

Catering to Blindness: *A Closer Look at a “Just” World*

To the Editor: Charity Scott’s “Belief in a Just World” (Jan-Feb 2008) contains valuable insight about the shape of public ethical discourse in America. However, she is so concerned with how to “sell” social reform in the short term that her essay misses an opportunity to subject the so-called belief in a just world (“you deserve what you get, and you get what you deserve”) to critical analysis. Where does this ideology come from, and what function does it serve? What causes this resentment and this blindness to the yawning gap between American ideals of justice and our actual social reality?

Instead of looking for ways to rectify this blindness, Scott counsels supporters of progressive social programs to cater to it. This belief system promotes self-esteem for achieving lower middle class stability and resentment against tax-based transfer programs. Why? Because these social programs are not financially set up to redistribute downward from the very top, but only from roughly the lower middle on down. Such programs, like the State Children’s Health Insurance Program (which are modest, though important for their beneficiaries), are chronically underfunded and controversial. We make people of limited means fight over crumbs and then consider it political progress when we extend health coverage to children who are three times richer than the poorest child, but not four—yet still a hundred times poorer than the children of the top quintile.

Supporters of progressive social policy should not cater to the beliefs that mask and perpetuate this state of affairs. They should work to undermine such beliefs by educating people about the true shape of American society. They should continue to ask the most basic—

the rudest—political questions of all: who gets what, when, where, and how?

Bruce Jennings

Center for Humans and Nature

Charity Scott replies:

By exploring a case study in Georgia, I was testing a research finding that support for social welfare spending increases when the causes of poverty are framed as being social rather than individual. The case study seemed to confirm this finding. The anger displayed by newspaper readers toward an individual family needing public health insurance for their children contrasted sharply with the overwhelming support for children’s health insurance when

framed as a matter of broader public policy. In suggesting that social welfare advocates be aware of this phenomenon, I was proposing possibly better ways to educate opponents of social welfare reform by reframing the larger social questions—including those that Bruce Jennings identifies—and by putting the problems of achieving health justice in terms that both advocates and opponents could agree on. Appealing to shared principles of fairness for vulnerable populations like children is one way of doing this; another is placing our country’s disparities in the broader context of socioeconomic conditions beyond individual control.

Having been astonished by the anger of the newspaper’s readership, I was try-

ing to account for this hostility on the basis of a view (the belief in a just world) that I believe perversely disadvantages those who try hardest to overcome social and economic inequities in our society. If I’ve learned one thing as a teacher, it’s that educating an angry audience is hard. Sometimes shifting the focus of conversation can be an effective strategy to open it up, so that the dialogues on injustice and inequality in our society that Jennings and I both want can take place. I join him in calling for more extended public discourse on fundamental questions of how our social stratification and inequities were caused and maintained. These are worthy subjects of future essays.

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LVADs and the Limits of Autonomy

To the Editor: I read with concern the recent case study (“Doctor, Will You Turn Off My LVAD?” Jan-Feb 2008) regarding deactivation of LVADs. Jeremy Simon’s commentary argues that physicians may decline to deactivate an LVAD even at the request of a capable patient. He finds that the patient’s right to decline any and all medical treatment does not apply here since the LVAD, once implanted, is no longer a treatment, but more like a patient’s organ. This novel argument would surely surprise the Food and Drug Administration, which approves the LVAD as a medical device, and Medicare, which

pays for it. By this logic, medication patches would not be medicines, and other battery-operated devices, such as implanted defibrillators or pacemakers, would not be medical treatments. Nowhere does law or logic support the notion that a treatment is no longer a treatment if it continues to function on its own outside a hospital. A physician who followed Simon's advice and refused the request of a capable patient to deactivate an LVAD would be well outside the bounds of medical ethics and the law. A review of bioethics literature would have supplied contrasting viewpoints. (Naturally, before agreeing to such a serious request, the physician should explore the patient's goals for treatment, values, and decision-making capacity.)

Tia Powell

New York State Task Force
on Life and the Law

To the Editor: I am one of the "much larger group . . . those who have implanted artificial devices" mentioned by Jeremy Sion in his case study. I am very grateful that I have had a fine quality of life for many years supported by a succession of pacemakers. But should my quality of life deteriorate, I am well within my rights to ask that my pacer be turned off—something I cannot do by myself. Further, if the agent I have identified in my advance directive finds my condition clearly does not meet my stated standards for acceptable quality of life, then he or she has the same power I have "to consent, refuse consent, or withdraw consent to any medical care, treatment, or service." The physician must be willing to follow my wishes.

Simon says that when a patient leaves the hospital, the LVAD ceases to be a medical treatment. He gives a rationale for this statement, and since that rationale does not apply to a pacemaker, I am not challenging it. But I wonder, might he decide that my pacemaker also ceases to be treatment and therefore refuse to turn it off?

