffering.

In the 1980s Elizabeth Bouvia brought suit to have a nasogastric tube providing her with nutrition and hydration removed and eventually received a court order to that end.[118] Bouvia was not terminally ill and, in fact, was expected to live fifteen or twenty more years.[119] However, as in the case of terminally ill patients seeking physician aid in dying, her medical condition was not subject to cure and her physical ailments permanently and irreversibly impaired her ability to function. She suffered from cerebral palsy, quadriplegia, and arthritis.[120] She subsisted on public assistance and was without an adequate family or social network to help in her care. She ended up in the hospital, although medical treatment was not really indicated. It is apparent that she wanted to die because she suffered, although it is certainly not clear that some of her suffering could not have been alleviated with nursing care, housing, or assisted living.[121]

The court in *Bouvia* recognizes her right to have the nasogastric tube withdrawn on the basis of her right to refuse medical treatment, even that which is life-sustaining.[122] But a recognition of a right to forgo medical treatment or life support that is based solely in concerns about the individual's liberty or autonomy would not require the court to discuss at length, as this court did, the diminished quality of Bouvia's life. While the court states that this decision is one for Bouvia alone to make, it affirms the ra-

ment is this uncurtailable ability to believe and to act on one's deepest beliefs about life, the right to suicide and the right to assistance in suicide are the prerogative of at least every sane adult." *Compassion in Dying*, 49 F.3d at 591.

116 *Compassion in Dying*, 79 F.3d at 832 n.120.

117 *Id.*

118 Bouvia v. Superior Court, 225 Cal. Rptr. 297 (Ct. App. 1986).

119 Indeed, she is still alive, having decided not to have her feeding tube removed after winning the court's approval to do so. According to newspaper reports, she "changed her plans almost immediately, when she realized that it would take several painful weeks for her to die." *10 Years After Winning Right to Die, Patient Lives*, ORLANDO SENTINEL, Dec. 17, 1993, at A5.

120 *Bouvia*, 225 Cal. Rptr. at 299, 300.

121 *See* Paul K. Longmore, *Elizabeth Bouvia, Assisted Suicide and Social Prejudice*, 3 ISSUES IN L. & MED. 141, 152-57 (1987) (describing Bouvia's life-long encounters with prejudice and the personal stresses—a miscarriage and separation from her husband—that preceded her petition for removal of her feeding tube).

122 *Bouvia*, 225 Cal. Rptr. at 305.

tionality of that decision.[123] As the court writes, "[i]n Elizabeth Bouvia's view, the quality of her life has been diminished to the point of hopelessness, uselessness, unenjoyability and frustration. She, as the patient, lying helplessly in bed, unable to care for herself, may consider her existence meaningless. *She cannot be faulted for so concluding.*"[124] While the court mentions the petitioner's pain ("endurable only by the constant administrations of morphine"),[125] it appears most concerned with her loss of dignity. Because of her physical dependence upon others, she is "imprisoned and must lie physically helpless subject to the ignominy, embarrassment, humiliation and dehumanizing aspects created by her helplessness."[126] Following that statement, the court refers to Bouvia as a "sufferer."[127]

A similar interplay between suffering and autonomy is present in cases involving the withdrawal of life support for the incompetent patient who was once competent, such as Karen Anne Quinlan[128] or Nancy Beth Cruzan.[129] Once again, the right to die is asserted when medical science can find neither a cure for the underlying condition nor improve functioning ability. If in these cases we can determine the patient's wishes regarding medical treatment through her advance directive or other evidence of her desires prior to incompetency, then it may be her autonomy that we are respecting by recognizing her right to die.[130] But without these, and similarly, in the case of individuals who have never been competent, when we talk about a *right to die,* we are not talking about autonomy, but about a right based in suffering in the sense of diminished quality of life.[131] Often the individual is not actually suffering physical pain or even emotional dis-

123 *Id.* at 304-05; *see also* Loren H. Roth et al., *Tests of Competency to Consent to Treatment,* 134 AM. J. PSYCHIATRY 279, 281 (1977) (asserting that in situations where the court is looking to the reasonableness of the patient's decision, whether explicitly so or not, "if patients do not decide the 'wrong' way, the issue of competency will probably not arise").

124 *Bouvia,* 225 Cal. Rptr. at 304 (emphasis added).

125 *Id.* at 305.

126 *Id.*

127 *Id.* (stating "we do not believe it is the policy of this State that all and every life must be preserved against the will of the sufferer").

128 *In re* Quinlan, 355 A.2d 647 (N.J. 1976).

129 Cruzan v. Director, Mo. Dep't of Health, 497 U.S. 261 (1990).

130 It is questionable, of course, whether the wishes of the individual expressed prior to the onset of incompetency are an appropriate measure of the wishes she would have now if she could know and express them. When, as a competent individual, she described the conditions under which she would prefer the withdrawal of medical treatment, she arguably did not know what she would want when in that later position of incompetency. In a sense, she is one person prior to incompetency and one person after, and so, in a very odd way, cannot speak for herself either before or after incompetency regarding her treatment preferences during the later period of incompetency.

Whether a right to refuse medical treatment, even life-sustaining medical treatment, can be made on the basis of autonomy, unencumbered by quality of life assessments made by members of the medical profession, is another question. While I do not attempt to answer that question here, it seems that to the extent we adopt a value system that puts the absence of suffering (especially suffering in the broad sense in which I use that term in this Article, which includes loss of dignity) above life, these decisions cannot be considered to be made purely autonomously.

131 Yale Kamisar writes:

> Although the Quinlan case was widely reported and discussed as a "right to die" case, Karen Ann Quinlan lacked the capacity to request anything. She did not (and in her condition, of course, could not) consent to her death or ask anyone to let her die. Nor had she made a living will or executed any other directive requesting that she be allowed to die without medical intervention.

tress as a result of lost abilities or knowledge of impending death. The incompetent patient might be unaware of such matters. As such she "suffers" chiefly a loss of dignity.

In cases of both physician-assisted suicide and withdrawal of life support, issues of autonomy are present, but not predominant. It is most accurate to think of autonomy as the means by which the claim comes before the court, which is comfortable with the language of autonomy, individualism, and liberty. But autonomy is not the deciding factor in these cases. Whether the claimant is considered competent and thus bringing the request capably and independent of coercion depends upon how much the claimant suffers and whether that level of suffering is an adequate reason to reach such a drastic decision. The suffering, the terminally ill, the alienated with disabilities, seek a right to die based on our compassion not because they *seek* autonomy, but because they have *lost* or *fear losing* autonomy. Our compassion does not give them this autonomy; it depends, rather, on the surrender of that autonomy to a medical professional.

III. Why Such Rights? Why Now?

I think we can look at a number of possible reasons why there is pressure to talk about and recognize rights based in suffering, especially in the delivery of care at the edges of life. First, we now rely heavily and increasingly upon science, and more particularly on technology,[132] to answer life's challenges, and to solve life's problems. This means that we turn to medicine not only to provide relief from or cure of disease, but also to provide solutions for aging, for childlessness, and for undesirable inherited traits. We also look to medicine to define for us what good health *is*, to tell us what is "normal" and what is not, which conditions are desirable and which are undesirable, what amount of suffering must be tolerated and how much is too much. Second, we appear to be developing a collective conscience, a shared empathy, and a feeling of responsibility for the welfare of others, especially in matters of health. As this collective conscience develops in a country whose jurisprudence gives great deference to individual rights, there is a developing sense that in matters of social welfare we have certain rights. These certain "positive" rights are rights *to* certain goods or services, rather than simply rights to non-interference with respect to obtaining such goods or services. This plays out in the health care

Yale Kamisar, *When Is There a Constitutional "Right to Die"? When Is There* No *Constitutional "Right to Live"?*, 25 Ga. L. Rev. 1203, 1208 (1991). In cases like *Quinlan* and *Cruzan*, where termination of life-sustaining treatment is sought for an individual who is not terminally ill but is in a persistent vegetative state, the principal argument for terminating treatment is that she is "better off dead" or "might as well be dead," which grapples with "the hopelessly elusive question of a life not worth living." *Id.* at 1212 (citing Richard Sherlock, Preserving Life: Public Policy and the Life Not Worth Living 137 (1987)); *see also* Bernadette Tobin, *Did You Think About Buying Her a Cat? Some Reflections on the Concept of Autonomy*, 11 J. Contemp. Health L. & Pol'y 417 (1995).

132 Science is a mode of thinking whereby experimentation and exacting logic are used "to explain observed phenomena." Edward S. Golub, The Limits of Medicine 44 (1994). Science is in effect an attempt to know the world; technology is the tool through which scientific principles are applied. *Id.* While science is "based on the idea that the world is knowable, . . . [t]echnology is based on the idea that we can bring about purposeful change; it is knowledge that is applied." *Id.*

arena in an incrementally emerging right to health care. This right emerges in those situations when our collective conscience cannot turn away—when the suffering is acute and visible—such as when a patient arrives at the emergency room in need of immediate attention.[133] In the situations I have described in the first Section of this Article, those situations at the edges of life, the developing collective conscience pushes us to recognize the individual's right to the best that medicine can provide to alleviate or avoid suffering; in those situations, the best that medicine can provide is a route to the avoidance or termination of life itself.

A. Medical Science and Technology

We are adopting essentially a medical model in our response to suffering that incorporates medical definitions and perceptions of suffering, medical perceptions and tolerances of risk, and medical solutions to suffering through technology.

With respect to perceptions of suffering, we look to medical science to provide not just information but also opinions about what nature has dealt us in terms of our physical and mental attributes and to determine what it means to suffer.[134] We often assume suffering when there is a deviation from the norm in appearance or abilities: persons with disabilities suffer, the elderly person who can no longer take care of herself suffers, the person with a cleft palate suffers, the infertile suffer.

Science has created some of the expectations about how life should be, thus causing us to turn to science to realize those expectations for us.[135] For example, with the availability of new reproductive technologies we expect fertility. With the advent of a supposed "cure," a failure to conceive is adjudged to be due to an infertility problem at a much earlier time than had previously been the case. Rather than expecting couples to try to get

133 In such instances the hospital and the physicians staffing the emergency room have a statutory duty to stabilize the patient prior to transfer to another facility. *See infra* note 178 and accompanying text.

134 Some of the situations that we turn to science to solve have arguably not only been defined by science, but have been created by the science itself, which has clearly prolonged the dying process and thus caused some patients to insist they have a right to withdrawal of life sustaining treatment. In this article I am more concerned with naturally caused suffering (or perceived suffering), with what nature has dealt us, and how we look to medical science to provide the means by which to judge what we have been dealt and determine if it falls below a certain level of acceptability.

135 Edward Golub argues that although "[b]y all objective standards, people in the industrialized nations are healthier than they ever have been, . . . there is growing dissatisfaction with health care and growing evidence that people perceive themselves as less healthy." GOLUB, *supra* note 132 at 224. He argues that:

> [W]e have all been willing partners in making promises about and expecting miracles from scientific medicine. Scientists have promised wondrous cures as a result of basic research, physicians have promised to roll back death and eliminate pain through specialization and high-tech medicine, the pharmaceutical industry warns that if profits are curtailed they will stop developing innovative lifesaving drugs, the press breathlessly reports yet another medical miracle, and patients urge all of them on by wanting desperately to believe each of them.

Id. Golub believes that our current health care problems arise in part from "making science a secular religion and then expecting miracles from it, and from not having developed a context in which to understand and handle physical suffering and death in a scientific world." *Id.* at 225.

pregnant on their own for two or three years, physicians now consider them infertile and appropriate subjects for treatment after one year.[136]

Likewise, medical technology has created for us an expectation of healthier lives. But what is health? Others have long pointed out that medical science has created disease where it did not previously exist: if alcoholism is now a disease, science will be expected to provide the pharmaceutical means to cure or control it, or to detect its possible genetic basis and eugenically avoid it. Extreme shyness is now being treated with prescription drugs,[137] as are the increasing number of children diagnosed with attention-deficit disorder and hyperactivity.[138] Criminal disposition may eventually be considered a disease, or at least a medical condition, if we find a gene for it—and scientists are busy looking.[139] Once found, "criminality" would be potentially subject to a medical cure through gene splicing or embryo selection. Researchers are looking for a gene for homosexuality with the same potential consequences.[140]

---

136 In her book, *Women as Wombs*, Janice Raymond suggests that, "[d]octors increasingly expand the definition of infertility. The currently accepted medical definition is inability to conceive after one year of intercourse without contraception." JANICE G. RAYMOND, WOMEN AS WOMBS 3 (1993) (citing Erwin Chargraff, *Engineering a Molecular Nightmare*, 327 NATURE 199 (1987)). Raymond notes that, "[i]n the last decade, the number of years has dwindled from two to one. However, as many as half the couples seeking treatment for infertility will conceive in the usual heterosexual way, without any help from fertility treatments, and even after technical fertility treatment has failed." *Id.* (citation omitted).

137 *Dateline* (NBC television broadcast, Mar. 10, 1996) (describing how Prozac is used to treat shyness).

138 Lyn Nell Hancock, *Mother's Little Helper*, NEWSWEEK, Mar. 18, 1996, at 51, 52 (reporting that 1.3 million American children take Ritalin regularly for Attention-Deficit/Hyperactivity Disorder, and that many doctors are convinced that the drug is overprescribed and that many children who need therapy to modify their behavior and special help for school get little more than pills).

