

## ASSUMING RESPONSIBILITY

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### I. INTRODUCTION

Anyone who sees another person suffering ought to feel concern. Furthermore, anyone who is able to help someone who is suffering should help. The sufferer's vulnerability can only be met in a principled way by acts of responsibility by those who can help.

This Essay is about how this preeminent principle of responsibility to the sufferer relates to health care.<sup>1</sup> Health care is fundamentally about the prevention and alleviation of suffering, and yet we do not think of health law, policy, and ethics as fundamentally about responsibilities. We think instead in terms of rights or compassion or economic theory—all things that matter, certainly—but in focusing on these other issues, we avoid questions of responsibility and our duties to relieve suffering. And who is this “we” with responsibilities to others? On this question, many of us will differ. But in my mind, the answer is “all of us.” Doctors, nurses, hospitals, insurers, politicians, parents, lawyers, law professors, and patients *all* have some responsibilities within our health care system—to each other and themselves—to direct resources and make other decisions to aid the sufferer.

The principle that we have a responsibility to help the sufferer in our midst is one that I am going to assume rather than defend. It has a deep history in the cultural, religious, political, and social traditions of our country.<sup>2</sup> Especially when the plight of the sufferer

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1. Because this is an Essay, I have limited the number of footnotes in the text of the Essay. Instead, I have included an annotated bibliography at the end of the Essay that I believe more fully reflects the debt owed to other scholars, whose works I drew upon in broad ways rather than simply for particular points.

2. See Robert A. Gross, *Giving in America: From Charity to Philanthropy*, in CHARITY, PHILANTHROPY, AND CIVILITY IN AMERICAN HISTORY 29, 30 (Lawrence

is acute and visible, our collective conscience calls for action. We have seen this most recently in the outpouring of aid to people dispossessed by Hurricane Katrina, but we also have seen it repeatedly across the health care field, as when laws have been passed to require treatment for people who arrive in emergency rooms (rather than allowing them to be dumped on other hospitals),<sup>3</sup> or when research agendas, government funding priorities, or financing rules change to address health conditions that have commanded our attention because of the stories of those suffering.<sup>4</sup> When the failure of what we loosely call a health care “system” becomes most horrifically visible, we act, but often in a piecemeal, ad hoc, temporal fashion. While the will to rescue is strong, a system that requires sufferers to vie for visibility, gives those who succeed some flurry of incomplete, sometimes ineffectual, often too-late assistance, and leaves those who remain invisible out in the cold, is really no “system” at all and is hardly principled at that. So while we primitively understand our responsibilities to others who are suffering, we have neither adequately explored the contours of those responsibilities, nor taken them seriously enough.

We have instead focused on rights; however, rights in health care do not directly, or even indirectly, address suffering to much positive effect.

## II. SUFFERING AND RIGHTS

As patients, we have rights to bodily integrity, to informed consent, and to procreative choice. We may have contract or tort rights against insurers or doctors. Physicians usually have rights to choose whom they want to treat, to govern themselves as a profession, and to a certain amount of procedural fairness in access to hospitals and insurance organizations. The disabled, the insurers, and the trial lawyers all clamor to express their rights as well.

Among all these rights, however, there are no rights to relief

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3. See Emergency Medical Treatment and Active Labor Act, 42 U.S.C. § 1395dd(b)(1) (2000) (requiring hospitals participating in the federal Medicare program to stabilize individuals who come to them with emergency medical conditions); see also *infra* notes 14-17 and accompanying text.

4. See, e.g., 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, 54-55 (1993) (describing a Medicaid plan variation that dropped coverage for expensive organ transplants in order to provide basic care to more people; when a child died after he was unable to obtain a bone marrow transplant, the public outcry caused the Oregon legislature to restore Medicaid funding for transplants).

from suffering, where the suffering itself creates a claim. Indeed the question of rights to avoid suffering was recently put to the United States Supreme Court when it considered the claims of terminally ill patients to a constitutional right to physician-assisted suicide.<sup>5</sup> The Court rebuffed suggestions that there may be a constitutional right to avoid suffering and were likely correct in doing so.<sup>6</sup> Our constitutional rights have never been about the alleviation of suffering, and even if they evolved in that direction, the rights would be narrow liberty rights, only protecting against intrusions that hindered our own efforts to relieve our own suffering. They would be rights to be *left alone* rather than rights to be *helped*. Clearly, what suffering patients need is not merely to be protected against unwanted intrusions, but to be offered help.

