

Books

Review Essay

Genetic Testing Is Different

Stephen G. Post and Peter J. Whitehouse, eds. *Genetic Testing for Alzheimer Disease: Ethical and Clinical Issues*. Baltimore, MD: Johns Hopkins University Press, 1998. 512 pp. \$45.00 cloth.

Task Force on Genetic Testing, NIH-DOE Working Group on Ethical, Legal, and Social Implications of Human Genome Research. *Promoting Safe and Effective Genetic Testing in the United States: Principles and Recommendations*. Baltimore, MD: Johns Hopkins University Press, 1998. 204 pp. \$60.00 cloth, \$28.00 paper; also available on-line at www.nhgri.nih.gov/ELSI/TFGT_final/.

Our health care system is characterized by solemn affirmations of the importance of evidence-based medicine and the constant proliferation of clinical practice guidelines, which may or may not rest on solid bedrock of rigorously collected data as opposed to expert opinion. When one looks closely, however, one observes that the outcomes thought to be relevant are pretty narrow. Typical questions are does the intervention reduce blood pressure or reduce premature mortality or at best, does the drug improve quality of life?

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458 Journal of Health Politics, Policy and Law

When compared with the focus on physiological outcomes that characterizes most policy making in medicine, the analyses that are typically undertaken to define the appropriate use of genetic tests are remarkable for their breadth. These latter efforts have been far more attentive to the limitations of genetic testing and to the ways in which numerous aspects of our health care system and more general social structures affect the meaning and impact of genetic test results. The collection of essays about genetic testing for Alzheimer disease (AD), *Genetic Testing for Alzheimer Disease: Ethical and Clinical Issues*, edited by Stephen G. Post and Peter J. Whitehouse, is a superb explication of these problems. The authors of this text do discuss the heritability of the early onset forms of AD that are inherited in an autosomal dominant fashion, but the majority of the essays in the book focus on the role of the protein ApoE on the occurrence of AD.

When most people think of genetics, they think of single-gene disorders like cystic fibrosis, sickle cell disease, and Huntington disease. Single-gene disorders cause much human suffering and raise important social questions that have been topics of discussion for years and even decades. Yet far more of human disease, including almost all of the diseases afflicting people in resource-rich countries, is multifactorial in origin, resulting from the action of one or usually many more genes and environmental factors. Here the questions are murkier. How does one find contributing genes? What can and should one do with the knowledge that certain genes predispose a person to develop disease? What should one do if a mutation affects more than one organ, organ system, or disease process?

The ApoE story demonstrates these dilemmas very well. Alzheimer disease is a major public health problem, affecting an estimated 4 million Americans and imposing substantial health care and personal costs. In this cognitively oriented culture, the idea of becoming demented is the ultimate nightmare for many people. Some therapies are beginning to be developed, but all clinical researchers acknowledge that we are nowhere near to having truly effective interventions. It is known that many factors predispose people to develop AD, including a history of prior head trauma, lower educational attainment, and having two copies of or being homozygous for the $\epsilon 4$ allele of the ApoE gene, although the impact of each of these factors, taken independently, is quite modest. One can be homozygous for ApoE4 and not get AD, and one can get AD without having even one copy of ApoE4. To make matters even more complicated, ApoE also demonstrates a characteristic called pleiotropy that will almost

surely apply to many genes, namely that it affects more diseases than just AD. ApoE is also strongly correlated with cardiovascular risk, a condition that has even more profound public health consequences but for which effective therapies are available. We should not be surprised by the phenomenon of pleiotropy. It makes sense that important genes would affect more than one disease process in an organism as complex as the human, but it makes it harder to decide how to proceed.

The great strength of this book is its disciplined exploration from a variety of perspectives of the difficulties of deciding what to do with the knowledge about the contribution of ApoE to the development of AD. Let me give a few examples to provide a flavor of the richness of these essays. Kimberly Quaid, one of the leading experts in genetic testing for Huntington disease (HD) and its impact on individuals and families, explores the extent to which the lessons learned from HD can be extrapolated to the setting of AD. Eric Juengst argues persuasively that even though knowledge of ApoE status may have significant clinical utility in the prevention of cardiovascular disease, testing should not be done without full disclosure of the relevance of these findings to the risk of developing AD and the potential social consequences for those who are found to be at increased risk for the latter disease. Leonard Fleck thoughtfully explores the closely linked questions of whether ApoE testing should be made available and covered by third-party payment in a health care system that inevitably has limited resources. Stephen Post discusses the pressing need to bring public expectations of what genetics can deliver more closely in line with what can actually be delivered. Atwood Gaines concludes the book with an examination through the lens of medical and cultural anthropology of the social meanings of Alzheimer disease, genetics, and medical research. Not every perspective is included in this collection. Feminist voices, for example, are not heard, which is regrettable since women bear the brunt of having and caring for those afflicted with AD. Nonetheless, readers of this book will come away with a clear understanding of the importance of considering genetic testing from a wide array of perspectives, a breadth of inquiry that does not typify the rest of medicine.

