
The Vulnerability of the Sick

by David C. Thomasma

How society will provide healthcare to its most vulnerable populations is a complex and difficult question that quality of life utilitarianism cannot resolve. The situation is further complicated by reflections on historic experience (i.e., Nazi Germany) and our own tendencies to devalue the neurologically vulnerable, the poor, and the genetically "impure." This paper reviews this issue practically and philosophically and concludes that the answer lies in the collective experience of western civilization that all human life must be intrinsically valued. On the basis of an experiential a priori: every individual is crowned with dignity.

It all goes back to Aristotle. "All men are mortal" is the major premise. "John is a man," is the minor premise. The conclusion is inescapable: "Therefore John is mortal."

This paper is about that inevitability. As Pogo the philosopher (Kelly 1954) once put it, "We cannot be absolutely sure we are going to die, but we can be pretty damned sure." What then do we actually mean by saying that there is a special vulnerability of the sick that should drive our healthcare commitments? If, after all, we are all made of friable stuff and will be sick someday, then we are all equally vulnerable from the beginning. Birth and death are parentheses, setting off life's bumpy ride from the silence at either end.

The Vulnerability of Illness

Discussing gene therapy efforts to attack amyotrophic lateral sclerosis (ALS, or "Lou Gehrig's disease"), the president of a research institute said: "Of course, ALS is a terminal, awful disease. So when someone knows that he has it he is willing to do anything. It's a little like prisoners on death row. The question is whether or not we're ready for those experiments" (cited in Weiner 2000). Most of us would say the same thing. For those who love life, almost all dying is awful, since dying takes from us the source of most of our values and relationships. Still the comment about ALS does reveal the first of a number of special vulnerabilities of the sick.

We are all subject to illness and decay. In that we are equals. But the particular path fate has determined for one person compared to another is also a source of great anguish — especially if the disease ravages either the essential features of one's humanity or affects an individual's value system. Alzheimer's, for example, affects one's essential functions (Rowe 1998), while multiple sclerosis, for example, may strike an athlete's value system as heart disease can the steel worker's, or diabetes, the electrician's. Even a simple loss of vigor can be devastating to a mountain climber.

Hence the particular pathway that disease or old age takes in an individual's life is an added vulnerability to the general notion that all persons are mortal. Medicine must pay attention to both types of vulnerability.

The philosophy of medicine is more than a philosophical examination of the arts and sciences that comprise modern medical care. At its heart, medicine is a moral enterprise: the relation between the one seeking help and the professional offering it is based on profound human values, including the relief of suffering, bonding with others in the community, being at risk for vulnerability, alterations in one's social and familial roles, and the value of existence itself (Bergsma and Thomasma 2000). The moral basis of medicine is beneficence, acting in the best interests of others (Pellegrino and Thomasma 1988). Sometimes this

commitment impinges not only on the physician's self-interest, but also on the moral center of professional life itself. Putting the patient first is a public commitment that provides the foundation of a social role. Yet, does the response to the suffering of vulnerability arise from a choice made by others (e.g., doctors or nurses), or from something deeper?

The Meaning of Vulnerability in Society

Because we are limited by our own mortality, treatment of each individual is a kind of treatment of ourselves. Compassion for the suffering of others grounds the ethic of relieving suffering (Loewy 1991), and serves the enlightened self-interest of the community. Without actions and programs to counteract the finitude of human existence, the whole community is threatened by extinction, not just the individuals in that community.

In advanced societies, social programs exist for almost every conceivable vulnerable individual.

While we intend to minimize suffering and maximize the common good, individual persons in high numbers face neglect of their needs.

There are programs for battered wives, for children of alcoholics, for the homeless, for the poor, for the sick. We can be justifiably proud of our society's efforts to care for those who have special needs.

Yet sometimes our attitudes demonstrate that only a narrow margin separates the way we treat physically and mentally damaged people in our society from the way official policy treated them in Nazi Germany. People who fall outside the norm tend to attract negative attention. They are sometimes resented. They are often treated as outcasts, as the lepers of the twenty-first century. Over 42 million Americans cannot gain regular access to healthcare. Persons with AIDS must struggle to be respected. Patients whose coverage

runs out are often dumped on public institutions, transferred like tinder from private to public institutions without their consent ("Emergency Room Law" 1990). Educational systems must often be forced by parents to finally acknowledge the need for special education for the developmentally disabled. In each of these instances, social policy is dictated by the powerful to the detriment of the powerless. In this regard, a list of our social woes is at least as comprehensive as our social achievements.