Realizing that liberty rights—rights to be left alone—do not answer the problems of suffering since what is needed is help, we might think that we can rely on altruism, volunteerism, compassion, or benevolence—how medical ethicists refer to the concern for the well-being of others. But clearly this has not been sufficient. Too many people are sick, disabled, or dead because of inadequate health care in this country to think that a system of liberty rights plus benevolence is working. True, the professional ethic of benevolence is something more than a-thousand-points-of-light volunteerism, but what is it, really? A duty of care to patients that doctors have assumed through contract?<sup>7</sup> What a doctor must do to

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5. *Washington v. Glucksberg*, 521 U.S. 702, 705-06 (1997) (holding that a state prohibition against aiding suicide did not violate the Fourteenth Amendment). For a fuller discussion of the Supreme Court's response to the claim of patient suffering in this case, see Lois Shepherd, *Looking Forward with the Right of Privacy*, 49 U. KAN. L. REV. 251, 278-301 (2001) (arguing that the Supreme Court was correct in rejecting a liberty interest in avoiding suffering—neither precedent nor the concept of liberty supports such an interest). For a contrasting view, see Robert A. Burt, *The Supreme Court Speaks: Not Assisted Suicide but a Constitutional Right to Palliative Care*, 337 NEW ENG. J. MED. 1234, 1234 (1997) (arguing that a majority of the Court appeared willing in the *Glucksberg* case to recognize a new constitutionally protected liberty interest related to suffering—a right to palliative care).

6. See Shepherd, *supra* note 5, at 281-82.

7. I say assumed through contract, because doctors generally do not have a duty to treat individuals with whom they have not established a doctor-patient relationship. See, e.g., *Childs v. Weis*, 440 S.W.2d 104, 107 (Tex. Civ. App. 1969) (holding that a doctor has no duty to treat a person in an emergency if no doctor-patient relationship exists). This no-duty rule has faced some inroads, primarily for institutions. See generally RICHARD A. EPSTEIN, *MORTAL PERIL* 91-105 (1997) (discussing the Emergency Medical Treatment and Active Labor Act and the duties imposed on hospitals); Karen H. Rothenberg, *Who Cares?: The Evolution of the Legal Duty to Provide Emergency Care*, 26 HOUS. L. REV. 21, 33-53 (1989) (analyzing cases from various jurisdictions addressing the

avoid a lawsuit? Surely it means more than a tort standard, but how much more? This question is largely unanswered. Moreover, defining professional benevolence would not solve the problem since professionals are not the only ones with responsibility for the health needs of others (to wit, families, surrogates, and corporations).

Benevolence has become subordinate to autonomy, to everyone's liberty to do what they please and thus carries little accountability. If we did strengthen the concept of benevolence, extending its reach beyond professionals, defining everyone's obligations and holding everyone accountable, then benevolence might work as a meaningful foundational principle of health care. But then it would look a lot like what I am calling responsibility.

### III. THE GOALS OF MEDICINE AND HEALTH CARE AS A BUSINESS

But perhaps I am overlooking the *collective* results of respect for patient autonomy and liberty rights and a culture that insists upon everyone's right to choose for himself what he wishes to do. Perhaps this in fact *is* the way to the prevention and alleviation of health-related suffering—through the efficient mechanism of the market being driven by consumer demand. In other words, we do not need to take on or assign responsibilities, or even sort through various potential ways of thinking about responsibility, because the consumer will direct the markets to efficient allocations of resources that are directed to that good we all seek—the delivery of health care services to prevent and relieve our suffering.

Economic analysis of the law can indeed provide us with many useful answers. We can learn about how to create effective incentives and penalties for various activities that we want to encourage or discourage. We can learn about the consequences of certain actions that may not be readily apparent, recognize the true costs of decisions to allocate resources one way rather than another, and be made to focus on information deficiencies and unlikely alliances.

But if we push economic analysis beyond its usefulness as a tool and suppose that it should define the *goals* of medicine—under the view that health care is simply a business and consumer choice is the beginning and end of the story—then we ignore the central importance of good health care to the absence or reduction of human suffering and the opportunity to lead a good life. We might like to think that we can revise the statement in the Introduction of this Essay, that “health care is fundamentally about the prevention and

alleviation of suffering” to read “health care is fundamentally about the *business* of the prevention and alleviation of suffering,” but that cannot be. No one is in *that* business.

The consumer model of health care cedes power to those who are wealthy and well, to actually redefine the goals of medicine by what they purchase, changing our collective understanding of what it is that doctors do. The health care goods purchased in these instances may not even promote good health. Does anyone believe that Michael Jackson’s plastic surgeons were really helping him? What about elective Cesarean sections for parents’ convenience? Breast augmentation surgeries given as high school graduation gifts? The implantation of five or six embryos in the fertility treatments of white, economically advantaged infertile couples (a practice that has hopefully ended)?

It matters if the goals of medicine are something other than the preservation and restoration of health or the provision of comfort when health fails. As we are continually reminded, we have limited health care resources; there is not enough for everyone to have everything she wants or needs. Our current health care delivery practices mean, as others have explained, that health care *is* rationed—by price. Since there is not enough to go around, those lacking the resources to pay are the ones who will go without. While we might prefer (and in fact, might even be responsible for creating) a different health care system altogether that does not ration on the basis of ability to pay, the current system becomes less defensible the more it blindly follows consumer dollars to provide services that do not preserve or restore health.