139 P.A. Brennen & S.A. Mednick, *Genetic Perspectives on Crime*, 370 ACTA PSYCHIAT. SCAND. SUPP. 19 (1993) (examining the empirical evidence for a genetic influence in the etiology of antisocial behavior); A. Freyne & A. O'Connor, *XYY Genotype and Crime: 2 Cases*, 32 MED. SCI. & L. 261 (1992); John Horgan, *Genes and Crime: A U.S. Plan to Reduce Violence Rekindles an Old Controversy*, SCI. AM., Feb. 1993, at 24. *But see* Dwight L. Greene, *Naughty by Nurture: Black Male Joyriding—Is Everything Gonna Be Alright?*, 4 COLUM. J. GENDER & L. 73 (1994), where the author writes:

> In the context of criminal behavior, genetics is controversial in part because the predisposition to disease is equated with a predisposition to commit certain kinds of crime, usually violent. What is criminal, however, is socially, not physiologically determined. The same act of violence may or may not be a crime depending upon the social significance attached to the violence. Hitting on a football field may be sanctioned while hitting on a street corner may not. In both cases, the propensity for violence may be identical.

Id. at 115 n.147. Accusations of racism caused the National Institute of Health (NIH) to withdraw funding for an academic conference on genetics and criminal behavior, entitled *Genetic Factors in Crime: Findings, Uses and Implications*, that was originally scheduled to be held in October 1992 at the University of Maryland. Dorothy E. Roberts, *Crime, Race, and Reproduction*, 67 TUL. L. REV. 1945, 1965 n.98 (1993) (citations omitted). In suspending its funding, the NIH claimed that the project "too readily accepted and gave credence to the notion that violence and crime had genetic causes." Maureen P. Coffey, *Note, The Genetic Defense: Excuse or Explanation?* 35 WM. & MARY L. REV. 353, 353 (1993). Coffey notes that "[o]ther critics, more vehement in their attack, charged that the conference perpetuated racist misconceptions and embodied either a 'politically-fueled revival of the discredited theories of eugenics' or 'reductionism gone wild.'" *Id.* (citations omitted).

140 *See* Dean H. Hamer et al., *A Linkage Between DNA Markers on the X Chromosome and Male Sexual Orientation*, 261 SCIENCE 321 (1993) (reporting results that indicate with a statistical confidence level of more than 99%, that at least one subtype of male sexual orientation is genetically influenced); Stella Hu et al., *Linkage Between Sexual Orientation and Chromosome Xq28 in Males But Not in Females*, 11 NATURE GENETICS 248 (1995) (reporting results that corroborate previously

In addition to providing its own definitions of suffering, medicine also prescribes tolerances for risk.[141] These prescriptions are understandably conservative, at least with respect to circumstances over which medical science appears to have no control. As I have noted earlier, genetic counselors and physicians working with expectant parents find risks for genetic disabilities intolerably high, when parents may be more willing to accept them.[142] And in at least six cases in which courts have ordered women to undergo Cesarean sections, the women ignored the order and gave vaginal birth to healthy babies.[143] The statistical probabilities advanced by the physicians in one of these cases, *Jefferson v. Griffin Spalding County Hospital Authority*,[144] may be instructive. In *Jefferson*, physicians maintained that without surgery, the woman's condition of placenta previa posed a 99% risk that the baby would die and a 50% chance that the pregnant woman would die; but if the surgery were performed, both the baby and the woman would have a 100% chance of survival. Perhaps this represents a healthy distrust of results occurring naturally, without medical intervention, and an equally healthy degree of physician confidence in their own curative powers. But should these attitudes about risk be demanded of individual patients or effectively imposed upon them as we import medical norms into our legal framework through rights based in suffering?

Finally, the medical response to suffering is to alleviate it or, if alleviation is not possible, to avoid it. The risk/benefit analysis medical professionals conduct to determine whether a therapy or treatment should be undertaken necessarily and understandably opens the discussion for quality of life assessments. Risk/benefit assessments became an accepted part of the practice of medicine in the nineteenth century when physicians began to abandon their refusal to use anesthetic because of the risk to life.[145] Prior to that time, physicians were so driven by the duty to preserve life at all cost in terms of pain or suffering that any potentially curative procedure was undertaken, no matter how painful.[146] The introduction of anesthetic—which could greatly or entirely relieve pain during a procedure,

---

reported linkage between the X chromosome (Xq28) and male homosexuality in selected kinships); Ferren MacIntyre & Kenneth W. Estep, *Sperm Competition and the Persistence of Genes for Male Homosexuality*, 31 BIOSYSTEMS 223 (1993) (supporting theory of genetic component to the development of male homosexuality); William J. Turner, *Homosexuality, Type I: An Xq28 Phenomenon*, 24 ARCHIVES OF SEXUAL BEHAVIOR 109 (1995). But note that some gays and lesbians fear that the Hamer report, *supra*, "might lead to efforts to detect homosexuality, resulting in further discrimination against them." Ralph C. Brashier, *Disinheritance and the Modern Family*, 45 CASE W. RES. L. REV. 83, 160 n.247 (1994); *see also* John R. Quinn, *The Lost Language of the Irishgaymale: Textualization in Ireland's Law and Literature (or the Most Hidden Ireland)*, 26 COLUM. HUM. RTS. L. REV. 553, 576 (1995) (Genetics and biology may lead to intolerance or oppression, possibly even facilitating "ghettoization, quarantine, and the like. Ultimately, biology could foster the horrors of eugenics: the discovery of a genetic basis for homosexuality could engender efforts to eliminate or alter the genes to 'cure' the condition, or to abort fetuses determined to carry the gene.").

141 Even using the term "risk" as opposed to a more neutral term, such as "chance," implies value judgements about the condition being assessed. *See* Walter E. Nance, *Parables, in* PRESCRIBING OUR FUTURE: ETHICAL ISSUES IN GENETIC COUNSELING, *supra* note 49, at 89, 91.

142 *See supra* notes 58-63 and accompanying text.

143 Janet Gallagher, *Fetus as Patient, in* REPRODUCTIVE LAWS FOR THE 1990s 185, 186 (Sherrill Cohen & Nadine Taub eds., 1989).

144 274 S.E.2d 457 (Ga. 1981).

145 Pernick, *supra* note 9, at 29.

146 *Id.* at 28.

but at some risk to life—required a rethinking of that position and a more moderate risk/benefit approach followed.[147]

And certainly this seems reasonable enough. We see doctors as best equipped to give us the facts—the chances, the outcomes, the conditions—because they have experience and education in conducting such analyses. But as anyone who has faced such wrenching choices can attest, assessing statistics, probabilities, and risk does not take into account any personal criteria for quality of life—our relationships, our religious beliefs, our ethical norms, our tolerance for pain, or the strength of our desire to live.

Futility is the justification physicians rely on to refuse to perform or advise patients against certain treatments, generally life-prolonging treatments.[148] Futility does not simply mean that the doctors think that this particular treatment will fail. We have seen that in *Baby K*.[149] In that case the hospital sought a declaratory judgment that, under the Emergency Medical Treatment and Active Labor Act (EMTALA),[150] the Rehabilitation Act of 1973,[151] and the Americans with Disabilities Act,[152] it had no obligation to provide respiratory support for an anencephalic infant. The argument was not that the respiratory support would not be effective to restore the infant's breathing; it would be. It was that the infant had no quality of life and thus could not benefit from the restored breathing.[153] Futility, as applied, means that the doctors do not think the treatment will enable you

147 *Id.* at 29.

148 Physicians sometimes rely on futility to write DNR orders for patients without their consent or the consent of their families. There are three different justifications generally offered for issuing a DNR order, including (1) withholding CPR where it is of no medical benefit; (2) withholding CPR where there will likely be a poor quality of life after CPR; and (3) withholding CPR where there is a poor quality of life before CPR is administered. Tom Tomlinson & Howard Brody, *Sounding Board—Ethics and Communication in Do-Not-Resuscitate Orders*, 318 NEW ENG. J. MED. 43 (1988). Tomlinson and Brody argue for the importance of making the distinction between the three. The authors believe that in the latter two situations, where the justification depends on an assessment of quality of life, the decision must be based on the values of the individual patient. *Id.* at 44; *see also infra* note 154.

149 *In re* Baby K, 832 F. Supp. 1022 (E.D. Va. 1993), *aff'd*, 16 F.3d 590 (4th Cir. 1994).

150 Emergency Medical Treatment and Active Labor Act, 42 U.S.C. § 1395dd (1994).

151 Rehabilitation Act of 1973, § 504, 29 U.S.C. § 794 (1994).

152 Americans with Disabilities Act of 1990, Pub. L. No. 101-336, 104 Stat. 376 (codified as amended in scattered sections of 29 U.S.C., 47 U.S.C. and 42 U.S.C. §§ 12101-213 (1994)). The hospital also sought similar declaratory and injunctive relief under the Child Abuse Amendments of 1984, 42 U.S.C. §§ 5101-06, 5111-13, 5115, 10401-15 (1994), and the Virginia Medical Malpractice Act, Va. Code Ann. §§ 8.01-581.1 to .20 (Michie 1991). *In re Baby K*, 832 F. Supp. at 1026.

153 *Baby K*, 832 F. Supp. at 1027. In *Baby K*, the hospital sought to withhold ventilator treatment when such treatment would be "'futile' or 'inhumane.'" *Id.* The court held, however, that:

> The use of a mechanical ventilator to assist breathing is not "futile" or "inhumane" in relieving the *acute* symptoms of respiratory difficulty which is the emergency medical condition that must be treated under EMTALA. To hold otherwise would allow hospitals to deny emergency treatment to numerous classes of patients, such as accident victims who have terminal cancer or AIDS, on the grounds that they eventually will die anyway from those diseases and that emergency care for them would therefore be "futile."

Id.; *see also* Marcia Angell, *The Case of Helga Walglie: A New Kind of "Right to Die" Case*, 325 NEW ENG. J. MED. 511 (1991) (discussing a Minnesota probate court's rejection of a hospital's effort to replace the patient's surrogate decision maker (patient's husband) on grounds that he insisted upon the continuation of life sustaining treatment for the elderly patient in a persistent vegetative state); and notes 273-74 and accompanying text.

to have a good enough life.[154] If the medical profession cannot give you a better life, then perhaps you should have no life at all.

B. A Growing Collective Conscience

Along with a growing acceptance of a medical model of suffering, changes in the legal culture reflect a heightened public awareness and appreciation of others' suffering. This may be due, in part, to the fact that historical distinctions between public and private have blurred, so that, according to Hannah Arendt, the two realms "constantly flow into each other like waves in the never-resting stream of the life process itself."[155] Concerns that were originally and exclusively the province of the family, where the necessary tasks for the survival of life took place, have become a "collective" concern. We are now a "collective of families economically organized into the facsimile of one super-human family."[156]

Most Americans believe that through government, we have some responsibility to care for those in need.[157] Since the New Deal, our government has provided a number of assistance programs for housing, food, and other basic needs.[158] If we were to compare ours to Greek civilization, as Arendt does, we would find that nothing like our modern understanding regarding social responsibility existed in classic times.[159] Nor as recently as the nineteenth century did our nation take on such collective responsibility. But now we may be moving, slowly to be sure, into an era not only of national superfamilies, but of one international family, with the push toward human rights (revealing a concern for the welfare of all), the activism of the United Nations and peacekeeping efforts, and the increasing ability to become aware, through media and electronic communication, of the needs of people in other countries.

Personal health was historically a most private aspect of life: doctors would go to their patients' homes to administer care instead of patients going to clinics or hospitals, and the aged would die at home instead of in

154 In her study of how physicians talk about futility, Mildred Z. Solomon found that when physicians invoked futility arguments against pursuing further treatment for a patient, those arguments "most often . . . were used to support evaluative judgments based on quality of life considerations, only rarely to designate treatments that were medically inefficacious." Solomon writes that throughout interviews with physicians, "physicians sought to frame value judgments as medical decisions." Mildred Z. Solomon, *How Physicians Talk about Futility; Making Words Mean Too Many Things*, 21 J. LAW MED. & ETHICS, 231, 232-33 (1993); *see also* Boozang, *supra* note 77, at 26 (disapproving physician adoption of a "futility" exception to DNR policies, "which allows physicians to withhold CPR from patients without their consent or knowledge if the physician determines that resuscitation would not be medically beneficial").

155 HANNAH ARENDT, THE HUMAN CONDITION 33 (1958). Arendt explains that what she calls "the social realm" has, with the rise of the modern nation state, overtaken the public and private realms in life. *Id.* at 28.

156 *Id.* at 29.

157 Current public opinion supports government's role in providing for those undergoing economic hardship. Robert Y. Shapiro et al., *The Polls: Public Assistance*, 51 PUB. OPINION Q. 120 (1987). Attitudes about the need for public assistance programs have been relatively stable since the first surveys were conducted in the 1930s. *Id.* at 120.

158 *See generally* MICHAEL B. KATZ, THE UNDESERVING POOR (1989) (providing a critical historical review and an analysis of contemporary poverty policy, encompassing the period from the 1960s War on Poverty to the conservative war on welfare).

159 ARENDT, *supra* note 155.

hospitals or nursing care facilities.[160] We have thankfully left behind much of the ignorance and isolation imposed by the strictures of privacy in personal health. It is now commonplace to be privy to information about the personal health of others; we have national pleas for transplantable organs, television accounts of live births and heart or brain surgeries, personal accounts of illnesses on talk shows, in self-help books, and even at the national conventions of political parties. Elizabeth Glaser, in a speech at the 1992 National Democratic Convention, encouraged increased federal efforts in AIDS research, and described the death of her daughter from AIDS and her own and her son's affliction with the disease.[161] Additionally, whereas breast cancer and other diseases affecting private aspects of our bodies used to be considered subjects inappropriate for public disclosure and discussion, this taboo has clearly (and thankfully) passed.