Expendability and the Common Good

Society has a difficult time with those who are most vulnerable. The reasons are complex, and I will focus on only one of them to show that what we call "quality of life utilitarianism" actually represents a dangerous social policy and poor ethical reasoning. Consider the issue of expendability.

Expendability is a judgment regarding the balance between the needs of vulnerable individuals and the needs and wants of society itself. From a purely utilitarian standpoint, those who contribute nothing to society — and drain its resources — are expendable. Nazi party euthanasia theorists, called such persons "ballast existence." In their view, when economic times are prosperous, society does not ask questions about caring for expendable individuals. But when times get difficult, such "ballast existence" must be eliminated. Nazi psychiatrists, Drs. Binding and Hoche, put it this way: "The question of whether the expense of maintaining these categories is in every aspect justifiable was not an urgent one in former times. Today's conditions are less prosperous, and we have to consider it" (as quoted and translated by Lauter and Meyer 1984).

At first blush, such an explicit downgrading of the intrinsic value of human life seems foreign to our way of thinking. Many react with dismay, even anger, at such a statement. We also have the advantage of hindsight about the horrible consequences of such thinking. The stench of the death camps is a pall that still hangs over western civilization (Pellegrino and Thomasma 2000).

Yet attitudes of superiority affect our thinking and, perhaps especially, our efforts to construct rational healthcare allocation plans. While we intend to minimize suffering and maximize the common good, individual persons in high numbers face neglect of their needs.

Take the Oregon (United States) plan for healthcare allocation for the poor. Faced with rising healthcare costs, and limited state funds for Medicaid, legislators and the public received federal approval for an experimental rational allocation plan. This plan is based on the principle of the greatest good for the greatest number. In it, goods and services that carry the least risk and the most benefit are to be provided first, while those carrying the greatest risk and least benefit are moved to the bottom of the list and are often not funded.

Although the plan is frankly utilitarian, it differs significantly from the attitudes in Nazi Germany. There, the quality of individual lives was judged, not the objective quality of the goods and services to be offered.

Nonetheless, one can easily imagine that certain vulnerable individuals may need specialized goods and services that will not be available. Such goods and services benefit only a few and carry high burdens for many. A bone marrow transplant or high technology interventions for the elderly are good examples. This utilitarianism is the basis for Daniel Callahan's argument that high-technology medicine should be controlled by an ageist cutoff. The money saved should go toward caring for the younger generation (Callahan 1998).

The danger of social programs that depend on utilitarian thinking is that we become accustomed to measuring the value of individual human lives on the basis of external quality-of-life judgments. At heart, this judgment is extremely subjective: "That individual's life is not worth living." Coupled with it is the social judgment that our resources would be better spent on lives that are worth living.

What corrective to these judgments can we offer? How may we guard against making such judgments while simultaneously providing for the common good?

The Principle of Vulnerability

In a previous work, Edmund D. Pellegrino and I (1981) derived an axiom of vulnerability from the nature of medicine as a special kind of human activity. We held that to attain the goal of the medical encounter — a right and good healing action for a particular patient — several axioms are necessary, and violating even one of them imperils the goal. Observing the vulnerability principle is one of these necessary axioms.

The principle of vulnerability can be stated this way: In human relations generally, if there are inequities of power, knowledge, or material means, the obligation is upon the stronger to respect and protect the vulnerability of the other, and not to exploit the less advantaged. This principle of general ethics is applicable to all sorts of human relationships. It generates an obligation of altruism (i.e., an obligation to take others into account in our use of power, knowledge, or other possessions), and it becomes a bilateral or multilateral affair when more than two persons are involved.

Goodin, in *Protecting the Vulnerable* (1985), analyzes important cases regarding the vulnerable in contracts, business relations, professional ethics, family relations, among friends, and with respect to benefactors. He builds an inexorable case in social justice that society bears specific responsibilities toward those who, in any particular relationship, are more vulnerable to exploitation or harm. The heart of his argument is that we usually assume that the basis for special responsibilities to protect the vulnerable comes from self-assumed duties and obligations, often self-assumed through contracts, implied or explicit. A good example of the former might be the obligation of families to provide for their children first, before caring for others in society (Goodin 1985, pp. 4-5), or the obligation of a health professional for his or her own patients over other needy persons in society. Veatch (1986, 1981) appears to argue the

opposite on this point, stressing the social contract and the obligation to society from which one is exempted to care for the vulnerable individual.