But thinking about all the issues is not enough. What is really needed is a way to use all these insights to inform clinical practice. Some of the authors in Post and Whitehouse's book do make suggestions about practice, but ultimately their recommendations are only as effective as their persuasive power to those who actually read the book. Notably, however, the genetics community has been unusually proactive in attempting to

develop recommendations for practice that take into account all the implications of genetic information. Shortly after the cystic fibrosis gene was discovered, leading geneticists and genetics organizations quickly called for a moratorium on the routine offering of carrier testing, calling instead for studies to be conducted about how best to proceed (American Society of Human Genetics 1990; National Institutes of Health 1990). More than ten years later, studies have been done and consensus guidelines have been promulgated and are in the process of being implemented. More recently, geneticists and oncologists called for caution in testing for mutations that predispose individuals to develop cancer (for these mutations, the predisposition is far stronger than that of ApoE and AD). (National Advisory Council for Human Genome Research 1994; American Society of Clinical Oncology 1996).

This process of dealing with disease genes one by one, laudable as it is, nonetheless raises cause for concern. It depends on the interest of particular individuals and groups about particular disease processes, which may not always be present as knowledge about genetics increases. The ten-thousandth-disease gene may not be as exciting as the first few even though the implications of its use may be just as complex. The action of independent groups also creates the possibility that conflicting approaches will be adopted. The Task Force on Genetic Testing (Task Force), which had both lay and professional membership, was convened by the NIH-DOE Working Group on Ethical, Legal, and Social Implications of Human Genome Research to develop a more durable and consistent framework for policy making.

In their comprehensive report, *Promoting Safe and Effective Genetic Testing in the United States: Principles and Recommendations*, the Task Force addressed a number of issues relating to genetic testing, of which the more prominent are the role of voluntariness, full disclosure, and informed consent for genetic testing.¹ The group affirmed the importance of preserving the privacy and confidentiality of genetic information. They were very concerned about ensuring optimal practices in both the research and clinical contexts and discussed both the role of institutional review boards and the critical need to educate clinicians about the appropriate use of these tests. The Task Force discussed at length the need for quality control and long-term oversight as well as the vexing problem of

1. This report also contains some wonderful appendixes addressing current practices in genetic testing, an analysis of the informational materials that are used for genetic testing, a history of newborn screening for phenylketonuria, and a history of reproductive genetic testing for sickle cell disease, Tay-Sachs disease, Down's syndrome, and neural tube defects.

how to ensure the availability of high-quality testing for rare disorders, particularly in light of some of the requirements imposed by the Clinical Laboratory Improvement Act.

More to the point of this review, the Task Force described several issues that in their view must be addressed in assessing the appropriateness of genetic testing. These include: (1) determining whether the presence of mutations is causally related to the presence of disease; (2) assessing the *analytical validity* of a test (does it accurately detect the presence or absence of a *mutation*); (3) assessing the *clinical validity* of a test (does the test result accurately predict/detect the occurrence of *disease*, an analysis affected by such factors as the penetrance and heterogeneity of the disorder); and (4) finally assessing the *clinical utility* of a test. The authors made clear that addressing the last of these issues requires consideration not only of the availability of effective interventions but also of the larger social implications of the test results. The breadth of inquiry in Post and Whitehouse's book would appear to be what the Task Force had in mind. The important contribution of setting forth this framework is to demonstrate that while these issues are inter-related and overlap in various ways, each involves special problems that deserve to be addressed separately. The Task Force did not tell us how to weigh these issues but rather called for the Secretary of Health and Human Services to establish an advisory committee to decide these questions.

The Secretary accepted this invitation, chartering the Secretary's Advisory Committee on Genetic Testing (SACGT) in June 1998. This committee will soon complete a report on the adequacy of oversight of genetic testing. Although their report is not final, it appears that the SACGT will call for a multipronged process involving the Food and Drug Administration, the Department of Health and Human Services, especially the Centers for Disease Control and Prevention, and the public.² One of the disappointing aspects of the proposed recommendations is that while the committee appropriately recognizes that some tests require more scrutiny than others—for example, where the contribution of mutations to disease is poorly understood, where effective interventions are lacking, or where the social implications of test results are particularly challenging—it eschews the responsibility of deciding which

2. The final report, entitled *Enchancing the Oversight of Genetic Tests: Recommendations of the SACGT*, can be found at www.4.od.nih.gov/oba/FINAL%20SACGTreport713700correctedpage27.htm.

tests require what level of examination or even providing a detailed set of criteria for making these distinctions.