We are not only privy to information about the personal health of others, we share in various ways a responsibility with respect to others' health. Thus, we accept a national program of childhood immunizations. Those who have private health insurance share indirectly in the costs of the uncompensated care provided by hospitals through their practices of cost-shifting, which leads to higher private insurance premiums.[162] We assume responsibility to warn individuals of the risks of smoking, to ensure that drugs and medical devices placed in the market are safe, and to provide, through tax dollars, some assistance to those who need medical care.[163] To the extent that we move more toward managed care[164] with its "gatekeepers"[165] and utilization review,[166] along with financial incentives for physicians and other providers to manage the costs of one patient with an eye

160 *See* Jonathan R. MacBride, Comment, *A Death Without Dignity: How the Lower Courts Have Refused to Recognize That the Right of Privacy and the Fourteenth Amendment Liberty Interest Protect an Individual's Choice of Physician-Assisted Suicide*, 68 TEMP. L. REV. 755 (1995), where the author notes: "Fifty years ago most people died at home, and only twenty percent of Americans died in a hospital or health-care facility. Today, however, eighty percent of Americans die in a hospital or other health-care facility." *Id.* at 795 (citations omitted).

161 Sydney S. Schanberg, *AIDS Speeches Bring Rare Moments of Stillness*, NEWSDAY, July 17, 1992, at 51, *available in* 1992 WL 7545195.

162 Theodore R. Marmor & Michael S. Barr, *Making Sense of the National Health Insurance Reform Debate*, 10 YALE L. & POL'Y REV. 228, 249 (1992); *see also* Robert G. Evans, *Tension, Compression, and Shear: Directions, Stresses, and Outcomes of Health Care Cost Control*, 15 J. HEALTH POL. POL'Y & L. 101 (1990).

163 It is important to note not only that we share collectively in providing care to some of those who cannot afford it through public insurance programs, but also that the federal tax subsidy of employer-provided health insurance (which amounted to about $33.5 billion in 1990) means that we share collectively in the provision of such health benefits to employees who are not poor. BARRY R. FURROW ET AL., HEALTH LAW: CASES, MATERIALS AND PROBLEMS 543-44 (1991).

164 "Managed care" is a form of health care delivery which takes on a variety of forms and organizations, (the most familiar of which is the health maintenance organization (HMO)), which are "all intended to manage the use of health care services by consumers." *Id.* at 472.

165 Subscribers to HMOs must choose a "primary care provider," or "gatekeeper," who is responsible for controlling access to other services or specialists. Eric Larson, *The Soul of an HMO*, TIME, Jan. 22, 1996, at 45, 46.

166 Typically, HMOs contract with larger groups of physicians who then provide the actual medical care for patients. *Id.* When a patient seeks treatment through her gatekeeper, the gatekeeper's recommendations must be approved by the medical group's utilization-review managers, or by the HMO itself, before the patient can follow the physician's recommendation. *Id.*

towards what resources will be left for others,[167] we will only move further toward a collectivist character in health care delivery.

This collective conscience with respect to matters of individual welfare, and health in particular, is reflected in the incrementally growing provision of health care in this country. The President's Commission for the Study of Ethical Problems in Medical and Biomedical and Behavioral Research, convened in 1983 to study the question of national health care rights and responsibilities, decided that there was no right to health care. It nevertheless determined that society had an "ethical obligation to ensure equitable access to health care for all."[168] At that time and still today, the patchwork of medical insurance programs for the "deserving poor,"[169] the elderly, the disabled, the veterans, and others on federal, state, and local levels has proven inadequate to ensure access to care for all.[170] But while reform efforts, at least at the federal level, have stalled or been abandoned, there has been some expansion of legally required access to care. The expansion is largely in the area of emergency medicine, where suffering is acute and highly visible.

While physicians traditionally have been able to choose whom they wish to serve,[171] and hospitals have also at times claimed that they had no

167 HMOs collect monthly payments from subscribers, and then reserve money for administrative costs, marketing costs, salaries, bonuses, and profits. *Id.* The HMO then pays the medical group a set fee for every patient assigned to the group—a practice called capitation. *Id.* at 47. The medical group withholds enough from this fee to cover operating costs and profits, then pays the primary care physicians. *Id.* If a doctor spends less than the capitated rate, he makes a profit; if he spends more he suffers a loss. *Id.* Thus, "[e]very time a capitated doctor performs a service or admits a patient to a hospital it cuts into his income." *Id.*

168 President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Securing Access to Health Care: The Ethical Implications of Differences in the Availability of Health Services* 4 (U.S. Gov't Printing Office, 1983). Note, however, that the Commission's Report stated that a similar commission in 1952 concluded that "access to the means for the attainment and preservation of health is a basic human right." *Id.* (citation omitted).

169 Medicaid, the joint federal and state program organized to assist the poor by providing health benefits, targets certain favored groups: the elderly, the blind, the permanently and totally disabled, dependent children and their families eligible for Aid to Families with Dependent Children, and other discrete groups of persons. FURROW, *supra* note 163, at 568-69.

170 *See* Barry R. Furrow, *Forcing Rescue: The Landscape of Health Care Provider Obligations to Treat Patients*, 3 HEALTH MATRIX 31 (1993). According to a 1986 study, nearly 14 million Americans said they did not even seek health care because they were unable to afford it. "The situation has only deteriorated since 1986. 'The uninsured are less likely to . . . receive prenatal care, less likely to have their blood pressure checked, and less likely to see a physician even when they have serious symptoms.' When uninsured patients do seek care from hospitals, they are often turned away or superficially treated and transferred to stressed and overburdened public hospitals. When they do receive health care in hospitals, indigent patients experience a higher mortality rate because they do not receive as many high cost procedures." *Id.* at 31-32 (citations omitted).

171 A point obviously very dear to physicians; in The American Medical Association's *Principles of Medical Ethics*, an avowed statement of "standards of conduct which define the essential of honorable behavior for the physician," is the self-serving proclamation that physicians are free to choose whom to serve. AMERICAN MEDICAL ASSOCIATION, PRINCIPLES OF MEDICAL ETHICS (1980), *quoted in* BARRY R. FURROW ET AL., BIOETHICS: HEALTH CARE LAW AND ETHICS 31-32 (1991). The full provision is that "a physician shall, in the provision of appropriate patient care, except in emergencies, be free to choose whom to serve, with whom to associate, and the environment in which to provide medical services." Since the statement was adopted in 1980, legal recognition of duties in some emergencies have already emerged. *See infra* note 172; *see also* Childs v. Weis, 440 S.W.2d 104, 107 (Tex. App. 1969) (holding that a doctor has no duty to treat patient in an emergency if no doctor-patient relationship exists).

duty to treat particular patients,[172] beginning in the 1960s, courts have struggled with doctrine to find duties to patients in acute suffering. Thus, a number of common law legal theories have been cited to impose upon hospitals, and therefore upon emergency room on-call physicians, a duty to treat patients who are in dire need of medical assistance.[173] These include the characterization of a private hospital as a "quasi-public" entity,[174] a reliance theory based in tort,[175] and a duty imposed on the basis of public policy,[176] all of which are theories shaky at the foundations.[177] Regulation through liability exposure having proven on the whole ineffective, the U.S. Congress in 1986 passed the Emergency Medical Treatment and Active Labor Act,[178] which requires that hospitals (in order to be eligible for Medicare reimbursement) stabilize individuals who come to them with emergency medical conditions.

The provision of health care as a response to suffering can also be seen in the implementation of some of the state health care reform efforts. For example, in 1987, Oregon chose to expand the number of participants in

172 *See* Chandler v. Hospital Auth., 548 So. 2d 1384, 1387 (Ala. 1989) (ruling that although a hospital has no affirmative duty to treat patients in an emergency situation, once treatment has been initiated, hospital must provide care); Citizens Hosp. Ass'n v. Schoulin, 262 So. 2d 303 (Ala. Civ. App. 1972) (stating that a hospital has no duty to treat a patient it finds unacceptable).

173 The courts have imposed a duty of "necessary rescue" in cases where a person would be left helpless without the help of the professional. Furrow, *supra* note 170, at 44. "The physician's right to unilaterally terminate treatment is thus particularly circumscribed in emergency situations, defined as situations where the patient has a 'critical need' for that physician's attention. A provider can be 'conscripted' to rescue through webs of obligation created by emergency situations." *Id.*; *see* Valdez v. Lyman-Roberts Hosp., Inc., 638 S.W.2d 111, 114 (Tex. App. 1982) (finding that liability of a private hospital may be based upon the refusal of service to a patient in a case of unmistakable medical emergency); Wilmington Gen. Hosp. v. Manlove, 174 A.2d 135, 140 (Del. 1961) (holding that hospitals maintaining emergency departments are required to admit patients whose injury or illness is an "unmistakable emergency" if the patient has relied upon a well-established custom of the hospital to render aid in such a case); Guerrero v. Copper Queen Hosp., 537 P.2d 1329, 1331 (Ariz. 1975) (en banc) (ruling that the duty of a private hospital to accept patients in an emergency arises from the state's licensing scheme); Wheeler v. Barker, 208 P.2d 68, 71 (Cal. Dist. Ct. App. 1949) (finding a "duty to do what the occasion demands" in emergency situations where it is not possible to obtain patient consent).

174 *See* Manlove v. Wilmington Gen. Hosp., 169 A.2d 18, 22 (Del. Super. Ct.) (stating that a private hospital was a quasi-public entity because it was a recipient of tax exemptions, public subsidies, and a corporate charter), *aff'd on other grounds*, 174 A.2d 135 (Del. 1961) (affirming the order of the Superior Court but rejecting its reasoning).

175 *See Wilmington Gen. Hosp.*, 174 A.2d at 140 (finding a duty to give treatment in an emergency case arises under reliance theory); Stanturf v. Sipes, 447 S.W.2d 558, 562 (Mo. 1969) (finding that a hospital was required to treat the plaintiff who, in an emergency situation, relied on "the long established rule of the hospital to accept all persons for treatment upon the payment of a $25 admittance fee"); *Valdez*, 638 S.W.2d at 114 n.1 (finding that hospital's liability may rest on refusal to treat patient in unmistakable emergency if patient has relied upon hospital's custom to provide care in such circumstances).

176 *Guerrero*, 537 P.2d at 1331 (interpreting state public policy to require general hospitals to maintain emergency care facilities and finding that "such a hospital may not deny emergency care to any patient without cause"); Thompson v. Sun City Community Hosp., Inc., 688 P.2d 605, 609-11 (Ariz. 1984) (affirming and expanding *Guerrero*).

177 *See* Karen H. Rothenberg, *Who Cares?: The Evolution of the Legal Duty to Provide Emergency Care*, 26 HOUS. L. REV. 21, 33-53 (1989).

178 By enacting the Emergency Medical Treatment and Active Labor Act, Pub. L. No. 99-272, 100 Stat. 164 (codified as amended at 42 U.S.C. § 1395dd (1994)), Congress sought to remedy the growing problem of private hospitals' refusal to provide emergency care to indigent or uninsured patients. Erin A. Nealy, *Medical Decision-Making for Children: A Struggle for Autonomy*, 49 SMU L. REV. 133, 150 (1995) (citations omitted).

its Medicaid plan by dropping coverage for organ transplants.[179] When a seven-year-old died because he was unable to obtain a bone marrow transplant through the Medicaid program, the public outcry in response to his acute and visible suffering caused the Oregon legislature to restore Medicaid funding for organ transplants.[180]

C. Conceptual Support for Rights Based in Suffering

In the collective conscience, we share not only a growing awareness of the suffering, and especially the visible suffering, of others, but a growing sense of responsibility to help others avoid avoidable suffering. We find conceptual support for this heightened social responsibility in such theories as the feminist ethic of care. The ethic of care requires attending to responsibilities and relationships, rather than attending to rights and fairness (the ethic of justice).[181] Rather than learning and then applying abstract principles, such as equality, reciprocity, and property rights that have universal applicability (since all are grounded in an ethic of justice), an individual or society acting under the ethic of care would seek responses that are appropriate to the particular case.[182]

Much of the recent work on the ethic of care is an outgrowth of Carol Gilligan's 1982 work, *In a Different Voice*, in which she presents her empirical findings that women and men tend to reason about moral problems from different approaches.[183] Women consider the world as "comprised of

179 W. John Thomas, *The Oregon Medicaid Proposal: Ethical Paralysis, Tragic Democracy and the Fate of a Utilitarian Health Care Program*, 72 OR. L. REV. 47, 54 (1993) (noting that the Oregon state legislature determined that basic care for 5700 people could be provided by eliminating coverage for the approximately thirty transplants performed each year).

180 *Id.* Following the death of Coby Howard, the Oregon Health Services Commission (OHSC) proposed an alternative rationing scheme that prioritized the services to be offered to Medicaid patients. Caitlin J. Halligan, Note, *"Just What the Doctor Ordered": Oregon's Medicaid Rationing Process and Public Participation in Risk Regulation*, 83 GEO. L.J. 2697, 2713-14 (1995). The OHSC's ordering of medical services demonstrated a preference for life-saving treatments, and services promising full recovery ranked higher than those that merely "improved quality of life without a complete return to health." *Id.* The OHSC also ranked preventive service quite high on the list. *Id.*

Seeking a waiver of Medicaid regulations, the OHSC submitted the final draft of the prioritization procedure to the Department of Health and Human Services (HHS) for approval. *Id.* at 2716. The HHS denied the waiver, claiming that the ranking system's incorporation of the results of telephone "quality of life" surveys, used to assess public opinion as to preference of services to be made available, discriminated against the disabled, because the public held "'stereotypical assumptions about persons with disabilities.'" *Id.* The HHS also claimed that the OHSC's prioritization of preventive measures over treatment of severe conditions further discriminated against the disabled. *Id.*

Subsequent to the denial of its waiver request, Oregon negotiated revisions of the Medicaid reforms, completely omitting the quality of life valuations. *Id.* at 2717. The HHS approved the revised plan in March 1993, and the state implemented the plan in February 1994. *Id.*

181 WILL KYMLICKA, CONTEMPORAY POLITICAL PHILOSOPHY: AN INTRODUCTION 265 (1990). *See generally* NEL NODDINGS, CARING: A FEMININE APPROACH TO ETHICS & MORAL EDUCATON 2 (1984) (caring is "rooted in receptivity, relatedness, and responsiveness").