It is not only consumer demands for specialty care that skew health care resources away from the prevention and alleviation of suffering. Indeed, the vested economic interests of insurers, personal injury lawyers, hospital corporations, and others mean that patient choice is often illusory. The drive for pharmaceutical profits, for example, can mean that drugs are pushed to market before they are proven to be safe. The economic interests of lawyers can encourage wasteful defensive medicine, and tilt malpractice awards towards those with greater injuries but weaker proof of negligence and away from those whom negligence has truly injured.

One could argue that the tension between all these players in the market—between hospitals, doctors, insurers, patients, insureds, lawyers, pharmaceutical companies, and so on—will give us the right amount and kind of health care on a large scale, but it would not assure that attention is paid to the *individual* whose suffering could be avoided or alleviated with appropriate health care. No one would argue that if everyone looks out for his own interests, everyone’s interests will be protected. Indeed, how could

the market work anyway—and when would we know it is working—when we already have so many layers of governmental regulation, financing, and licensing that the most we can achieve is a *market in theory* rather than a true market? While economic analysis is helpful and consumer choice important, it will take more to explain what health care is and should be about.

Traditionally, health care has been thought of as the preservation and restoration of health (and thus the avoidance of suffering) and the provision of comfort to those suffering from health-related causes.<sup>8</sup> It should remain so. If we have a responsibility to the sufferer and the provision of health care services can prevent and alleviate suffering, then we are responsible for continuing to define the goals of medicine toward that suffering.

But something more is lost when we define health care as simply a business. It is not only the suffering of the individual that is ignored, but the *vulnerability* caused by suffering that makes responding an ethical imperative. Seeing health care as a business and the patient as a consumer or client fundamentally avoids seeing the patient as he really is: sick, sometimes desperate, sometimes dying, seeking care, comfort, direction, and (sometimes life-saving) aid from others with the resources, special skills and knowledge to help. The adult cancer patient cannot honestly be described as a “savvy consumer” when it comes to health care; nor can the child with cancer or the parent of that child. Understanding the individual seeking health care as a consumer, rather than a patient, wildly imagines him as having more choices than he actually does and as having far more control of his own health and his own suffering than he actually possesses.

#### IV. RELATIONSHIPS OF RESPONSIBILITY

Given, then, that the proper role of health care is the prevention and alleviation of suffering, and that we have a responsibility to aid the sufferer in our midst, what does that mean with respect to responsibility for health care? Who is the “sufferer in our midst” and in exactly whose midst are we talking about? Do some people have more responsibility than others? Do individuals have responsibility for themselves? What does responsibility entail? Finally, what does the law have to do with it?

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8. There is, interestingly, an old case that says something of the sort, which Mark Hall has pointed out to me. See *Pfeiffer v. Dyer*, 145 A. 284, 285 (Pa. 1929) (describing physicians as “those who devote their lives to ministering to human suffering” and affirming physicians’ freedom to charge patients according to their ability to pay).

I would argue that it means that our relationships to one another regarding health care are *relationships of responsibility*. Health care decisions by their nature involve a matrix of others and a complex array of responsibilities between them. While we often think of our individual health as being private and decisions regarding it as individual, health is uniquely *interpersonal*. Not only might our health conditions and health habits affect others—for example, communicable diseases and second-hand smoke—but our health care decisions affect others as well. For example, a couple's decision to abort a fetus diagnosed with Down syndrome may, in conjunction with similar decisions made by other couples, contribute to less support for existing individuals with Down syndrome and their family members and less welcome to future individuals born with Down syndrome. What we might think of as one of the most private and personal of choices—and certainly one we should exercise caution in judging—can undoubtedly have effects on others that bring increased suffering. Because many of our health conditions, health habits, and health care decisions relate ultimately to other individuals' suffering and diminished opportunities for a good life, they must be made with an awareness of responsibility to others.

This interconnectedness in health care is even more pronounced when we move beyond the individual patient to the health care professional, hospital, insurance company, governmental entity, pharmaceutical company, and others involved in health care. The decisions and actions of these parties can have even more direct effects on the suffering of individuals. Consider, for example, decisions to fund or pursue certain kinds of research or treatments over others, accept certain kinds of patients rather than others, exercise greater or lesser oversight of medical practice, or create a labyrinth of bureaucracies that delay care or staffing schedules that make care hurried, impersonal, or sloppy. As these examples evidence, it is not just the obvious and glaring instances where the contracted professional has dropped the ball that was clearly in her court—as in a merited malpractice claim—that we can trace the effects of actions to an increase in the suffering of others.

Thus, we should all be understood as having responsibility in many different ways, simply because we are fellow human beings, including the duty to understand and appreciate how our acts or omissions increase or fail to prevent or alleviate the suffering of others. When the need of the sufferer is most acute, we must become aware of that need, provide assistance, work or vote for the adoption of policies to reduce or alleviate such forms of suffering, or pay taxes or make other contributions to finance solutions to the suffering.