At any rate, the assumption that caring for the vulnerable arises from individual or social contract duties is probably wrong, according to Goodin. Instead, the obligation is grounded in the vulnerability of the persons themselves: "Examining several cases closely, however, suggests it is the vulnerability of the beneficiary rather than any voluntary commitment per se on the part of the benefactor which generates these special responsibilities" (Goodin 1985, p. xi). The beauty of this argument is that it rests on real cases that have been adjudicated in American courts.

Goodin's conclusion is based on how we actually behave, on how the deepest values expressed in our social thought and jurisprudential theories are brought to bear on individual persons in conflict in our society.

Vulnerability and Justice

No single principle of justice can easily supply special moral obligations to care for certain segments of the population, even if they are obviously suffering. The vulnerability principle, while developed in various ways in philosophical and political literature, is also a religious principle of justice. As St. Augustine (b. 354) articulated it long ago, "to each according to his need" is the basis of a committed community.

Further, if vulnerability is, indeed, the basis of responsibilities, then many people are vulnerable with respect to us and all of us are potentially vulnerable in our common finitude. Since special responsibilities toward certain groups within society is one our firmest moral intuitions, this moral intuition must also embrace all who are vulnerable, even if they fall outside our "normal" understanding of those to whom we are specially responsible.

The problem with this argument is that social thought and jurisprudential theory can be counterargued by those whom Hume says have "limited benevolence" in society (Brand 1976). We

are all-too-familiar with the "me-too" generation, the social narcissism that infects our society, and strident calls for autonomy and individualism on the part of libertarians (Engelhardt 1986). For them, there is no duty that is not explicitly and freely accepted by individuals. That people are vulnerable, poor, downtrodden, or devalued is unfortunate but not unjust. Persons who have not directly caused such problems are not responsible for their solution, unless they voluntarily assume those responsibilities.

Indeed, Rawls's arguments for social duties in justice are based on a theory of self-interest. Behind a veil of ignorance about our own eventual social standing, we are impelled to altruism to protect our own needs and interests. That is why David Ozar (1988) argues that it is insufficient, in terms of social justice, to concentrate solely on the rules governing good contracts to fulfill our obligations. At the base of all contracts and covenants between persons is a duty to right any imbalance within those contracts.

But where does this claim come from? Can it be sustained philosophically? One way it might be is by social agreement about the nature of human society. Originally, western society was infused by a religious vision of the interrelationship of individuals. But as this religious foundation eroded, agreement about what constitutes a good society was gradually lost. The principle of vulnerability found itself embodied in philosophical theories of social justice. Rawls (1971), for example, argues that we must protect people's "needs," "primary goods," or "vital interests." This duty applies despite differing social judgments regarding those needs and vital interests.

Protecting the Vulnerable

Many thinkers place the philosophical basis for protecting the vulnerable in a social contract — in, and through which, reasonable people try to protect their own self-interests. "Enlightened self-interest" was one of the catchwords of the 1960s, whereby businessmen and politicians "bought into" the civil rights movement because boycotts

and the threat of boycotts hit them in the pocketbook. This pragmatic corrective to social chaos fits entirely into John Adams's theory of the ideal republic being a "mixed polity." By "mixed polity," Adams meant a polity in which the natural law balances "the classes of mankind in the structure of government in order to assure political stability and to escape the cyclical overthrow of governments destroyed by the vices of corruption that otherwise go unchecked" (Andrew Reck 1987, p. 503). Thus, from the point of view of natural reason, caring for the most vulnerable in society is grounded in a theory of checks and balances intended to avoid the unraveling of civilization. We see what happens when the balance fails, as it did, for example, in Rwanda in the 1990s, and in Russia after glasnost. We see it also in today's China, where corruption is so serious that even some corrupt politicians are being put to death (Chicago *Tribune* 2000).

But an even better way than checks and balances pragmatism to protect the vulnerable in society is provided by the kind of utilitarianism hinted at in the example of the Oregon Health Plan. I have already noted that this plan differs in a significant way from what I call "quality of life utilitarianism." The difference lies in how the allocation of goods and services is rendered. In the Oregon plan, the allocation is objective, in that it regards the benefits and burdens of specific treatments with respect to the common good. It does not make the subjective judgment that a particular life is not worth living (Callahan 1990). By contrast to social programs that do make such judgments (e.g., those in Nazi Germany), we might call this theory "objective standards utilitarianism."