182 KYMLICKA, *supra* note 181, at 265.

183 CAROL GILLIGAN, IN A DIFFERENT VOICE: PSYCHOLOGICAL THEORY AND WOMEN'S DEVELOPMENT (1982). *But see* CATHARINE A. MACKINNON, FEMINISM UNMODIFIED: DISCOURSES ON LIFE AND LAW 39 (1987) (arguing that Gilligan's theories are left-over remnants of oppression); Pamela S. Karlan & Daniel R. Ortiz, *In a Diffident Voice: Relational Feminism, Abortion Rights, and the Feminist Legal Agenda*, 87 NW. U. L. REV. 858, 861 (1993) (arguing that the relational feminism view asserted by Gilligan and others, "fundamentally strains against many women's needs," particularly

relationships rather than of people standing alone, a world that coheres through human connection rather than through systems of rules."[184] Gilligan further writes:

> The moral imperative that emerges repeatedly in interviews with women is an injunction to care, a responsibility to discern and alleviate the "real and recognizable trouble" of this world. For men the moral imperative appears rather as an injunction to respect the rights of others and thus to protect from interference the rights to life and self-fulfillment.[185]

Whether there are gender differences in moral reasoning or not, a matter of much dispute,[186] the ethic of care that has grown out of Gilligan's and others' work[187] has received much attention on its own terms.[188]

Attention to the particular circumstances of the case, the particular case of suffering, and to the "real and recognizable trouble" that individuals face, seems acutely present in the case of physician-assisted suicide. Timothy Quill has given a detailed narrative of his encounter with Diane to whom he gave a prescription for barbiturates, with instructions for the amount needed for a lethal dosage.[189] Not only has he told us about her disease, its progression, and its predicted progression, but he has told us about her earlier battles with alcoholism and depression, her need to be in control of her death as well as her life, and the fact that she will suffer

---

in the realm of the abortion debate, where relational feminism and its "communitarian underpinnings and tendency to impose moral responsibility in situations of need make defending abortion difficult").

184 GILLIGAN, *supra* note 183, at 29. For example, Gilligan recounts an experiment designed to measure moral development in adolescence by presenting participants with a conflict between moral norms. Male and female children approached the resolution of the dilemma quite differently. In this experiment, the dilemma presented is whether a man, Heinz, should steal a drug which he cannot afford, in order to save the life of his dying wife. The druggist refuses to lower the price, yet Heinz's wife will die without the medication. An eleven-year-old boy responded immediately and unequivocally that Heinz should steal the drug, analyzing the dilemma as one between life and property, with life as the prevailing and logical choice. The boy set up the moral dilemma as an equation, or math problem, and proceeded to a rationally derived solution that rested on an assumption of "a societal consensus around moral values that allows one to know and expect others to recognize what is 'the right thing to do.'" *Id.* at 25-26.

In contrast, the eleven-year-old girl responded with less certainty, and considered neither property nor law in her answer. Rather, she was concerned with the effect that stealing would have on the relationship between Heinz and his wife, reasoning that if Heinz stole the drug he might end up in jail, forever precluded from helping his wife. *Id.* at 28. Thus, the girl viewed the problem as "a narrative of relationships that extends over time," envisioning the continued interdependence of Heinz and his wife, and contemplating the value of the wife's life in the context of others around her. *Id.* Given that the girl's moral reasoning was based on the belief that, "'if somebody has something that would keep somebody alive, then it's not right not to give it to them,'" she was resolving the dilemma based upon the druggist's failure to respond, not upon his assertion of his legal rights. *Id.*

The boy was confident that even a judge would agree that stealing is the correct thing for Heinz to do, while the girl was confident that Heinz and the druggist could reach an agreement through negotiation and compromise, thereby obviating the need to steal. "Both children thus recognize the need for agreement but see it as mediated in different ways—he impersonally through systems of logic and law, she personally through communication in relationship." *Id.* at 29.

185 *Id.* at 19.

186 *See, e.g.*, MACKINNON, *supra* note 183, at 39.

187 *See, e.g.*, NODDINGS, *supra* note 181.

188 *See, e.g.*, Donald P. Judges, *Taking Care Seriously: Relational Feminism, Sexual Difference, and Abortion*, 73 N.C. L. REV. 1323 (1995).

189 Quill, *supra* note 92.

greatly if not given the means to control her death.[190] Similarly, in *Compassion in Dying*, the Washington state litigation over physician-assisted suicide, both the district and appellate courts give us accounts of the individual suffering of the plaintiffs.[191] In *Bouvia v. Superior Court*, where the court permitted the withdrawal of Elizabeth Bouvia's feeding tube, her physical and mental suffering is catalogued in detail.[192]

But in the latter two instances, we are not merely talking about an individual physician, such as Dr. Quill, trying to make a judgment consonant with his medical training and morality. While the courts in *Compassion in Dying* and *Bouvia* lent compassionate ears to the individualized suffering of the plaintiff, they were not concerned merely with the appropriate response a particular relationship of care would require; they were concerned about universal *rights*.[193] Yet rights are associated with the "ethic of justice," not the ethic of care.

As we continue to move along the path of a collective conscience in matters of health, the responsibility we feel for the care of others becomes duty, and in the language of advocacy for recognition and adherence to that duty, we see constant recourse to the familiar language of rights. To give proper weight to a concern within our rights-based constitutional framework, there is pressure to discover or proclaim (depending on your natural law or positivist proclivities) a right. Thus, to ensure that we properly adhere to the collective duty we feel to alleviate individuals' suffering, there is pressure to recognize an individual's right to claim the resources needed for the alleviation of that suffering.

Rights to have one's suffering alleviated or avoided do seem to pull from both the ethic of care (requiring a particularized response to an individual's suffering) and the ethic of justice (expressing concern for others by respecting rights-claims). But Gilligan claims that rights and the ethic of justice are incompatible with the ethic of care.[194] Others, however, have sought to explore where the two ethics merge or could be conjoined,[195]

190 *Id.* at 692-93. Quill describes his initial response to her request: "Knowing of her desire for independence and her decision to stay in control, I thought this request made perfect sense." When he has given her the prescription and advice regarding how to use the barbiturates to kill herself, he writes, "I wrote the prescription with an uneasy feeling about the boundaries I was exploring—spiritual, legal, professional, and personal. Yet I also felt strongly that I was setting her free to get the most out of the time she had left, and to maintain dignity and control on her own terms until her death." *Id.* at 693. *See generally* Patricia Wesley, *Dying Safely*, 8 ISSUES IN L. & MED. 467 (1993) (critiquing what she calls Quill's "seductive text" and arguing that Quill, according to the account he himself provides, was not simply a self-effacing physician who respected his patient's autonomy, but was a "powerful actor" in Diane's story, injecting his own values into her medical decisions).

191 *See supra* note 104 and accompanying text.

192 *See supra* notes 118-27 and accompanying text.

193 Timothy Quill also used his published experience with Diane as a springboard for a proposal legalizing physician-assisted suicide, though he does not in that proposal suggest that suffering individuals have a *right* to physician aid in dying. Timothy E. Quill et al., *Care of the Hopelessly Ill: Proposed Clinical Criteria for Physician-Assisted Suicide*, 327 N. ENG. J. MED. 1380 (1992).

194 Carol Gilligan, *Remapping the Moral Domain: New Images of the Self in Relationship*, *in* RECONSTRUCTING INDIVIDUALISM: AUTONOMY, INDIVIDUALITY, AND THE SELF IN WESTERN THOUGHT 237 (Thomas C. Heller et al. eds., 1986).

195 *See, e.g.*, Elizabeth Ann Bartlett, *Beyond Either/Or: Justice and Care in the Ethics of Albert Camus*, *in* EXPLORATIONS IN FEMINIST ETHICS 82 (Eve Browning Cole & Susan Coultrap-McQuin eds., 1992) ("ethics of care and justice must work in conjunction to secure their mutual goals of

some suggesting that rights provide a minimal level of acceptable behavior when caring relationships are absent,[196] or that the ethic of care can inform the interpretation of rights.[197] But rights based in suffering do not merely define minimal levels of behavior or reflect a "caring" interpretation of currently recognized rights; they create new, unprecedented expectations of rescue-like behavior. How consistent are such rights—which appear to be prompted by caring concerns for the suffering of others—with the ethic of care?

With respect to the beginning of life and a prenatal diagnosis of disability, the ethic of care would appear to require a compassionate response to the prospective parents' suffering, and sensitivity to the difficult choices they must make; if the child is born, a similar caring and accepting response would be expected, as all persons with disabilities are valued by the ethic of care. The right not to be born does not suggest any such care.

Similarly, with respect to the terminally ill, the ethic of care would appear to require, at a minimum, the provision of medical care to those who are ill, and in particular, the provision of adequate, competent comfort care; in addition, the ethic of care would seek to provide such individuals with the company of those they love. Again, the right to die and the right to physician-assisted suicide do not suggest such care.[198]

Rather, the right not to be born and the right to die, while borne out of concerns of individual suffering, are, by their universal nature, absent of individualized care. As I discuss in the next Section, the combination of rights (ethic of justice) and concern about suffering (ethic of care) is potentially destructive of our strongly held principles of equality and liberty (or autonomy) and ultimately, of care as well. It is important then to ask not only what social forces or new political or theoretical ideas prompt a recognition of, or pressure to recognize, rights based in suffering, but also to ask how recognition of such rights would fit within or challenge our existing framework of rights.

IV. Implications of Rights Based in Suffering

If we let medical definitions of and responses to suffering prevail, and give these the weight of law, we risk two grave results. First, we crowd out other definitions and responses to suffering. Our law combined with medicine will create the norms for behavior at the edges of life. Individuals acting singly, in families, or as communities will have less influence than doctors in setting such norms. Second, we face a potential erosion of rights

the respect of human dignity"); Robin S. Dillon, *Care and Respect, in* Explorations in Feminist Ethics, *supra*, at 69, 77 (advocating recognition of "care respect," which calls attention to both the moral significance of common humanity and the particular, concrete individual).

196 *See, e.g.*, Rita Manning, *Just Caring, in* Explorations in Feminist Ethics, *supra* note 195, at 45; Judges, *supra* note 188, at 1382-88 (rights are "care's substitute in impersonal relations, and reliance on rights evidences care's absence"; rights can protect individuals "when caring can no longer be counted on to prevent harm and promote well-being").

197 Judges, *supra* note 188, at 1389-98.

198 *But see* Leslie Bender, *A Feminist Analysis of Physician-Assisted Dying and Voluntary Active Euthanasia*, 59 Tenn. L. Rev. 519 (1992) (arguing that a care-based analysis can support physician assistance in dying).

we have traditionally held dear. We have now, through medicine, the tools to evaluate the worth of an individual's life or continued life, and, through law, the language of rights to support action taken on the basis of that evaluation. But as we recognize an individual's right to relief from suffering, we risk an erosion of that individual's rights to liberty and equality, and provide the language and the justification for taking a suffering individual's life for another's good.

A. Permitting Other Definitions of and Responses to Suffering

In a recently published essay, Leonard Harris considers the eunuchization of George Washington Carver.[199] He describes how the doctor who made Carver a eunuch could have done so while believing he was respecting Carver's autonomy, and in particular, his bodily integrity, his best interests, and his right to equal treatment. This is so, according to Harris, because Carver's doctor would have been giving content to these concepts by importing into them contemporary social ideas about the inferiority of African-Americans and an understanding of the life that lay ahead of Carver as an African-American. Castration was therapeutic because it would allow Carver to hold a higher status than most slaves; he would be perceived as less of a threat to white women and therefore would avoid being lynched; as a house servant he would likely receive some education.[200] In Harris's account, in keeping with the doctrine of informed consent, a component of our notion of autonomy, eleven-year-old Carver is consulted. He appears ambivalent about the procedure, but does not appear to protest in the face of these reasonable assessments about the efficacy of castration in improving his life prospects.[201] The doctor castrating George Washington Carver could do so in keeping with notions of autonomy and bodily integrity because, according to Harris, "the body is a socially constructed and constituted subject entwined and configured by the physician and the physician's social context."[202]

If *autonomy*, which is supposed to be *value-neutral*, can be so tainted in its application by prejudicial and discriminatory social attitudes and conditions, then how much more so shall rights based in the much more subjective and emotionally charged realm of *suffering* be subject to such skewed application? By its very nature, suffering is laden with subjectively placed content. If we adopt what I have called the medical model of suffering, and import into our ethical and legal norms medical definitions of, tolerances for, and solutions to, suffering, then we give up other definitions, tolerances, solutions. At first we may be deferring to physicians and the medical community. After the norms have been imported, however, we will feel comfortable declaring for ourselves when the suffering of individuals is occurring, is sufficient, and should not take place. Our language, our options, our opportunities for other responses will have been limited to

199 Leonard Harris, *Autonomy Under Duress, in* AFRICAN-AMERICAN PERSPECTIVES ON BIOMEDICAL ETHICS 133 (Harley E. Flack & Edmund D. Pellegrino eds., 1992).
200 *Id.* at 136.
201 *Id.* at 137.
202 *Id.* at 147.

that with which we have grown familiar. The behavior of the mother of Baby K, for example, becomes incomprehensible to us. Why did she insist that her anencephalic daughter be resuscitated, like any other child in respiratory distress? The medical evidence clearly indicated that her daughter had no life worth living.