Yet while everyone, in my view, is responsible to some extent, some relationships of responsibility require more attention and action from an individual actor than others, are more properly accountable, and, thus, are more appropriately the subject of ethics codes and law. Heightened responsibilities can be imputed because of the expectations of others, especially if the creation of those expectations has been to our benefit. Large employers, for example, may have obligations to provide health coverage to their employees because of general expectations created over time that our health insurance system is largely tied to employer-provided health benefits or because of past practices of using health benefits to attract and retain workers. Doctors may have heightened responsibilities—beyond those they have contractually assumed—because of their invitation of our trust, their privileged status through limited public licensure and professional self-regulation, or their unique ability to provide aid in times of ill health. Family members may have responsibilities for the care of relatives because of relatives' dependency. Individuals may have responsibility for the unseen outcomes of their own actions, even though the actions seem neutral or even benevolent. The federal government may have heightened responsibility; the tax subsidy provided to higher wage earners in the form of tax-free employer-provided insurance premiums has demonstrably skewed the market for insurance, making it more difficult for individuals who do not receive insurance coverage through employment to find affordable insurance coverage.<sup>9</sup> In other words, the federal government, through its tax policy, has contributed to the “market failure” of the health insurance markets—which may carry with it responsibilities to aid those outside the tax subsidy.

In fact, the ethics and law of health care delivery already recognize a number of relationships of responsibility. For example, doctors have duties of confidentiality that are not merely contract-based;<sup>10</sup> non profit hospitals have duties to their communities to provide charity care in exchange for their tax-exempt status;<sup>11</sup>

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9. *See generally* MARK A. HALL et al., *HEALTH CARE LAW AND ETHICS* 893-911 (6th ed. 2003) (explaining private health insurance); Thomas Bodenheimer & Kevin Grumbach, *Paying for Health Care*, 272 *JAMA* 634 (1997) (discussing evolution and effects of employment-based private insurance).

10. *See Pierce v. Caday*, 422 S.E.2d 371, 372-74 (Va. 1992) (upholding a trial court determination that a suit against a physician for “unauthorized and impermissible dissemination of medical records” was an action in tort, not contract).

11. *See Lugo v. Miller*, 640 F.2d 823, 825 (6th Cir. 1981) (discussing Internal Revenue Service Revenue Rulings describing the requirements for a non-profit hospital to qualify as a tax-exempt, charitable organization).



governments, typically state and local, have recognized responsibilities to the public health of their communities in terms of the spread of infectious disease;<sup>12</sup> health care surrogates certainly have responsibilities to the patient for whom they are called to make decisions.<sup>13</sup> But while in some contexts we have good explanations for why someone has responsibility and what that responsibility is, this is the exception rather than the rule. The number and depth of such explanations pale in comparison to the myriad explanations and theories that have developed regarding rights relating to health care.

Especially in the legal realm—whether we are assessing what courts, legislatures, or administrative agencies should do—we have yet to develop a robust explanation for who is responsible for what and why. Understanding the interpersonal nature of health care and health care's relation to the prevention and alleviation of suffering makes clear that questions of responsibility lie in the shadows of nearly every important decision regarding health law, from questions of access to quality to patient choice. As it now stands, our understanding of responsibility is fuzzy, vague, and ultimately ineffectual as an analytical tool for solving problems. For example, we vaguely think of the physician as a fiduciary, which in other contexts mandates a duty to put the interests of the principal (here the patient) first, yet we permit rampant conflicts of interest in the context of research. The recent literature about patient trust tells us that patients thrive when they trust their physicians.<sup>14</sup> The largely unanswered question is what that heightened trust, which physicians invite, foster, and benefit from, ultimately requires in return from physicians aside from confidentiality.

Those wishing to spur government provision of health care or related financing may appeal to responsibility, but with little compelling description or explanation about the source of that responsibility. If we want to say that the government (or any other entity or individual) has responsibility to provide certain things, we must explain why and explore who else might have responsibility and why. It is likely that in every situation there will be multiple parties with various levels of responsibility. These are the models and grids of responsibility that we have failed to develop, and this is an area to which we have paid inadequate attention in our pursuit of every person's, corporation's, and government's right to

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12. LAWRENCE O. GOSTIN, *PUBLIC HEALTH LAW* 9-11 (2000).

13. Lynn A. Jansen & Lainie Friedman Ross, *Patient Confidentiality and the Surrogate's Right to Know*, 28 J.L. MED. & ETHICS 137, 140 (2000).

14. Mark A. Hall, *Law, Medicine, and Trust*, 55 STAN. L. REV. 463, 479 (2002).

independence from the obligation for others.