Ruth Fischbach asks, "Once administered, can medical treatment be discontinued at the patient's request?" I believe this question was clearly answered by Judge Cardozo in 1914 when he wrote, "Every human being of adult years and sound mind has a right to determine what shall be done to his own body."

Betsy Carpenter

Portola Valley, California

To the Editor: In Matthew Wynia's essay ("Laying the Groundwork for a Defense against Participation in Torture?" Jan-Feb 2008), the legal definition for torture he quotes focuses on pain and suffering, intentions, and gathering of information. Considering how much pain and suffering we sometimes inflict in medicine and how much we depend upon pain and suffering to give us information, the difference between us and torturers is found most clearly in our intentions.

With this in mind, I found it ironic to turn the page and read the LVAD case study, in which Mr. P suffers far more egregiously than does a prisoner being waterboarded. Of course, no one seeks to torture Mr. P, and so the two pieces are apples and oranges. Yet we can all garner information by reflecting on Mr. P's pain and suffering, and doing so caused me to wonder if the legal definition of torture Wynia offers is truly complete.

This definition ignores at least two significant principles: agency (and the abuse inherent in attempts to violate another's agency), and the deprivation or manipulation of our hunger for compassion. Simon's commentary describes Mr. P as having agency—a key to avoiding torture. But a weak, seriously ill patient living a life of poor quality and debilitated by fatigue and pain is notoriously inept at recognizing and rationally weighing his choices. Agency without compassion can equal a hellish existence. I gratefully note that Fischbach expanded on Simon's best concepts by

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BY ALICE DREGER

Much as I liked Danny from the start, it was hard to reconcile my life's work with his. Mine has been about getting people past anatomical stereotypes. His seemed to be about making money off them.

"Financial Ties in Clinical Trials: Do Volunteers Care?"

BY SUSAN GILBERT

Anyone who assumes that revealing financial ties is like dropping a bomb is in for a surprise. Most of the disclosures of financial conflicts of interest were unlikely to affect potential subjects' willingness to participate in a clinical trial.

"The Liberal Backlash against Juno"

BY JOHN LANTOS

Why does it raise hackles on the coasts and play so well in the heartland?

"How to Break the Stem Cell Logjam"

BY JESSE REYNOLDS

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Also: **Françoise Baylis** argues that the most important moral difference between iPS and embryonic stem cell research may be that the creation of iPS cells does not harm women, **Daniel Callahan** examines why medical cost control will be even harder to achieve than universal care, **Allison Jost** criticizes Merck's ad campaign for Gardasil for glossing over the fact that HPV is a sexually transmitted disease, and **Wendy Parmet** wonders whether the FDA's new "Safety First" initiative isn't at odds with its preemption of lawsuits against drug makers.

offering a health care paradigm that includes compassion as a stated goal. Rather than leaving Mr. P alone with his choices, she advocates proffering compassionate assistance when assessing the limited alternatives available to him.

Those of us familiar with SERE schools have found to our humiliation that everyone can be broken, but we also know that compassion is healing medicine. In this case, no one intends to cause Mr. P harm. Nevertheless, if we do not take action to alleviate his confusion, isolation, pain, and exhaustion, we perpetuate a form of torture. We are lucky to have the option of clearly showing our intentions, lest Mr. P perceive us as his enemy.

Steve Lineback

Jeremy Simon and Ruth Fischbach reply:

We thank Tia Powell for responding to our case commentary, but we are puzzled by the strength of her reaction to Jeremy Simon's argument. We do not consider its suggestions to be outside the bounds of law or ethics. To make the argument sharper, consider an internally powered, fully self-contained, implantable artificial heart with no external connections, which, while not currently available, is certainly not fantasy. Powell would argue that a patient has the right to have this device removed should he desire. We believe that this claim is debatable, as we do not see a clear ethical difference between a fully implanted mechanical heart and a transplanted biological heart, which no physician would remove, even at a patient's request. Simon believes that the line between pacemaker and transplant has been crossed with destination LVADs. Fischbach does not agree, but we both believe that ethicists, clinicians, and jurists should consider these issues. Even respect for autonomy has its limits.

We would also like to make a few points about the legal and ethics status of Simon's position. First, the case study

was intended to stimulate discussion of an interesting and important ethical issue that tests the limits of patient autonomy. It was not presented as a formal ethics consult. Second, even were a clinician to act on Simon's position, we do not think she would be violating any clear ethical or legal standards. No doctor may be forced to act against her conscience to end a patient's life. A physician moved by Simon's argument would be covered by this doctrine. As for legal precedents, if there have been any cases regarding the removal of destination LVADs, there certainly have not been enough for the case law in this matter to be considered settled.