Quality of life assessments abound in determinations of the presence of suffering and its degree of severity. When we think about doctors or courts making quality of life assessments in the context of decisions concerning medical treatment, or the refusal of medical treatment, we generally think of them as focusing on the physical pain of the individual or the diminished abilities of the individual. When assessments are made about diminished abilities, this gives us pause: Is this another form of discrimination on the basis of disabilities? Advocates for persons with disabilities would say the presence of disabilities does not equate to increased suffering of the individual. Marsha Saxton, while she recognizes that some persons with disabilities do suffer, asserts that as a group, people with disabilities do not suffer any more than any other group or category of people.[203] She further observes that the suffering that persons with disabilities do experience is "primarily a result of not enough human caring, acceptance, and respect."[204] And the absence of human caring, acceptance, and respect certainly seems apparent in the *Bouvia* case, where the woman with quadriplegia who wanted the hospital to allow her to starve herself to death had recently suffered a miscarriage, had her husband leave her, had her parents tell her they could no longer take care of her, and had unsuccessfully searched for housing adequate for her situation.[205]

Physicians look not only at diminished abilities, however, but even at cosmetic differences as sources of suffering, and sometimes courts have given credence to this view. Thus, in the name of the best interests of the child, a New York family court has overridden the decision of a mother not to force her son to undergo cosmetic surgery for neurofibromatosis, the judge concluding that without corrective surgery, a "normal, happy existence" would "unquestionably be *impossible.*"[206] Assessments about quality of

---

203 Marsha Saxton, *Prenatal Screening and Discriminatory Attitudes About Disability*, 13 WOMEN & HEALTH 217, 222 (1987). Saxton, a person with spina bifida and a former director of a center for persons with disabilities, notes that:

> [J]ust as the larger population, some of these individuals experience considerable difficulty in their lives while others do fine, have jobs, and enjoy a full and satisfying life with friends and family. . . . As a group, people with disabilities do not "suffer" any more than any other group or category of humans. Our limitations may be more outwardly visible, our need for help more apparent, but like anybody else, the "suffering" we may experience is primarily a result of not enough human caring, acceptance, and respect.

Id. at 221-22.

204 *Id.* at 222; *see also* HARLAN LANE, THE MASK OF BENEVOLENCE: DISABLING THE DEAF COMMUNITY (1992). Lane writes: "What is unforgivable [to hearing people] is that members of the deaf community insist they are fine—for example, two-thirds of deaf adults interviewed in a 1988 survey thought their social life was better than hearing people's—when in fact we can give them a thousand reasons why they can't be." *Id.* at 9. While deafness is considered a disability by hearing people, and by the Americans with Disabilities Act, 42 U.S.C. §§ 12,101-12,213 (1994), many members of the deaf community do not consider deafness a disability. *Id.*

205 Longmore, *supra* note 121.

206 In re Sampson, 317 N.Y.S.2d 641, 657 (N.Y. Fam. Ct. 1970), *aff'd*, 323 N.Y.S.2d 253 (N.Y. App. Div. 1971), *aff'd*, 278 N.E.2d 918 (N.Y. 1972) (emphasis added) (quoted in JOSEPH GOLD-

life when the cosmetic difference is minimal are more controversial and less judicially sanctioned. But recently an abortion practitioner testified before Congress that he had performed nine "partial birth" abortions—controversial late term abortions in which the fetus is partially outside the mother's body (usually its feet) when its skull is pierced, causing death—"solely because [the fetuses had] cleft palates."[207]

These contemporary cases resemble Harris's narrative; is it then reasonable to assume that someone will suffer or is suffering in part because of her race or gender? The New York State Task Force convened to consider the issue of assisted suicide concluded that:

> No matter how carefully any guidelines are framed, assisted suicide and euthanasia will be practiced through the prism of social inequality and bias that characterizes the delivery of services in all segments of our society, including health care. The practices will pose the greatest risks to those who are poor, elderly, members of a minority group, or without access to good medical care.[208]

One might point out that society had its ways long before the advent of medical technology to end the suffering of children born with genetic impairments or the aged whose ability to function was diminished as a result of aging or disease. These individuals could be left behind or be the last fed; in the extreme, infanticide and involuntary euthanasia have been prac-

---

STEIN ET AL., IN THE BEST INTEREST OF THE CHILD 165 (1986)). The judge declared the child "neglected" in order to veto the mother's decision and require the facial surgery recommended by the Commissioner of Health.

207 John Leo, *Harder Hearts on Abortion*, U.S. NEWS & WORLD REP., Nov. 20, 1995, at 42.

208 THE NEW YORK STATE TASK FORCE ON LIFE AND THE LAW, WHEN DEATH IS SOUGHT: ASSISTED SUICIDE AND EUTHANASIA IN THE MEDICAL CONTEXT xii (1994). As of the spring of 1994, 12 of the 19 individuals whose suicides Jack Kevorkian had assisted were middle-aged women. Nancy J. Osgood & Susan A. Eisenhandler, *Gender and Assisted and Acquiescent Suicide: A Suicidologist's Perspective*, 9 ISSUES IN L. & MED. 361 (1994). Osgood and Eisenhandler note that although there are no accurate statistics on victims of assisted suicide available at this time, "[i]f the Kevorkian cases accurately reflect the total of all assisted suicide cases, then it would appear that individuals who die from assisted suicide are more likely to be older women." *Id.* at 362-63. This disproportional use of physician-assisted suicide by women may reflect our culture's tendency to devalue older women. Boozang, *supra* note 77, at 32 n.34 (explaining that in our society, women are considered to age more rapidly than men, causing them to experience not only the devaluation associated with old age, but also "the additional loss of societal value and status connected with women's loss of beauty and youth, as well as their sexuality and reproductive functions").

The disproportionate number of women committing physician-assisted suicide may also reflect physicians' attitudes about female dependency that cause physicians to make decisions for their female patients. *Id.* (physicians doubt the ability of women to make rational decisions concerning their own health care, choosing instead to "commandeer these decisions and execute them from a biased perspective about their female patients' needs"). Physicians are also more apt to dismiss women's complaints as emotional, resulting in inadequate care. *Id.* (citing Council on Ethical and Judicial Affairs, American Medical Association, *Gender Disparities in Clinical Decision Making*, 266 JAMA 559, 560 (1991)) (Although "[w]omen undergo more examinations, laboratory tests, and blood pressure checks, and receive more drug prescriptions and return appointments than men," women are generally denied access to major diagnostic or therapeutic interventions such as dialysis, kidney transplants, and cardiac catheterization.).

See also Earl S. Ford & Richard S. Cooper, *Implications of Race/Ethnicity for Health and Health Care Use*, 30 HEALTH SERVICES RES. 237, 244 (1995) (reasons for the disparity in medical care given to African Americans are "likely to be multifactorial and complex," but it is possible that "subtle or overt racism by the health care providers or the health care system" may contribute).

ticed.[209] Such practices might have been necessary for the survival of some communities; for others, such as technologically advanced Nazi Germany,[210] there is no plausible excuse. In neither case, however, would we be entitled to claim that infanticide or euthanasia was the individual subject's *right.*

But we do seem to be willing to talk about rights to die or rights not to be born when the individual asserting that right (or on whose behalf it is being asserted), appears to have a reduced quality of life. And this, it appears, goes under the name of progress. Derek Humphrey writes in *Final Exit* that "[t]he time is not far off when physician-assisted suicide in justifiable cases will be lawful in enlightened countries,"[211] and calls proposals to legalize physician-assisted suicide "reform."[212] In a recent article of *Barrister,* the magazine of the Young Lawyers' Division of the American Bar Association, an attorney working to legalize physician-assisted suicide was

209 The practice of leaving unwanted children exposed to the elements and, less commonly, deliberately destroying them, has been present not only in more "primitive" societies, but also in the history of the West, usually as a means of relieving the strain on family and community resources. *See generally* William L. Langer, *Infanticide, A Historical Survey,* 1 J. OF PSYCHOHISTORY 353 (1974); Susan C. M. Scrimshaw, *Infanticide in Human Populations: Societal and Individual Concerns, in* INFANTICIDE: COMPARATIVE AND EVOLUTIONARY PERSPECTIVES 439 (Glenn Hausfater & Sarah Blaffer Hardy eds., 1984); *see also* Laila Williamson, *Infanticide: An Anthropological Analysis, in* INFANTICIDE AND THE VALUE OF LIFE 61, 73 (Marvin Kohl ed., 1978).

In Greco-Roman civilization, the infanticide of children with disabilities was common because people believed such children were harbingers of the future, and that an undesired future could be changed by killing the child. Kathryn L. Moseley, *The History of Infanticide in Western Society,* 1 ISSUES OF L. & MED. 345, 346 (1986). During the Middle Ages, newborns with disabilities were suspected of being "changelings," or supernatural beings who were not the actual children of the parents. *Id.* at 352. Since the only way to force the "right" child to appear was to abuse the "changeling" in some way, children with disabilities were often the victims of physical abuse and infanticide. *Id.* at 353. Under these beliefs, the parents were without blame, because it was believed that the real child had been spirited away by fairies out of envy, leaving the parents as innocent victims who had lost their "right" child. *Id.* The Christian version of the changeling myth took the superstition one step further, claiming that the child was not taken by fairies, but was "the demonical child of the devil himself." *Id.* Moseley asserts that "[i]fanticide of the handicapped newborn has been relatively common in Western society. . . . Ancient attitudes continue to have an impact on our notions of the value of disabled newborns and continue to play a role in their loss of life." *Id.* at 361.

210 Shortly after the start of World War II, Germany began performing euthanasia by gassing handicapped infants, the elderly, and long-term psychiatric patients in order to make room in the hospital wards for the war-wounded. Robert N. Proctor, *Nazi Doctors, Racial Medicine, and Human Experimentation, in* THE NAZI DOCTORS AND THE NUREMBURG CODE 24 (George J. Annas & Michael A. Grodin eds., 1992). Proctor writes about the "banality" and "popularity" of the euthanasia operation:

> In 1941, for example, the psychiatric institution of Hadamar celebrated the cremation of its ten-thousandth patient in a special ceremony, where everyone in attendance—secretaries, nurses, and psychiatrists—received a bottle of beer for the occasion. The operation was also popular *outside* the medical community. Parents were made to feel shame and embarrassment at having to raise an abnormal or malformed child. Hospital archives are full of letters from parents requesting their children be granted euthanasia.

Id. at 25. In proposing a "solution" to the "'Jewish Question,'" the Nazis decided upon euthanasia by gas, since "the technical apparatus already existed for the destruction of the mentally ill." *Id.* Thus, once the euthanasia operation of the mentally incompetent patients was complete, the hospital gas chambers were dismantled and shipped to the concentration camps. *Id.* Proctor notes that, "[i]n this sense, there was continuity in both theory and practice between the destruction of the lives not worth living in Germany's mental hospitals and the destruction of Germany's ethnic and social minorities." *Id.*

211 HUMPHREY, *supra* note 91, at 18.

212 *Id.*

heralded as one of twenty-one young lawyers "leading us into the twenty-first century,"[213] where an attorney working for the opposite camp, I venture to say, would not have been.

But, it may be argued, we are only talking here about a right not to be born and a right to die, rights to have one's suffering alleviated or avoided that can be exercised only by the individual claiming such right. No one is forcing anyone to exercise these rights, and so concerns about rights based in suffering are misplaced. This view, however, ignores the complex and reciprocal interactions between legal and general culture. Our recognition of rights and our language of rights establishes social norms of behavior. For example, the right to speak may impose an ethical obligation to speak—"You could have said something, why didn't you?" The right to abortion and its reliance in part, at least in rhetoric, on the best interest of the child (for example, the parents were not ready to provide a good home for the child, an additional child would take the parents' time away from other children, a child born with disabilities will suffer) may lead, may indeed have already led, to an ethical obligation to act in accordance with those concerns—at times turning the right to abort into an ethical obligation to abort.[214] So too with the right to die with dignity. Is recognition of the right in public opinion and law establishing a norm that one *should* die with dignity? Will dying characterized by senility or dementia, by drooling, by groans of distress, by incapacity to care for oneself, be acceptable?[215] Isn't what really bothers Timothy Quill's patient, Diane, the fact that she will become dependent upon others—not that she will suffer physical pain?[216] If we tended to devote the time and emotional resources to care for those who are sick and dying, and to learn to treat such individuals with respect and not as a burden, would the suffering of some individuals who claim that they wish to die (and who may in fact wish to die) be alleviated? How much suffering, we must ask, could we alleviate with the prescription suggested by Marsha Saxton with respect to persons with disabilities: more "human caring, acceptance, and respect"?

If we let prevail the medical model of suffering, its definitions, risk tolerances, and responses, we crowd out other responses to suffering, such as more "human caring, acceptance and respect." There is a myriad of other responses to suffering that may have merit—from individual re-

213 Gwen A. Baumann, *21 Leading Young Lawyers Different Yet Alike*, BARRISTER, Summer 1995, at 8.

214 *See supra* notes 71-72 and accompanying text.

215 The Ninth Circuit's opinion in Compassion in Dying v. Washington, 79 F.3d 790 (9th Cir.) (en banc), *cert. granted sub nom.* Washington v. Glucksberg, 65 U.S.L.W. 3085 (U.S. Oct 1, 1996), cites with some implicit approval the attitudes of many philosophers and writers concerning the nobility of dying "at the right time." *Id.* at 807. For example, the court tells us that Hume believed "that a decision by a terminally ill patient to end his life was often laudable," *id.* at 808 (citations omitted); that Plato "suggested that if life itself became immoderate, then suicide became a rational, justifiable act," *id.* at 807 (citations omitted); and that Montaigne wrote of Cato, who killed himself to avoid dishonor, "[s]uch courage is above philosophy," *id.* at 807 (citations omitted); *see also supra* note 90.