What might a sharper eye on responsibilities inherent in existing relationships bring? One might object that assignments and impositions of responsibility might backfire, if the object is to address human needs and related suffering, because persons or entities might then choose to avoid existing positive, helpful relationships if they are redefined to carry heavier burdens of responsibility. Richard Epstein, for example, has argued that the Emergency Medical Treatment and Active Labor Act (“EMTALA”), enacted in 1986, has wrought such results.<sup>15</sup> As a condition of participation in the federal Medicare program, EMTALA requires that hospitals provide emergency screening and stabilizing treatment to emergency room visitors.<sup>16</sup> The Act was passed in response to patient “dumping” in the early 1980s, when uninsured individuals in critical need of emergency treatment were transferred to public hospitals or denied treatment by private hospitals because the patient was unable to pay for care.<sup>17</sup> Epstein argues that requiring hospitals to provide free care in this manner substantially contributed to the reduction or elimination of emergency room services—an unintended and undesirable consequence of imposing new responsibilities.<sup>18</sup>

This example, if the causal effects are as Epstein urges, certainly counsels that we should proceed with caution when imposing responsibility where it was previously absent. But it does not mean that an in-depth exploration of the contours of our responsibilities is not a worthwhile, pressing project. Some of those efforts, as Carol Heimer’s article suggests,<sup>19</sup> should be aimed at discovering how best to encourage people and entities to voluntarily take on new responsibilities or act on long-recognized, but weakly executed, responsibilities. Moreover, the problem Epstein identifies is not necessarily one of recognizing too much responsibility; it could be one of recognizing too little. Thus, while the burden of treating emergency patients might appropriately be placed on hospitals, which have the skilled professionals, equipment, and so forth to provide the treatment, the burden of *paying* for that treatment might be more appropriately taken on by a governmental entity.

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15. EPSTEIN, *supra* note 6, at 91-105.

16. 42 U.S.C. § 1395dd(a) (2000).

17. EPSTEIN, *supra* note 7, at 93.

18. *Id.* at 97-98.

19. Carol A. Heimer, *Responsibility in Health care: Spanning the Boundary Between Law and Medicine*, 41 WAKE FOREST L. REV. 465, 491-95 (2006).

## V. SOLUTIONS

Courts, lawyers, policymakers, and academics all tend to try to fit health law problems into existing templates of contractual, tort, or constitutional rights, correspondingly narrow duties, and a small cast of repeat characters. Instead, I propose that, when faced with a problem in health care delivery—whether it is a problem of payment, safety, or respecting patients' wishes—we begin first, and almost radically, with the assumption that the problem has a solution. Second, we should assume that the best method of solving the problem lies in determining who has the ability to solve the problem and how much responsibility they have for solving it. Rights are the second order question, and may eventually triumph in the query. Our determination of rights may ultimately result in a failure to impose any affirmative legal obligation on the party who can most easily and effectively solve the problem or the party who carries the greatest moral obligation for solving it. However, we postpone the question of rights so that the question of responsibility can be answered.

If we take the example of an obese, pre-diabetic child, we should start with the assumption that there is a concrete solution to his developing health problem. This does not seem too difficult; the solution may entail a nutritional diet, exercise, and monitoring. (It may be more complicated, but let us assume for purposes of this discussion that it is not.) Next, we look to see who has the ability to solve the problem and whether that ability in and of itself carries with it heightened responsibilities, or whether other factors might do so (for example, past actions that contributed to the problem or a relationship of dependency). In this scenario there are a number of individuals or entities who might have some responsibility to act in ways to improve the child's health—the child's parents, his doctors, his school lunch program, his school (if it provides little physical education or punishes children by taking away their recesses), manufacturers who advertise processed foods, local government (if it has failed to provide safe places for play or adopted land-use plans that have made access to affordable groceries difficult for inner-city residents), federal funding programs that provide incentives away from opportunities for physical exercise, and perhaps the child himself. There are others, probably many others, who could do something differently that would lead to improvement in this child's health.

I am not saying that I know the answer to this child's problem or to the problem of childhood obesity in general. But I do believe that the answer lies in looking to those who might be able to offer aid or make effective changes, and asking about their

responsibilities to do so. Certainly with a problem as visible as the obesity of school children, something like the kind of approach I am suggesting does occur “on the ground,” so to speak—in newspaper editorials, PTA meetings, or local city commission meetings. (Sometimes, too, in refreshing academic articles.) Someone will offer a specific course of action, but often these sound like voices in the wilderness; indeed, there are plenty who will argue that eating tasty, inexpensive, unhealthy food is everyone’s right. And, often the voices are pointing only to the actions *others* need to take and do not assume any for the speaker. The speaker who urges the responsibilities of others does so from the comfort of knowing he is protected by the right to be free from having such obligations imposed from outside—but then, everybody else is also protected in this way, and so the urgings have less effect than they might. The ethic of responsibility currently has shallow roots, due in part to the failure to penetrate our hard bedrock of rights, either with adequate theories of responsibilities or appreciation that we are all, to some extent, responsible.