How would such objective standards protect the vulnerable? If the standards established are fair to all in society, then they must be based on medical indications rather than quality of life judgments (Thomasma 1986). At the very least, all individuals within the same class of medical disablement will be treated alike, whether they are disabled, aged, homeless, depressed, or have another underlying diagnosis, such as AIDS. The problem with the

Oregon plan is not that it establishes objective criteria for treatment, but the fact that only the poor are subject to its classifications.

A Theory of Relationals

When secular pluralism is taken seriously, no single foundational belief system can predominate. There are so many competing versions of the moral life, one can only come to a moral decision through negotiation and compromise, while respecting peaceably each person and the community as a whole (Engelhardt 1986, Moreno 1995). Compared to western religious traditions that anchor response to vulnerability in the sacredness of human life as God created it, the secular version of negotiation is often a particularly weak form of this doctrine (Thomasma 1999). The reason persons are to be respected comes not from their innate dignity or sacredness, but from the principle of tolerance for opposing viewpoints that is required by a peaceable society (Engelhardt 1986). Further, the secular critique of the sanctity of life doctrine seems to undermine its application to current events and ethical issues. The traditional intellectual resources that ground medical theory and practice are commonly disparaged as antiquated and irrelevant to high technology and entrepreneurial medicine.

However, the duty to treat the vulnerable with special care may yet be grounded in the level of the capacity to suffer.

According to Erich Loewy (1991), the greater the potential to suffer among entities, the greater is the value of those lives compared to other entities who cannot suffer to that extent. Duties and obligations to others flow from this capacity to suffer and our empathy toward the suffering, rather than from a metaphysical hierarchy that assigns inherent dignity to beings on a scale of rationality, free choice, or the special sanctity of human life (Loewy 1990). The origin of the ethics of obligation and human dignity lies in respect for the natural organism and its level of neurological development, rather than in its capacity for free choice. To argue that there is an inherent human dignity becomes problematic in the light of Loewy's argument.

A similar objection is posed by Peter Singer (1995), who has long advocated for the rights of animals as beings no less vulnerable than human beings. Singer rejects specieism in favor of a continuum of being. The idea that human life has a "special sacredness" that drives us to act on its behalf and subject other life forms to its support (as we might in using a healthy baboon's heart to repair a sick infant's), is repugnant to his thesis. At the same time, however, this conviction is often used as the ultimate justification for medicine's desire to preserve life. For Singer, the demise of this ethic was occasioned by the increasing secularization of society and by new technology in medicine itself. Singer argues that rather than "patch up" holes in the sanctity of life ethic, it would be better to abandon this ethic altogether in favor of a more consistent clinical and public policy medical ethics. "Technological advances in medicine have," he says, "made it impossible to retain the principle of the sanctity of human life" (Singer 1995, p. 75).

The basis of Singer's critique of the sanctity of life ethic is that it is inconsistent and confusing. Small wonder, since what he presents is little more than a caricature. His statements do not distinguish between the ethic derived from the doctrine, the different types of ethics that share a commitment to respect human life, and a seemingly deliberate, rhetorical effort to identify the sanctity of life doctrine with the most extreme forms of vitalism. He also characterizes the Pro-Life and the Catholic tradition together as "unthinking," therefore explicitly suggesting that no right-thinking, rational human being could possibly adopt such positions. In fact, that is not true. His description of the ethic fails on so many counts that it is nothing more than a straw man. At root, Singer's assumption that accepting the sanctity of life ethic commits one to vitalism is false. There are other viable interpretations of the doctrine. In his final chapter, Singer enumerates a rational, autonomous, technological ethic for today's world that is consistent with all the assumptions of a modern, scientific society.

Ruth Macklin's *Against Relativism* (1999), is a good place to begin a consideration of the cultural

versus the philosophical basis of human dignity as the inherent source of duties to protect the vulnerable. She combines a rich diversity of medical practices in many cultures, including some that may appear bizarre or repulsive to westerners, with a search for "ethical universals" on the basis of which we might be able to make moral judgments about these practices.

Her reaction to a South American physician who allowed a young woman to bleed to death after a botched abortion is a case in point. The physician's view was that the patient's abortion was immoral and that he could not add to the evil by saving her from the consequences of her action. Macklin was, as she recounts, horrified. But this reaction leads to a conviction that, despite the pluralism of our times, some standard must be instilled in every physician by which to judge the source of any physical difficulty irrelevant as compared to the duty to save life or honor the wishes of patients. Camus's (1948) remark about the purpose of human concourse can be readily adopted for medicine: "The other person in need, rather than my moral convictions, sets the norm."