216 *See* Quill, *supra* note 92, at 693 (Quill emphasizes Diane's "desire for independence and her decision to stay in control."). *But see* Wesley, *supra* note 190, at 469 (suggesting the possibility that Diane's view that "she must be independent and in control, no matter what the cost," may have impaired her "ability to fully assess all her options as she faced a life-threatening illness").

sponses, such as spiritual or religious inspiration,[217] and individual resolve, a Viktor Frankl quest for deeper understanding from what one suffers,[218] to societal responses, such as the provision of equal opportunities and accessibility for persons with disabilities, and research into cures for persons suffering from diseases (not a priority when the births of such individuals can simply be avoided).[219] These other responses will not be necessary if the problem of the suffering individual is always "fixed" with a medical solution; a sanitized, clinical, professionally endorsed and executed solution: at the edges of life, avoid the births of genetically different children by prenatal diagnosis and abortion, and aid the elderly, the sick, and the severely disabled toward death.

B. Erosion of Rights

While the alleviation of suffering has long guided many moral actions, the duty to help others has remained for many centuries what Kant would call an "imperfect duty."[220] Only "perfect duties" have corresponding rights; for example, the perfect duty not to unjustly harm another means that individuals have a right not to be unjustly harmed.[221] This perfect duty resembles the rights to non-interference that we recognize under the basic notion of liberty.[222] We have rights to be free from the harms unjustly imposed upon us by others, just as we are generally free in our actions so long as we do not unjustly harm others. But the duty to aid others, being an imperfect duty, has not traditionally accorded one the right to that aid.[223] In the Anglo-American legal tradition, persons do not have a legal duty to rescue another (and the person in distress does not have a

217 ARNOLD TOYNBEE, AN HISTORIAN'S APPROACH TO RELIGION 296 (1979) ("The practical test of a religion, always and everywhere, is its success or failure in helping human souls to respond to the challenge of Suffering and Sin.").

218 VIKTOR EMIL FRANKL, MAN'S SEARCH FOR MEANING (1963).

219 Martha A. Field, *Killing "the Handicapped"—Before and After Birth*, 16 HARV. WOMEN'S L.J. 79, 117-18 (1993).

220 JEFFRIE G. MURPHY, KANT: THE PHILOSOPHY OF RIGHT 51 (1970). Murphy writes:

> A duty is imperfect if no one is in a position to demand by *right* that it be complied with. I have, according to Kant, a duty to promote human happiness. This duty is imperfect, however, because no one can demand by right that I make him happy, can regard himself as wronged if I fail to make him happy.

Id. An "imperfect duty," such as the duty of benevolence, is "not constantly and universally binding; that is, we are not obligated or duty-bound to help everyone all the time." John Arras & Robert Hunt, *Ethical Theory in the Medical Context*, *in* JOHN ARRAS & N. RHODEN, BIOMEDICAL ETHICS: A GUIDE TO DECISIONMAKING 16 (3d ed. 1989). This does not mean, however, that we are not morally bound to exercise benevolence; rather, it means "that inclination can play a legitimate role in determining whom to aid and when to aid them." *Id.*

221 MURPHY, *supra* note 220, at 51. It is never right to violate a perfect duty. Arras & Hunt, *supra* note 220, at 16. Perfect duties to others are "juridical duties" or "duties of justice" and the "proper object of coercion by the State." MURPHY, *supra* note 220, at 51-52. "[P]erfect duties are matched by perfect rights; specifically, the perfect duty to refrain from violating the liberty or integrity of others is matched by a corresponding *right* to be free from such violation." Arras & Hunt, supra note 220, at 16.

222 MURPHY, *supra* note 220, at 51-52.

223 "Because of [a] reluctance to countenance 'nonfeasance' as a basis of liability, the law has persistently refused to impose on a stranger the moral obligation of common humanity to go to the aid of another human being who is in danger, even if the other is in danger of losing his life." W. PAGE KEETON ET AL., PROSSER AND KEETON ON THE LAW OF TORTS § 56, at 375 (5th ed. 1984); *see also* JOEL FEINBERG, HARM TO OTHERS (1984).

legal right to be rescued) unless they are in a special relationship that requires such care.[224]

Thus, talk of rights and legal recognition of rights in our country has been predominantly that of "negative" rights, or rights to non-interference. Claims that people are entitled to certain goods, such as adequate housing or food, that they have "positive rights" much like rights based in the idea that one's suffering should be alleviated, have historically been rejected in both our democratic processes and by our judiciary.[225] Two overarching principles are generally invoked to support recognition of particular rights, whether from a constitutional[226] or a philosophical perspective.[227] These are the principles of liberty and equality. The right to abortion, for example, has been justified under both of these approaches—i.e., women have a right to abortion because they have a right to non-interference with their body and their lives (the liberty argument)[228] and women have a right to the same opportunities as men, and cannot enjoy such opportunities without the right to abortion and thus control over their reproductive selves (the equality argument).[229] Other rights that are normally seen as stemming from concerns over freedom can also be justified under equality concerns—thus, freedom of speech is not simply concerned about the individual liberty of the speaker to express himself, but is also concerned

---

In contrast to the legal tradition, our country's majoritarian religious tradition, that of Christianity, calls upon people to help others, much more so than it calls upon people to respect others' rights to be left alone or to be treated equally. The Good Samaritan story focuses not on how the beaten traveler was wronged and treated unfairly by his robbers, but on how the Samaritan alleviated his suffering. As a call to duty, then, the Christian tradition has a longstanding recognition of suffering. But while there may be a duty to aid another, there does not appear to be a corresponding right held by the suffering individual of the end of that suffering, although there may be special dispensation in heaven.

224 KEETON ET AL., *supra* note 223, at 376 (Carrier has a duty to take reasonable affirmative steps to aid a passenger in peril; innkeeper has a duty to aid his guest; employer has a duty to an employee who is injured in the course of his employment; host has a duty to aid his guest; shopkeeper has a duty to aid his business visitor; jailor has a duty to aid his prisoner.).

225 In *DeShaney v. Winnebago County Dep't of Soc. Servs.*, 489 U.S. 189 (1989), the Supreme Court held that a state child welfare agency bore no duty to rescue a four-year-old child who had been beaten into mental retardation by his father, even though the state agents knew of the abusive situation. The Court reasoned that: "[T]he Due Process Clauses generally confer no affirmative right to governmental aid, even where such aid may be necessary to secure life, liberty, or property interests of which the government itself may not deprive the individual." *Id.* at 196; *see also* Harris v. McRae, 448 U.S. 297, 317-18 (1980) (discussing the Due Process Clause of the Fifth Amendment and finding that no obligation exists to fund abortions or other medical services); Lindsey v. Normet, 405 U.S. 56, 74 (1972) (discussing the Due Process Clause of the Fourteenth Amendment and finding that no obligation exists to provide adequate housing); Youngberg v. Romeo, 457 U.S. 307, 317 (1982) ("As a general matter, a State is under no constitutional duty to provide substantive services for those within its border.").

226 *See* U.S. Const. amend. XIV, § 1 (Due Process and Equal Protection Clauses); U.S. CONST. amend. V (Due Process Clause).

227 For the idea that equality is the foundational principle for all rights and liberties, see RONALD DWORKIN, TAKING RIGHTS SERIOUSLY 272-74 (1978); John Rawls, *Justice as Fairness*, 67 PHIL. REV. 164, 165-66 (1958). *But see* Mark Tushnet, *An Essay on Rights*, 62 TEX. L. REV. 1363 (1984) (arguing that we lack a substantive theory of rights); Peter Westen, *The Empty Idea of Equality*, 95 HARV. L. REV. 537 (1982) (arguing that statements of equality collapse into more basic statements of rights, rendering the concept of equality superfluous).

228 Planned Parenthood v. Casey, 505 U.S. 833, 869 (1992) (stating right to abort is based on a liberty interest) (plurality opinion).

229 *See id.* at 927 (Blackmun, J., concurring) (stating that the assumption that women should carry to term rests upon a conception of a woman's role that triggers the protection of the Equal Protection Clause).

about that individual's liberty to do so as compared to others—if only some of us were allowed to speak, we would have a power, and thus an unequal advantage over others.

But while some particular rights draw appeal from both equality and liberty, the relationship between liberty and equality in many instances is an uneasy one. Some specific rights appeal more to one of these qualities than to the other, and rights often are in conflict in a particular situation. The most obvious example is that the right to equality of goods or even opportunities for livelihood may conflict with the rights of others in freedom from interference with their own goods acquired through legitimate means, whether work (fruits of their labor) or inheritance (respecting the freedom of persons to direct how their legitimately acquired goods are distributed upon death). This uneasy balancing[230] often involves the conflicting rights of two individuals; for example, my freedom of speech may have to be curtailed in the interest of your freedom of religion in a captive audience situation. We have no formula to balance the particular rights of persons in conflict, nor to balance the underlying liberty and equality concerns reflected in such particular rights.[231]

Legal recognition of rights based in liberty and equality entails duties of non-interference and equal protection of the laws, respectively; in the realm of medical ethics, rights based in liberty and equality parallel principles of autonomy and equal respect. If we are to recognize rights based in suffering as we have long recognized rights based in liberty and equality, then corresponding duties will follow. These duties are unlikely to be limited to relieving self-identified suffering; that is, to relieve suffering when the sufferer has identified the suffering he wishes to have alleviated.[232] Instead, acknowledging rights to relief from suffering will entail the duty to make quality of life judgments to determine the meaning or existence of suffering and will require action upon such judgments at the expense of liberty and equality.

The enjoyment of a *right* to relief from suffering (as in a right to physician-assisted suicide or a right not to be born) demands a direct, corresponding duty on the part of others: one cannot exercise a right to physician-assisted suicide unless someone or society makes a quality of life judgment that "weighs" one type of suffering against that of another, to determine if the suffering is severe enough to warrant granting the request. If, as I have argued, the issue is *not* autonomy, but *suffering*, then the issue is not how the *suffering individual* feels, but how *we* feel; whether *we* feel the suffering merits relief through death, and we decide who can or cannot die. Some courts have already recognized the inevitability of this sort of

230 A mild description according to Critical Legal Scholars. *See, e.g.*, ROBERTO MANGABEIRA UNGER, KNOWLEDGE & POLITICS (1975).

231 In attempting to balance interests, these interests must be reduced "to some common measure of value." Tushnet, *supra* note 227, at 1372. "The choice of the measure of value [to be assigned to each interest] must be guided by some substantive theory of rights. . . . [yet] the Supreme Court has not provided us with such a theory." *Id.* Rights are also, of course, "balanced" against interests of the state as well.

232 Such a duty might be thought of as a duty to enable someone to exercise their autonomy; the corresponding right being understood not simply as autonomy, but "enabled autonomy."

assessment in wrongful life cases; that is, that judicial factfinders are faced with determining whether a life with disabilities is worse than no life at all.

These are decisions I say are not ours to make. Recognizing rights based in suffering requires that *we* (meaning those unconnected to the decision: physicians, courts, society) make decisions about other people's suffering, their quality of life and therefore their value in living. If we decide that the suffering is severe and the quality of life substantially diminished, then we are justified in treating this unequal life differently. We are justified in making decisions that erode autonomy and equality in the name of providing required relief from suffering.

The potential (though improbable) application of wrongful life suits against parents, and the more likely and already apparent economic, professional, and social pressure on parents to abort "defective" fetuses, acknowledge the right of children to avoid suffering. But they do so at the cost of individual instances of parental autonomy and, as I have argued elsewhere, as a general matter, they threaten the highly important relationship of attachment between parent and child.[233] Others have written eloquently about the deleterious effect such norms have on persons with disabilities.[234]

When the individual seeks relief from suffering through the termination of life, rather than its avoidance, rights based in suffering carry the same potential harms. The norm of a planned and painless, dignified death, and the norm that only healthy lives are worth living, will place pressure on persons who are terminally ill, elderly, or disabled, to seek medical assistance towards death. In addition, even when the patient is competent and alert, the well-documented power imbalance in the relationship between physician and patient[235] will likely compromise that individual's autonomy in making these decisions. In these ways, the individual's liberty/autonomy interest in avoiding euthanasia and her interest in being treated equally with those who do not suffer stand at risk.[236] The problem, of course, is worse in the case of individuals who are incompetent, as they often are in these situations; the incompetent individual whose life of suffering is to be ended does not in practice have much, or any, say in the matter.

---

233 *See generally* Shepherd, *supra* note 22 (proposing a right to familial attachment which would allow parents to conceive and bear children with their given genetic identity).

234 *See* Hubbard, *supra* note 72, at 232, 234 (arguing that present day programs of prenatal diagnosis mirror the eugenic practices of the Nazis, creating the belief that "disability is unmitigated disaster, that we would be better off if people with disabilities did not exist," thereby perpetuating a "fear of difference" that is damaging to both disabled individuals and to society); ROTHMAN, *supra* note 54, at 154 (explaining that perceiving a disabled child as "defective" exacerbates the experience of estrangement and "otherness" that all disabled people endure); Field, *supra* note 219, at 117-24 (arguing against laws that encourage or sponsor the abortion of fetuses on the basis of predicted disability because of the harm such legal rules have on the population of persons who have disabilities).

235 *See* KATZ, *supra* note 84.

236 *See, e.g.*, Lee v. Oregon, 891 F. Supp. 1429 (D. Or. 1995) (holding that implementation of a measure passed by the Oregon voters that authorized physician assisted suicide for terminally ill patients would violate the Equal Protection Clause). See discussion *supra* at note 198. Measure 16 was also challenged on substantive due process grounds, which were discussed by the court at the preliminary injunction stage, Lee v. Oregon, 869 F. Supp. 1491, 1497-99 (D. Or. 1994), but which were not ultimately decided. *Id.* at 1437.

Looking ahead to the most stark consequences that may follow recognition of rights based in suffering, I fear we may create situations where the life of the suffering individual is balanced against the life of another who may benefit from the termination of the life of the suffering individual. In other words, we may create our own Sophie's Choice.