We could sketch out a similar starting point of responsibility analysis with respect to other health care problems. Take what appears to be an exclusively private matter that is predominantly understood in terms of patient autonomy and rights—the case of a competent, disabled individual who wishes to be taken off a life-saving ventilator or feeding tube. Before determining whether the patient should be allowed to exercise her “right to die,” we must ask whether the responsibilities owed to this patient have been met. Has the individual received proper rehabilitation opportunities, adequate social services, respect and care from physicians, other care givers, family and friends, and appropriate patient advocacy? Does her decision affect unseen others, such as the disabled or others who might feel pressure to do the same?

These are the questions that the California Court of Appeals conspicuously failed to ask in the well-known case of Elizabeth Bouvia.<sup>20</sup> Bouvia, a quadriplegic who sought a court order authorizing the removal of a recently inserted feeding tube, had lived independently, been a successful student, and married, when a series of setbacks—a miscarriage, a divorce, difficulty in finding appropriate housing and support services—caused her to want to die by refusing nutrition and hydration.<sup>21</sup> The California court granted her request, on the principle that a person of sound mind has a right to refuse medical treatment, but not before agreeing that her life

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

21. *Id.* at 300.

was pretty awful—in fact, in the court’s word, “meaningless.”<sup>22</sup> Ignoring the misfortunes of Bouvia’s recent past and the utter abandonment her present situation represented, the court bought into stereotypes of persons with disabilities<sup>23</sup> and failed in its responsibility to Bouvia—in part, by failing to ask about the responsibilities of others to her.

## VI. RESPONSIBILITIES WITHOUT RIGHTS

My proposal to focus on responsibilities does not merely suggest that we should more carefully delineate those responsibilities that stem from rights in health care law that we already recognize or might in the future recognize. Instead, it allows for a temporary suspension of rights-centered talk and the self-regard that it signifies and a focus on responsibilities—regardless of legal enforceability—to others who suffer from health-related causes.

But is it possible to talk about responsibilities without coming back to rights? We commonly understand rights and responsibilities (or duties) to be “correlative.” For every right, there is a corresponding responsibility: a right to free speech entails a corresponding duty on the part of others not to interfere with that speech; a property right corresponds with a duty on the part of others not to trespass; a right to emergency treatment (if one existed) would correspond to a duty on the part of others to provide emergency treatment. So accustomed are we to this correlation between rights and responsibilities and so primed to think in terms of rights (lawyers especially), that we might mistakenly think that because every right worth having (legal academics understand this as a Hohfeldian “claim right”<sup>24</sup>) has a correlative responsibility, that every responsibility worth recognizing entails a right. If that were the case, a discussion of responsibilities would be moot because the discussion would take place (and in our rights-centered society is likely already taking place) centered around the right. Therefore, the right would establish the contours of the responsibility.

But that is not the case. Clearly, we can have responsibilities without rights. A helpful analogy might be to think of responsibility

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22. *Id.* at 304.

23. See Paul K. Longmore, *Elizabeth Bouvia, Assisted Suicide and Social Prejudice*, 3 ISSUES L. & MED. 141, 152-57 (1987) (describing Bouvia’s life-long encounters with prejudice, lack of social services support, and the personal stresses that preceded her petition for removal of her feeding tube).

24. WESLEY NEWCOMB HOHFELD, FUNDAMENTAL LEGAL CONCEPTIONS 36-38 (Walter Wheeler Cook ed., 1923) (distinguishing “claim rights” from liberties, power, and immunities); see also J.M. Balkin, *The Hohfeldian Approach to Law and Semiotics*, 44 U. MIAMI L. REV. 1119, 1122 n.9 (1990) (discussing Hohfeld’s distinction between “claim rights” and “liberty” rights).

as the walls that support a roof of rights. Without the walls, the roof will lie flat on the ground and cannot really function as, or accurately be described as, a roof. Responsibilities are a necessary component of rights—the walls hold up the roof. But the opposite is not true. The walls are still walls without a roof—they still function as walls (separating spaces, blocking wind, creating privacy) and are accurately described as walls. It is true the walls are stronger when a roof is placed on top of them, but the roof is not necessary.

Perhaps one good reason that we tend to focus on rights rather than responsibilities is because with clearly identified rights, we have recourse to the courts: the person whose rights have allegedly been violated has standing and a cause of action against people who violate her rights. The courts must pay attention, and if the plaintiff prevails, the defendant will be forced to recognize the plaintiff's rights. Simply because responsibilities are not always enforceable through corresponding rights does not make them meaningless or unimportant. There are many ways to hold individuals or entities accountable besides giving a party the right to sue for failure to meet responsibilities. In the health care arena, responsibilities can be enforced through accreditation standards of health care institutions, conditions of governmental funding, professional licensure standards for individual providers, preferential tax treatment, and codes of ethics.