Most importantly, we disagree with Powell regarding the relationship between even well-established ethical and legal consensus and the task of bioethicists. In the clinical setting, an ethics consultant owes the patient and physicians recommendations that accord with current standards. However, bioethicists also have a responsibility to reflect on the clinical challenges they face and to consider whether and how prior discussions may be relevant. Implicit in Simon's comments was the contention that previous legal and ethical analyses of withdrawal of care are of questionable applicability to the current case and will become less so as technology advances. Bioethicists have a duty to point out when facts have outpaced analysis, and to challenge ethical and legal consensus if these are outdated. Bioethics and law must adapt to changes in the world, but they can only do so if these changes are noted and considered.

Finally, to claim that the "treatments" Medicare pays for and the "treatments" a physician must terminate at a patient's request are necessarily the same is a fallacy. The words may be the same, but the criteria for Medicare reimbursement are not directly relevant to the ethics of terminating care.

Since Betsy Carpenter speaks not as an ethicist but as an affected patient, her

comments on this issue are especially valuable. As she notes, we did not discuss pacemakers in our commentaries, and our positions cannot be applied unmodified to the case of pacemakers. We would like to note, however, that while we agree that patients have the right to refuse care, we do not agree that all patient requests for care or for discontinuation of care must be honored by physicians. Patient autonomy is more absolute, both ethically and legally, when the patient is refusing interventions (the context of Judge Cardozo's statement in the Schloendorff decision) than when she is insisting that a doctor perform an intervention, but there is a limit to requests of either nature that the physician must—or even may—accede to. Sometimes these limits are imposed by the physician's own conscience, as with those who refuse to perform abortions. Sometimes they are more rigid and codified, as is usually the case with euthanasia. The question for medical ethics is where these limits lie.

We encourage continued debate on this topic that we trust will bring some clarity to this emerging ethical frontier.

States Shaping National Consensus

To the Editor: In "Federalism and Bioethics: States and Moral Pluralism" (Nov-Dec 2007), Fossett and colleagues rightly argue for increased attention to state actors and the ways in which federalism impacts bioethical discussions. By focusing only on national policies and practices, bioethicists ignore the importance of state governments in shaping implementation of policies, as well as state actions in areas outside the purview of the federal government.

While the authors' discussion of the increasing importance of state government is well taken (albeit somewhat overstated), they do not adequately address the impetus that drives people to look for national solutions to bioethical issues. The aim of crafting federal poli-

cies is not only the result of pragmatic political reasoning, but also a desire among people to achieve a national consensus on important moral issues. And federalism has an important role to play in shaping this debate.

While the importance of states may receive short shrift, we would do well to remember why bioethicists have focused on the national government in the first place. The federal government is far and away the largest funder of scientific research, and federal laws and regulations shape and constrain actions at the state level. While there has been a resurgence of interest in state politics, as well as an increased attention to issues of federalism, don't expect the national government to be supplanted by the states any time soon. The Supreme Court has been giving increased attention to the importance of federalism over the last twenty years, but largely as a means of preventing further expansion of federal power rather than restricting it; after all, the Court recently upheld the Partial-Birth Abortion Ban Act in *Gonzales v. Carhart*—national regula-

tion of a medical procedure that was justified under the federal government's commerce power.

And it is not clear that the federal government will be as divided on bioethics issues, particularly as it seems almost certain that embryonic stem cell research, the most contentious bioethics issue in recent memory, will no longer be used as a political football. While the authors assert that, "neither [side of the embryonic stem cell research debate] has been able to assemble a stable majority coalition in Congress," this is far from the case. Supporters of the research were able to assemble large majorities in both Republican and Democratic Congresses, although not the supermajority necessary to override a presidential veto, and polling continues to show that a large majority of Americans support the research. In addition, all the current presidential candidates support expanding research eligibility for federal funding, so we should expect to see increased federal funding for human embryonic stem cell research using new lines.

More importantly, it's not clear how satisfied the American people will be with fragmented solutions to ethical issues. The concern with federal policy is not simply an effort to score quick and decisive political victories, but also to make widespread statements about the moral consensus of the nation. But this does not mean there is no room for federalism. Rather, state action serves as a catalyst for advancing debates and focusing national attention on an issue. Just as successful state policies helped drive the passage of child labor laws and civil rights legislation, state action on issues such as embryonic stem cell research have helped maintain nationwide focus and demonstrated widespread support for it. And this role for states will be even more important in coming years, helping people to better understand the ethical issues posed by burgeoning biotechnologies. The states will have a large role to play in future bioethics discussions, but it will likely be as much in shaping national consensus as providing an alternative to it.

Sam Berger