We are left with a contemporary version of the tension between religious faith and secular society — one that pits relativism and consensus ethics against essentialist and normative ethics. Remember the view that one acquires one's true freedom through suffering and not from avoiding that suffering. In suffering one seems to lose one's self, one's autonomy, one's ultimate identity. Applying this insight to suffering and death, Therese Lysaught (1996, p. 193) rightly contends that "rather than this loss of autonomy and self signaling the ultimate destruction of the person, it is in fact the condition for the constitution of true identity." One can readily discern the opposition between this viewpoint and the secular humanism of Bertrand Russell (1957), Albert Camus (1955), Julian Huxley (1939), and Richard Taylor (1970), to mention only a few, all of whom adopt a nontheistic response to the meaning of life. Autonomy and self-determination are so predominant in this viewpoint that many of those adopting it do not even consider the obligation to

care for vulnerable human life in their analyses of beginning and end-of-life decisions (Thomson 1971, Rachels 1986).

It is clear that the attacks on the sanctity of life doctrine expose its vulnerability in a pluralistic society. Its religious origins are increasingly called into question by secular critical thinkers. For one thing, such critical thinking frees us from the slavery of unquestioned or unexamined ideas; as Socrates proclaimed, the "unexamined life is not worth living." For those who still want to cherish the value of human life, new thinking is required to answer objections to the theory and to persuade others about its importance and the dangers of abandoning it. As Colin McCarthy (1994, p. 97) succinctly puts it: "Whether expressed by Mother Teresa or Albert Schweitzer, reverence for life and the consistent honoring of that reverence is at the core of all life-or-death cases."

One way of doing ethics today, in a pluralistic environment, is to forgo the religious and metaphysical defense of important concepts like the sanctity of human life in favor of an experiential a priori. That is, when we begin to dialogue about values to be preserved in a pluralistic environment,

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we must place certain a priori, or established truths, on the table as starting points. Experiential a priori truths, unlike those purported to be grounded in metaphysics or religion, are based on the experience of our civilization, similar to the way one might examine one's ethical options against the backdrop of one's own moral experience and conscience. Indeed, it is a mark of a wise and prudent

individual to take cognizance of past experience, pitfalls, weaknesses, and mistakes in contemplating a decision.

Similarly, regarding bioethical and human life issues in medicine, we must analyze the past and place on the table some proposals for a priori truths regarding the value of human life. Given the Holocaust, it is not a stretch to reflect that, in the absence of a belief about the intrinsic value of human life, western medical and technological civilization tends to devalue the neurologically vulnerable and poor as well as the genetically "impure," to the point of active killing (Taylor, 1970). If this devaluing had not happened in Germany, it would have happened somewhere else in the West, given our propensity to "solve" problems by objectifying them. We are perhaps too apt to break each problem into its isolated and component parts. We do carefully develop expertise for each part, but then we isolate that expertise itself from common decision making and commodify its results. In the midst of this propensity, it is too easy to devalue the whole of human life in favor of gaining ascendancy over a part of it. A recent example of this tendency was the worry that if we did not conduct research on human embryos, France would get ahead of the United States in this crucial area.

Without overstating this habit of mind, since it has many good consequences as well as bad ones, I propose that the collective experience of western civilization is that human life must be intrinsically valued. Otherwise, despite the good intentions of many alternate proposals, harms are introduced into the common good of human life. Western medicine knows a priori that the vulnerability of the sick is grounded in human finitude, and because we all share that finitude, we are duty bound to address it in all our relationships, including the universal one of illness, decay, and death.

Conclusion

The vulnerable in society need special protections, and these protections are developed by considering that vulnerability, not social contracts, establishes

the duties that other powerful or less vulnerable people have toward them. To avoid making subjective quality-of-life judgments about vulnerable individuals, social policy should rest on objective treatment criteria for all individuals, regardless of their class or other social status, and regardless of underlying diseases, unless the latter will affect the outcome of treatment interventions.

Only in this way can we avoid the specter of a Nazi society. As we face uncertain economic times and rising healthcare costs, we must avoid thinking of any individual as "ballast existence," and a burden on the state and society. All individuals have intrinsic value as human beings. Each individual is crowned with dignity and honor.

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