Moreover, rights are not static. A framework of responsibility could lead to recognition of some new rights over time—although more rights to be left alone are not what I am suggesting. For example, an expansion of the duty to treat could occur through common law development, much as older cases found that common carriers had a duty to accommodate passengers. Legislation that explicitly recognizes obligations on the part of various parties could also establish new rights, as did the Americans with Disabilities Act<sup>25</sup> and EMTALA.<sup>26</sup> Certain newly recognized legal obligations might also be enforced through citizen complaints rather than rights, as is currently being experimented with under certain of the North American Free Trade Agreement's ("NAFTA") provisions.<sup>27</sup>

Finally, *interpretation* of existing legislation and existing common law can also be informed by a framework of responsibility

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25. 42 U.S.C. §§ 12101-12213 (2000).

26. 42 U.S.C. § 1395dd.

27. See David L. Markell, *The Commission for Environmental Cooperation's Citizen Submission Process*, 12 GEO. INT'L ENVTL. L. REV. 545, 550-63 (2000) (describing the citizen submission process of the environmental side agreement negotiated between the United States, Canada, and Mexico to the North American Free Trade Agreement).

that asks who is responsible and whether everything has been done that should have been done. Such an approach might mean that, in appropriate instances, courts will be more resistant to laws that limit the liability of those who acted irresponsibly and will narrowly construe those laws. Such an approach may also mean, unlike in the *Bouvia* case,<sup>28</sup> that courts will require some accounting of the activities of caregivers when a competent, non-terminal patient wishes to die, and thereby spur the care that should have been given.

Looking at the legal practice, a framework of responsibility could mean that health law or elder law attorneys look to what their clients really need (e.g., more blankets, or a telephone) rather than automatically assume that the answer lies in an assertion of their clients' rights (e.g., to be free of restraints or to be discharged from the hospital or nursing home). I do not mean to suggest that responsibilities and rights are incompatible—far from it. Getting the hospital to provide more blankets might mean that the patient will not need restraints if he is getting out of bed because he is cold. He would still have the right to be free of restraints, but the avenue to meeting his needs would not simply be to assert that right. Likewise, ensuring that the competent, disabled patient who wishes to die has received adequate care would still mean that she has the right to refuse treatment; however, she may no longer wish to exercise that right.

## VI. REDEFINING HEALTH LAW

Developing a focus on responsibility in health law, policy, and ethics would require redefinition of health law as an academic field of study. The lines separating bioethics, health law, and public health would become blurred and perhaps disappear altogether. This, in my view, is as it should be. The patient who appears to be standing at the center of a “bioethics dilemma” has arrived there within a context of public health policies and regulatory/financing health laws that may have failed him. For many, Terri Schiavo posed a bioethics dilemma: should we preserve her life or respect her liberty?<sup>29</sup> This dilemma had roots in a public health problem, i.e., eating disorders,<sup>30</sup> and had implications in financial realms, since the issue of who was to pay for her continued care lurked in the

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

29. John Leland, *Did Descartes Doom Terri Schiavo?*, N.Y. TIMES, Mar. 27, 2005, § 4, at 1.

30. Gary D. Fox, *The Lost Lesson of Terri Schiavo*, ST. PETERSBURG TIMES, Oct. 26, 2003, available at [http://www.sptimes.com/2003/10/26/news\\_pf/Floridian/The\\_lost\\_lesson\\_of\\_Te.shtml](http://www.sptimes.com/2003/10/26/news_pf/Floridian/The_lost_lesson_of_Te.shtml).

background.<sup>31</sup> The boundaries between bioethics, public health, and regulatory/financing health law are spanned by questions of responsibility—revealing a more accurate picture of causes and effects in health care and, more importantly, opening up possibilities for solutions that may be obscured by the current artificial division of these subjects.

## VII. DOING SOMETHING

Any fair assessment of our overall health in the United States would have to admit that we are in poor shape. Our infant mortality rate is too high,<sup>32</sup> we are overweight,<sup>33</sup> our health outcomes are unfairly influenced by race and gender,<sup>34</sup> we are over medicating boisterous, young schoolchildren<sup>35</sup> while under treating pain, and the teeth of the uninsured are rotting because what little medical care they can afford must go to more critical needs.<sup>36</sup> And this does not even account for poor health, and sometimes death, due to medical errors.

Furthermore, our health care delivery system is also fat with administrative costs, overblown corporate profits, and moral aggrandizement. The FDA has been accused of turning a blind eye toward reports of adverse effects of lucrative new drugs, choosing instead to give them the go-ahead.<sup>37</sup> Wal-Mart employees are on Medicaid,<sup>38</sup> hospitals are closing,<sup>39</sup> the ranks of the uninsured are

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31. Sarah Leuck, *Another Tough Issue Schiavo Case Brings Forth: Who Pays for Care?*, WALL ST. J., Mar. 24, 2005, at A4.