C. Sophie's Choice

Sophie is given the opportunity to save one of her children. Disembarking at Auschwitz-Birkenau, she encounters the medical doctor charged with selecting who among the truckload of prisoners shall live to work in the camp, and who shall be sent directly to the gas chamber. It is within the doctor's power to take the lives of both of her children; but rather than take both lives, he asks her to choose one to save and one to send to the gas chamber.[237]

She does not, however, have to make that choice. Prior to choosing between her children, she has to decide whether to participate in the evil game that the doctor has thrust upon her. Faced with two evils, the evil of choosing Eva over Jan or the evil of choosing Jan over Eva, she could instead choose not to participate in the evil.

The result is that both will die. One may well ask, isn't this an evil as well? It is, but it is not an evil in which she participates—not an evil of her creation.[238] She is asked to participate in the evil of another, and she could choose not to. Indeed, if her duty as a parent is to love her children unconditionally, that is her only moral option. To choose between them would be to act as though she loved one more than the other, such superior love conditioned upon some trait, perhaps unfathomable, and incapable of description or precise identification. To love one's children unconditionally means to love them equally; otherwise, a parent has placed conditions upon that love.

---

237 STYRON, *supra* note 1, at 483-84.

238 Alan Gewirth explains that all persons have an absolute "right not to be made the intended victim of a homicidal project." Alan Gewirth, *Are There Any Absolute Rights?*, *in* THEORIES OF RIGHTS 91, 108 (Jeremy Waldron ed., 1984). In explaining this right, Gewirth defines the word "project" to mean "a definite, deliberate design; hence, it excludes the kind of unforeseeable immediate crisis where, for example, the unfortunate driver of a trolley whose brakes have failed must choose between killing one person or five." *Id.* at 108. Gewirth provides the example of a man who is required by terrorists to torture his mother to death; if he doesn't, the terrorists will discharge nuclear weapons against a large city, causing millions of other people to die. Under these circumstances, the son would not be justified in torturing to death his mother, and in failing to murder his mother, he would not be morally responsible for the deaths of other innocent persons who might be killed by the terrorists. *Id.* at 104. This is because of the "principle of intervening action." *Id.* at 104-05.

> It follows from the principle of the intervening action that it is not the son but rather the terrorists who are morally as well as causally responsible for the many deaths that do or may ensue on his refusal to torture his mother to death. The important point is not that he lets these persons die rather than kills them, or that he does not harm them but only fails to help them, or that he intends their deaths only obliquely but not directly. The point is rather that [it] is only through the intervening of lethal actions of the terrorists that his refusal eventuates in the many deaths.

Id. at 104. While Gewirth uses the example of a mother-son relationship, he argues that the individual asked to torture to death an innocent person would not be justified in doing so even if there were no family relationship, as all innocent persons have "the [absolute] right not to be made the intended victims of a homicidal project." *Id.* at 108 *passim.*

Does this mean that a parent must spend her resources, whether financial, emotional, or otherwise, equally between her children? No, and this is an important point in the analysis which follows, where I will draw an analogy from Sophie's choice to future choices in medical ethics. Different children, of course, have different needs and desires when it comes to a parent's decisionmaking regarding resources; one child may need a private education, a special tutor, another may need more individual attention from the parent or may cause more worry.

But when it comes to questions of basic worth—whether one child's life is *worth* more to a parent than another child's life—it is a savage betrayal of parental love, of parental duty, to choose one life over another.[239] Indeed, the doctor in charge of selection realizes this fact at its most fundamental core; the narrator of Sophie's Choice explains: "[W]hat, in the private misery of his heart, I think he most intensely lusted to do was to inflict upon Sophie, or someone like her—some tender and perishable Christian—a totally unpardonable sin."[240]

Again, however, can we then say that it is better that *both* shall lose their lives? I say yes. If there are any principles that one might say in common fashion are worth dying for—and I submit there are, and I am certainly not alone in this—then the unconditional love of a parent for a child would stand at the top of the list. As the decisionmaker in the family—and, indeed, as the member of the family called upon to make this decision—Sophie must speak for her family and its values. It means both will die. But Eva, the one she chooses for the gas chamber, would not look back at her mother, "beseeching."[241]

If she had not decided—not chosen—both would have died, but she would have killed neither.[242] In deciding against Eva, she participates in the evil of her death. The point here is not to condemn Sophie, a victim herself, who had no time to reflect on the meaning and consequences of the action requested of her, even as such meaning and consequences might directly affect (and indeed ultimately destroy) her. But, unlike Sophie, we do have the leisure to reflect on her action, the leisure Sophie did not have, and we must attempt to understand what we lose in making certain choices, choices that may appear thrust on us that we have the power to refuse.

The illustration of Sophie's Choice is instructive for future decisionmaking in medical ethics. Sophie gives up unconditional love to reduce suffering; we want to give up autonomy and equality to reduce suffering.

239 Could Sophie have avoided committing this wrong by choosing by lots which child to save? First, it should be noted that this option is not before Sophie in the novel; the point of the story is that she is asked to make a conscious choice without the protection of a device of randomness. But given that, even supposing a choice by lottery were available to her, she is still asked to sacrifice one child to save the other; to use one as a means to the other. Her duties of parental love do not permit her, evenly randomly, to use her children as instruments to other ends. *See* Shirley Jackson, *The Lottery*, *in* THE SCAPEGOAT: RITUAL AND LITERATURE 238 (John B. Vickery & J'nan M. Sellery eds., 1972) (creating a fictional account of an annual ritual whereby residents of a village voluntarily draw lots to determine who shall be stoned to death).

240 STYRON, *supra* note 1, at 484.

241 *Id.*

242 *See supra* note 238.

Rather than the principle that a parent should love her children unconditionally, and thus equally, consider the principle that we should have equal respect for all persons. This principle, attributed to Immanuel Kant, is generally recognized in medical ethics as its most important tenet. As with the question of whether a parent must allocate all resources equally between her children,[243] it does not mean that we have to consider all individuals as having equal talents, or deserving the same rewards for their various endeavors, or having the same urgency of need.[244] It means at its most basic level that we will not decide that one person's life is worth more than another person's life and that we will not use individuals as means, but we will respect them as ends in themselves.[245]

To defend adequately the principle of equal respect for all persons would take us onto a different path of exploration. Thus, for purposes of this Article, I take it as given that decisions made in the area of medical ethics are governed generally by the principle that as a society we must have equal respect for persons. Our Constitution, of course, guarantees our citizens equal protection of the laws.[246] While the desirability of an ethic based instead on utilitarianism[247] is still debated, and cost-benefit analyses of a utilitarian nature have a considerable lure in this field, as a general matter, a deontological approach steeped in these Kantian notions has prevailed.[248] Thus, we impose strict requirements regarding the use of humans as subjects of research.[249] One family member cannot be required to donate organs or tissue, such as bone marrow, to another family mem-

243 *See supra* paragraph following paragraph containing note 238.

244 For example, recipients of scarce donor organs are selected primarily on the basis of their urgency of need and the probability of a successful transplant. Shepherd, *supra* note 85, at 809.

245 *See generally* Murphy, *supra* note 220, at 73-86 (explaining Kant's philosophy regarding the principle that persons should be treated as ends in themselves, rather than as means). Kant believed that our status as rational agents or persons gives rise to a right to self-determination, that is, a right to determine our destinies, and that such a right should always be respected. Arras & Hunt, *supra* note 220, at 18. The importance of this duty of respect is grounded in the "powerful and highly influential conception of the moral status of *persons*." Without this insistence that we treat others as equal, we jeopardize our autonomy and become nothing more than "things," whose worth consists not in an innate integrity and dignity, but only in the uses to which they can be put, utterly devoid of autonomy. *Id.* Recognition and preservation of equality and liberty are critical to our status as rational beings; Kant demands that, for our own sake, we treat others as moral equals, and holds that "the test of right action is that it can be universalized [or become a perfect duty] without violating the recognized equality of all human beings." *Id.* at 15.

246 U.S. CONST. amend. XIV.

247 "[T]he utilitarian ethic directs us to elect among available alternatives the one that results in the greatest net amount of happiness." Arras & Hunt, *supra* note 220, at 7-8. When faced with a conflict between justice and utility, act utilitarianism holds that the act providing the most utility should be favored. Rule utilitarianism, on the other hand, asks whether an act "conform[s] to a rule the general practice of which would result in the greatest net amount of happiness." *Id.* at 13.

248 The predominant objection to utilitarianism is that it would permit situations we would generally consider wrong, such as slavery, because it violates our deeply felt notions about the equal respect with which persons should be accorded. *See* MURPHY, *supra* note 220, at 40 (stating that Kant "was one of the first to raise what is now the classic objection to utilitarianism: that it is incompatible with justice."). *But see* MICHAEL J. SANDEL, LIBERALISM AND THE LIMITS OF JUSTICE (1982) (challenging the liberalism of Kant and the primacy of justice).

249 *See* Subpart A-Basic HHS Policy for Protection of Human Research Subjects, 45 C.F.R. §§ 46.101-46.117 (1995).

ber, even if it would save the latter's life.[250] Incompetent individuals can donate nonessential organs to their siblings only if the donation is in the best interest of the donor.[251] Even once a person is dead, doctors are not permitted to harvest cadaver organs without the decedent's earlier documented consent to a "gift" of the organs, or the consent of the decedent's family.[252] No individual can donate his or her essential organs while alive.

Or so it has been.

The Council on Ethical and Judicial Affairs of the American Medical Association [hereinafter Council] recently changed its position on the use of anencephalic newborns as organ donors.[253] While organ donation practices and the law in this country have long insisted that vital organs can only be removed from a deceased individual, the Council expressed a willingness to make an exception to the "dead donor" rule in the case of infants with anencephaly, who are born with a functioning brain stem but no other brain function.[254] While such infants are believed to "never experience any degree of consciousness,"[255] they are not considered dead. Currently, we determine that death has occurred if there is either an irreversible cessation of circulatory and respiratory function or an irreversible cessation of all functions of the entire brain, including the brain

250 McFall v. Shimp, 10 Pa. D. & C.3d 90 (Allegheny County Ct. 1978) (refusing to order individual to donate needed bone marrow to cousin). In this case, the court, while denouncing the refusal of donation on moral grounds, dramatically defends the law's refusal to order such donation:

> For a society which respects the rights of *one* individual, to sink its teeth into the jugular vein or neck of one of its members and suck from it sustenance for *another* member, is revolting to our hard-wrought concepts of jurisprudence. Forceable extraction of living body tissue causes revulsion to the judicial mind. Such would raise the spectre of the swastika and the Inquisition, reminiscent of the horrors this portends.

Id. at 92.

251 Kentucky's Court of Appeals affirmed a ruling authorizing the mother of an adult, incompetent son to direct the donation and transplant of this son's healthy kidney to her other, competent son, who had a fatal kidney disease. Strunk v. Strunk, 445 S.W.2d 145 (Ky. Ct. App. 1969). While ostensibly relying on the doctrine of substituted judgment to authorize the operation, the court's reasoning reveals its reliance on a best interests test. The court reasoned that it was in the incompetent son's best interest to try and save the life of the competent son, in that the incompetent son was "greatly dependent" upon his brother, and "his well-being would be jeopardized more severely by the loss of his brother than by the removal of a kidney." *Id.* at 146; *see also* Lausier v. Pescinski, 226 N.W.2d 180, 181 (Wis. 1975) (denying authority for operation to remove kidney from mentally ill brother for sister's benefit, the court found that "[t]here is absolutely no evidence here that any interests of the ward will be served by the transplant"). *Id.* at 181.

252 UNIF. ANATOMICAL GIFT ACT (1987) 8A U.L.A. 19 (1993). There are exceptions for cadaver corneas in some states, where by statute if a body is under the authority of the medical examiner's office, the corneas may be taken without the execution of a gift document by the decedent or the consent of the decedent's family. *See, e.g.*, KY. REV. STAT. ANN. § 311.187 (Banks-Baldwin 1994). Suits challenging the constitutionality of such statutes have had mixed results. *See* Georgia Lions Eye Bank v. Lavant, 335 S.E.2d 127 (Ga. 1985) (holding that the family of a deceased person has only a common law right not a constitutional right, to control the decedent's body); Brotherton v. Cleveland, 923 F.2d 477 (6th Cir. 1991) (finding that a decedent's wife had legitimate claim of entitlement in husband's body protected by the Due Process Clause; state's interest in harvesting corneas not substantial enough to allow it to take corneas without consent).

Also note that even if the family of the decedent wishes to donate the organs, the decedent's earlier documented or known oral refusal to donate her organs will override the family's later consent. UNIF. ANATOMICAL GIFT ACT (1987) §§ 2(i), 3(b)(2), 8A U.L.A. 34, 40-41 (1993).

253 Council Report, *supra* note 16.

254 *Id.*

255 *Id.* at 1615.

stem.[256] Neither of these descriptions fits the newborn with anencephaly.[257] Such infants rarely live past several days,[258] yet if surgeons wait until the anencephalic infant is dead before removing her organs, the quality of the organs is likely to have deteriorated beyond the point of usefulness for transplantation.[259]

The Council "temporarily suspended" its report following criticism from members of the American Medical Association and some state medical associations. According to the Chair of the Council, the suspension allows time for further research into questions about the consciousness of anencephalic infants and the problem of diagnosing infants with anencephaly.[260] The Council did not retract its essential position that infants who are anencephalic as we now understand that condition can be used as organ donors to benefit other ill children. If the Council's position became law, it would then be possible for the parents of an anencephalic newborn to donate her organs, and for physicians to take those organs, *even though she is still alive, even though she may be breathing on her own.* The Council's rationale for this position can be understood in terms of issues of suffering: suffering as it relates to the parents of the infant with anencephaly, to the infant in need of an organ transplant, and to the infant with anencephaly.