32. In 2003, the infant mortality rate in the United States was 6.8%, higher than the infant mortality rates of Australia, Canada, France, Germany, Italy, Japan, the Netherlands, Spain, Taiwan, and the United Kingdom. U.S. Census, Statistical Abstract of the United States, No. 1325 Vital Statistics by Country, available at <http://www.census.gov/prod/2004pubs/04statab/intlstat.pdf>.

33. Donald G. McNeil, Jr., *Obesity Rate is Nearly 25 Percent, Group Says*, N.Y. TIMES, Aug. 24, 2005, at A13.

34. Vence L. Bonham, *Race, Ethnicity, and Pain Treatment: Striving to Understand the Causes and Solutions to the Disparities in Pain Treatment*, 29 J.L. MED. & ETHICS 52, 52 (2001).

35. Jeffrey Kluger, *Medicating Young Minds*, TIME, Nov. 3, 2003, at 48.

36. Malcolm Gladwell, *The Moral Hazard Myth: The Bad Idea Behind our Failed Health Care System*, NEW YORKER, Aug. 29, 2005, at 44-49, available at [http://www.newyorker.com/printables/fact/050829fa\\_fact](http://www.newyorker.com/printables/fact/050829fa_fact).

37. David Kohn, *FDA Critics Propose Key Changes for Drug Safety; Independent Review Board, Cutting Financial Ties Urged*, THE BALT. SUN, Nov. 28, 2004, at A1 (quoting FDA safety officer Dr. David J. Graham as saying the agency was “giving a free pass to drugs on safety”).

38. See, e.g., Steven Greenhouse & Michael Barbaro, *Wal-Mart Memo Suggests Ways to Cut Employee Benefit Costs*, N.Y. TIMES, Oct. 26, 2005, at C1 (noting that forty-five percent of Wal-Mart employees are uninsured, five percent are on Medicaid as compared with 4% of the overall population, thirty-



growing,<sup>40</sup> preventive medicine is virtually off the policy radar screen, and a research community rife with conflicts of interest is conducting dangerous experiments on both the healthy and the unhealthy.<sup>41</sup>

Overseas, we export abstinence programs rather than reproductive health,<sup>42</sup> perform human subject experimentation that would not pass ethical standards in the United States,<sup>43</sup> and bring disease to every country to which we bring war.<sup>44</sup>

Somebody should do something, but who? Everybody. We must always answer for ourselves first. Instead, though, the health care arena has been characterized by the carving out and protection of interests, the assigning of blame, or the quick fix when a problem of suffering becomes too unbearable for us to collectively continue to look away. Then we shuffle or we patch things. You have a right to get treated in an emergency room, we suppose, if your heart quits beating, but you do not have a right to the medicine that we know will prevent a heart attack.

If we really do wish to prevent and alleviate suffering caused by disease, disability, and pain, then we need to begin talking about responsibility—accepting our own and requiring others to accept theirs. Certainly we can, and will, disagree over who is responsible and for what. But we are not fully engaged in that conversation yet, at least not in any comprehensive, sophisticated way. If that conversation does not take place—a conversation as engaging,

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eight percent of Wal-Mart employees spent one-sixth or more of their salaries on health care expenses in 2004, and Wal-Mart employees are generally sicker than the overall population).

39. See, e.g., Nancy Shute & Mary Brophy Marcus, *Crisis in the E.R.*, U.S. NEWS & WORLD REP., Sept. 10, 2001, at 55, 59 (“Between 1994 and 1999, more than 370 emergency departments across the country were shuttered at hospitals that were closed down or financially ailing.”).

40. U.S. CENSUS BUREAU, INCOME, POVERTY, AND HEALTH INSURANCE COVERAGE IN THE UNITED STATES: 2004, at 16 (2005), available at <http://www.census.gov/prod/2005pubs/p60-229.pdf> (noting the increase in the number of uninsured from 2003 to 2004 and the general increase in the percentage of the uninsured population between 1987 and 1998, as well as 2000 to 2004).

41. See Robert Gatter, *Walking the Talk of Trust in Human Subjects Research: The Challenge of Regulating Financial Conflicts of Interest*, 52 EMORY L.J. 327, 329, 331-33, 340-42 (2003).

42. See, e.g., Ellen Nakashima, *U.S. Official Defends Focus of AIDS Prevention Policy*, WASH. POST, July 15, 2004, at A17.

43. Sonia Shah, *Globalizing Clinical Research*, THE NATION, July 1, 2002, at 23, 23.

44. See Charles B. Smith et al., *Are There Characteristics of Infectious Diseases That Raise Special Ethical Issues?*, 4 DEVELOPING WORLD BIOETHICS 1, 14 (2004).

varied, and compelling as conversations about rights—then we will not develop a culture of responsibility, as we have developed a culture of rights, and we will continue to ignore the unnecessary suffering of others.

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