The suffering of the parents of infants born with anencephaly is given brief but prominent mention in the Council's Report. Permitting organ donation from infants with anencephaly would "provid[e] psychological relief for those parents who wish to give meaning to the short life of the anencephalic neonate."[261] The Council appears to have been motivated in large part by the recent case of *In re T.A.C.P.*,[262] in which the Florida

256 UNIF. DETERMINATION OF DEATH ACT, § 1, 12A U.L.A. 593 (1996). The definition of death under the common law was the irreversible cessation of respiratory and cardiac functions. Once these functions could be artificially provided, a new standard for determining death was needed. The Uniform Determination of Death Act, adopted in 32 jurisdictions by 1994, added the brain death standard as an alternative to the traditional cardiac-related standard. Shepherd, *supra* note 85, at 779-81.

257 *See In re* T.A.C.P., 609 So. 2d 588 (Fla. 1992) (holding that an anencephalic newborn is not considered "dead" for purposes of organ donation solely by reason of newborn's congenital deformity); *see also In re* Baby K, 16 F.3d 590 (4th Cir.), *cert. denied*, 115 S.Ct. 91 (1994) (holding that a hospital may not refuse to provide emergency respiratory support to infant born with anencephaly).

258 Council Report, *supra* note 16, at 1615. There is at least one case, however, when an anencephalic infant lived two and a half years. This is the famous Baby K. *In re* Baby K, 16 F.3d 590 (4th Cir.), *cert. denied*, 115 S.Ct. 91 (1994); Marylou Tousignant & Bill Miller, *Death of "Baby K" Leaves a Legacy of Legal Precedents*, WASH. POST, Apr. 7, 1995, at B3.

259 This is the case with solid organ donation generally; the "brain dead" candidate is the optimal candidate because with the assistance of artificial respiratory and cardiac function, the organs of the individual donor remain oxygenated, and suitable for transplantation. Without such artificial support, organs deteriorate rapidly.

260 Diane M. Gianelli, *Ethics Council Reverses Stand on Anencephalic Organ Donors*, AM. MED. NEWS, Dec. 25, 1995, at 3.

261 Council Report, *supra* note 16, at 1614. In one letter to the editor of the *Journal of the American Medical Association* a doctor criticizes the Council's use of the term "neonate": "The very language they use—'anencephalic neonates,' as opposed to 'the infant with anencephaly' bespeaks a degrading value judgment with which the mother of Baby K and, indeed, the mothers of most such infants vehemently disagree." Michael P. McQuillen, Letter to the Editor, 274 JAMA 1757, 1758 (1995).

262 609 So. 2d 588 (Fla. 1992).

Supreme Court held that infants with anencephaly could not be used as organ donors because they were not dead.[263] In reference to that case, the Chair of the Council later said, "They [referring to the parents in *T.A.C.P.*] were, if you want to call it that, actually deprived of salvaging something from this tragic experience . . . ."[264] The Chair's use of the language of deprivation suggests the presence of rights, rights based not on the autonomy of parents to make medical decisions for their children, but rights based in the parents' needs to find relief from their own suffering.

The Council also justifies its decision on the basis of the suffering of the many infants who could benefit from organ transplants.[265] As compared to the "suffering" of the infant with anencephaly, who suffers from an absence of any quality of life and a complete lack of dignity,[266] these infants' suffering *can* be alleviated through medical technology. Some of them may be saved if anencephalic infants can be used as a source of organs for transplantation.

The Council posits that the anencephalic infant cannot suffer or feel pain when its life is taken.[267] This, incidentally, is a point of some dispute, which the temporary suspension of the Council Report acknowledges. Nevertheless, if it is true that the infant with anencephaly feels no pain, then, like the terminally ill patient who is aided in dying by a physician, the infant with anencephaly will have a painless death when her vital organs are removed. It is a clean death: clinical, painless, antiseptic.[268] Next, the Council Report argues that such infants have no interests that must be protected because they have never and will never experience consciousness.[269] Because the "dead donor rule protects the fundamental interest in life of persons from whom organs are taken,"[270] and anencephalic infants have no interest in life, then the dead donor rule should not preclude taking the organs of such newborns with their parents' consent.[271] The Council Re-

263 The Council's Report cites this case as an example of how parents are not permitted to obtain psychological relief by donating the organs of their child. Council Report, *supra* note 16, at 1614; *see also AMA "Temporarily Suspends" Policy Regarding Procurement of Organs from Anencephalics*, TRANSPLANT NEWS, Jan. 17, 1996, *available in* 1996 WL 844801 (Council Chair said change in policy reflected concern about Florida case).

264 *AMA "Temporarily Suspends" Policy Regarding Procurement of Organs from Anencephalics*, *supra* note 263.

265 According to the Council's Report, 30% to 50% of children under the age of two die while waiting for transplants for hearts, livers, and kidneys. These figures are probably underestimations of the true need for suitable donor organs because many children are never placed on waiting lists. Council Report, *supra* note 16, at 1615.

266 *See infra* notes 267-75 and accompanying text.

267 Council Report, *supra* note 16, at 1615.

268 As are capital punishment executions performed by lethal injections. Some people protest the use of lethal injections for executions because it "medicalizes" and "sanitizes" this barbaric practice. Jack Cheevers, *State-sanctioned Executions Become Numbingly Clinical*, TALLAHASSEE DEMOCRAT, Jan. 21, 1996, at A1.

269 Council Report, *supra* note 16, at 1615.

270 *Id.*

271 *Id.* Some may argue that taking the organs of an infant with anencephaly does not violate the principle that we shall not use one person as a means to another's end because such infants are not *persons*. Although I do not have space here to provide adequate discussion of this issue, several points do bear mention. First, the infant with anencephaly is the live product of human reproduction, just like other infants; breathing on her own, she is certainly alive (persons who are brain dead cannot breathe on their own; ventilators breathe for them). Second, our human history of determining what or who is "less than human" (or only marginally a person) is almost

port, therefore, talks in terms of the *lack of interests* of the infant rather than the interests of the infant in being dead, the latter being more in line with what I have been referring to as rights based in suffering. But the backdrop to the Council Report is a developing culture that admits of such interest-oriented justifications for taking life because of the increasing acceptability of both making assessments about quality of life[272] and finding the means within the medical profession's toolbag to relieve those who suffer from an extremely poor quality of life. A life with "dignity," in the way that term is so loosely understood and applied, is not possible for the infant with anencephaly. Only through death can she achieve dignity.

The pending case of the parents of two-year-old Brianne Rideout illustrates the idea.[273] Brianne, a terminally ill child with brain cancer, had been placed on a ventilator and, as her disease progressed, became comatose. Her physicians unilaterally removed Brianne from the ventilator over the protests of her parents. The chief operating officer of the hospital defended the hospital's actions by describing them as "the physician's effort to continue to preserve the dignity of the child."[274]

The Council Report also follows on the heels of the *Baby K* case, discussed earlier, in which the attending hospital sought a court order supporting its refusal to resuscitate an anencephalic child; the hospital argued that it did not have to treat Baby K as it would another patient who came into the emergency room in respiratory distress; indeed, it was against the physicians' ethical and moral judgment to provide such care.[275]

This is our Sophie's choice. As in the novel, one child might live if we select the other to die. It is not entirely clear, and I do not really think it matters, if our role more closely resembles that of the medical doctor in Styron's novel, who creates the choice for Sophie, or that of Sophie, who has the burden of choice thrust upon her. To the extent that Sophie is the infinitely more sympathetic character, we may want to say that such choices, like the choice between the anencephalic infant and the other suffering newborn, are thrust upon us by nature. Under my analysis this characterization does not absolve us; selecting one person to die for the

---

exclusively abhorrent, from our treatment of the mentally ill to the disabled to members of racial minorities. Third, the slippery slope concern is ever present, i.e., that persons in persistent vegetative states will be the next organ donors, *see* Cruzan v. Director, Mo. Dep't of Health, 497 U.S. 261, 350 (1990) (Stevens, J., dissenting) ("there is no reasonable ground for believing that Nancy Beth Cruzan has any *personal* interest in the perpetuation of what the State has decided is her life"); *see also* ROBIN COOK, COMA (1977). Fourth, courts faced with the issue of the treatment of anencephalic infants have recognized them as persons, *see In re* Baby K, 16 F. 3d 590 (4th Cir.), *cert. denied*, 115 S. Ct. 91 (1994); *In re* T.A.C.P., 609 So. 2d 588 (Fla. 1992). Finally, and most significantly for our purposes here, the Council did not consider such infants to be other than persons. In response to criticism that the Council's proposal amounts to killing one patient to save another, Dr. John Glasson, Chair of the Council, acknowledged, "It is." *Ethics Outcry Over Baby-Organ Donor Plan, Doomed Newborns are Transplant Targets*, ARIZ. REPUBLIC/PHOENIX GAZETTE, May 24, 1995, at A3, *available in* 1995 WL 2796236.

272 Thus, while the Council Report pays necessary deference to the notion that respect for life is an "absolute value," regardless of a person's quality of life, it declares that such value is not absolute as against other values, with which it must be balanced, the other value in this case being the value of saving others' lives. Council Report, *supra* note 16, at 1616.

273 Frank Bruni, *A Fight Over Baby's Dignity and Death*, N.Y. TIMES, Mar. 9, 1996, at 6.

274 *Id.*

275 *See supra* note 153.

benefit of another person violates our duty to treat individuals with equal respect.[276]

The trade-off the Council makes is very clear. While in one breath it says that life is an "absolute value" regardless of a person's quality of life, in the next it says that such value is not, however, absolute as against the value of saving other people's lives who have a much higher quality of life.[277] Thus, the infant with anencephaly, who has such poor quality of life, as we are able to perceive it, is sacrificed for the infant who can, with that needed transplant, live a somewhat normal life. We are not talking about leaving the infant with anencephaly out in the elements to die or refusing to feed the anencephalic infant; those responses may seem cruel and barbaric. Instead, in the clinical sanctity of the hospital, under anesthesia and by the skilled hand of an impeccably trained physician, the infant's organs will merely be removed, incidentally causing her death.[278] If Hannah Arendt is right, that we have come in our social realm to be regarded as jobholders,[279] then it appears as though the anencephalic infant's job is to be an organ donor.

V. CONCLUSION

I believe that we have a moral duty to alleviate suffering and that physicians and other health care workers should be commended in their efforts to reduce suffering. We should continue research into more and better ways to use medical technology to relieve suffering. Every American should have access to medical care; our country's affluence requires that we carry

276 I acknowledge that value decisions are made (and must be made) in medicine. Sometimes, indeed, choices must be made among persons, such as deciding who will get a needed transplant. These decisions may be difficult and troubling, but as long as they are made within the framework of equal respect for persons, they seem to be decisions we can make and live with. When the decisions are not made within the framework of equal respect for persons, and especially when they violate the maxim that we will not use one person as a means to another, they are decisions we should refuse to make.

277 Council Report, *supra* note 16, at 1616; *see* GEORGE ORWELL, ANIMAL FARM 112 (Harcourt, Brace & Co. 1946) ("There was nothing there now except a single Commandment. It ran: 'All Animals Are Equal, But Some Animals Are More Equal Than Others'.").

278 Near the end of its report, the Council, anticipatorily defending against arguments of the slippery slope—i.e., that taking the organs from still living infants with anencephaly will be merely the first encroachment on the sanctity of the lives of other individuals living with impairments—makes an incredibly powerful argument *in support* of such concerns. The Report states:

> The problem with this argument, as with other slippery slope arguments, is that any change in policy can be challenged on slippery slope grounds. When patients requested permission to reject life-sustaining treatment, opponents argued that granting such permission would open the way to euthanasia. Permitting the use of contraceptives, particularly those that work after fertilization, opens the way to abortion. It is not enough, therefore, simply to invoke a slippery slope argument. Rather, it must be shown that the slippery slope risk is a serious one in the particular issue under consideration.

Council Report, *supra* note 16, at 1616. No matter how one feels about the desirability of rights to voluntary euthanasia or abortion, how can one seriously argue that the right to reject life-sustaining treatment and the right to access to contraceptives, respectively, were not precursors to the recognition of these rights? *See* Compassion in Dying v. Washington, 79 F.3d 790, 814-15 (9th Cir.) (discussing Cruzan v. Mo. Dep't of Health, 497 U.S. 261 (1990)), *cert. granted sub nom.* Washington v. Glucksberg, 65 U.S.L.W. 3085 (U.S. Oct. 1, 1996); Roe v. Wade, 410 U.S. 113, 152 (1973) (citing Griswold v. Connecticut, 381 U.S. 479 (1965)).

279 ARENDT, *supra* note 155, at 31. Tim Schardl, who assisted me in my research for this article, must be given credit for this insight.

through on our responsibility to help others by providing access to basic health services.

The question this Article presents is whether we should recognize individual *rights* to relief from or avoidance of suffering. This is the principle underlying the right not to be born and the right to die. We see its emergence, I suggest, because of our gradual and unreflective adoption of a medical model of suffering, our growing collective conscience, and our rights-based jurisprudence.

I have chosen a stark and disturbing example of where we may be headed if we give judicial recognition to the principle that an individual who is suffering has a right to have that suffering avoided or alleviated, even at the cost of life. Perhaps we could proceed into this future with adequate safeguards to protect that individual's other rights based in principles of equality and liberty. It seems unlikely, however, that the mere existence of such countervailing rights that must also be protected, weighed, and "balanced" against new rights based in suffering will be adequate to protect all the interests of the individual. The developing medical model of suffering that I have described is powerful. Adding rights to that medical-technological formula threatens to overwhelm other rights that do not have the same psychological and social force that medicalized suffering does. What is needed is a new alternative model of responses to suffering that includes, as a component of that model, medical solutions, but also includes other responses to suffering and that elevates above medical perceptions other, broader perspectives.