While it is not yet clear who ultimately will decide which genetic tests are ready for clinical use and which are not or precisely how it will be done, much progress has been made in defining what factors need to be taken into account and in developing a process that ensures that a wide variety of perspectives are taken into account. The progress toward developing an appropriate process is aided by the many other attempts to promote the appropriate use of genetic tests that are proceeding in parallel. One example is the project undertaken by the American Academy of Pediatrics and the Maternal and Child Health Branch to consider the future of newborn screening in the United States (AAP Newborn Screening Task Force 2000). Another is the ongoing effort, nationally and internationally, to define best practices for detecting and treating hereditary hemochromatosis (Burke et al. 1998). These efforts, too, were characterized by consideration of a broad array of risks and benefits. The optimal method for defining the use of genetic tests has not yet been achieved, but the direction is clear, due in no small part to the Task Force's efforts.

In thinking about these and many other concerted attempts to ensure that genetic testing is delivered optimally, I understand why genetic testing has come under such intense scrutiny. Some of the reasons are historical. Most of us cringe when we think about the history of eugenics in this country and the practices of forced sterilization described in *Buck v. Bell* (274 U.S. 200 [1927]) and *Skinner v. Oklahoma* (316 U.S. 535 [1942]). It did not help that genetics next came into the public view in the context of reproductive genetic testing. Both carrier testing and prenatal diagnosis raise touchy issues for many people. Some of the reasons for heightened concern about genetics are biological. We cannot change our DNA, at least not yet; if you have a mutation, you have it, whether or not you can do something to ameliorate its actions and effects.

As a general pediatrician, however, I am struck by how many of the concerns expressed about genetic testing could appropriately be voiced about other aspects of medicine as well. New tests and techniques frequently are introduced into practice before their risks and benefits are fully understood, only to be withdrawn or modified after widespread use demonstrates problems. To pick an example from my own experience, when I was a resident, we routinely did exchange transfusions on otherwise healthy, full-term neonates whose bilirubin levels exceeded twenty. Now we treat almost all of those babies, if at all, far less invasively, with phototherapy and fluids. Many medical diagnoses have implications that

extend far beyond the clinic. Physicians find themselves under enormous pressure from parents and teachers to put children on Ritalin for attention deficit hyperactivity disorder. Yet a few years ago, it was reported that the military refused to enlist anyone who had been given that diagnosis, thereby foreclosing a course that many young people have taken to enter into the labor market (Lansford 1998). And in our system of health care and employment, almost any diagnosis of disease or predisposing conditions can be harmful to your health and your pocketbook. Many of the most important determinants of health in our society—poverty, diet, education, cigarette smoking—are familial even though they are not in any meaningful way genetic. Given the striking parallels, why is most outcomes research and policy development so narrowly focused? The far-reaching process, as described in Post and Whitehouse, the Task Force, and the SACGT documents, that is evolving to govern the use of genetic testing should become a blueprint for evaluating the full array of medical practice.

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References

- American Academy of Pediatrics (AAP) Newborn Screening Task Force. 2000. Serving the Family from Birth to the Medical Home. Newborn Screening: A Blueprint for the Future—Call for a National Agenda on State Newborn Screening Programs. *Pediatrics* 106 (2 Pt. 2):389–422.
- American Society of Clinical Oncology. 1996. Statement of the American Society of Clinical Oncology: Genetic Testing for Cancer Susceptibility, Adopted on 20 February. *Journal of Clinical Oncology* 14:1730–1736.
- American Society of Human Genetics. 1990. The American Society of Human Genetics Statement on Cystic Fibrosis Screening. *American Journal of Human Genetics* 46:393.
- Burke, W., E. Thomson, M. J. Khoury, S. M. McDonnell, N. Press, P. C. Adams, J. C. Barton, E. Beutler, G. Brittenham, A. Buchanan, E. W. Clayton, M. E. Cogswell, E. M. Meslin, A. G. Motulsky, L. W. Powell, E. Sigal, B. S. Wilfond, and F. S. Collins. 1998. Hereditary Hemochromatosis: Gene Discovery and Its Implications for Population-Based Screening. *Journal of the American Medical Association* 280:172–178.
- Lansford, A. 1998. ADHD and the Military. *Developmental and Behavioral News* (fall). Available on-line at www.dbpeds.org/section/fall98/adhd_military.html (9 June 2000).

464 Journal of Health Politics, Policy and Law

National Advisory Council for Human Genome Research. 1994. Statement on Use of DNA Testing for Presymptomatic Identification of Cancer Risk. *Journal of the American Medical Association* 271:785.

National Institutes of Health. 1990. Statement from the National Institutes of Health Workshop on Population Screening for the Cystic Fibrosis Gene. *New England Journal of Medicine* 323:70–71.

Jack E. Triplett, ed. *Measuring the Prices of Medical Treatments*.

Washington, DC: Brookings Institution, 1999. 350 pp. \$54.95 cloth; \$22.95 paper.

“Continued escalation of health care costs threatens the economy of the United States, undermines the international competitiveness of the Nation, and strains Federal, State, and local budgets” (Health Security Act of 1993, 103d Cong., S. 1757/HR 3600, 21 November 1993). For thirty years, that contention—or a less extreme version—has dominated domestic health policy and spurred federal cost containment mechanisms ranging from the 1967 Comprehensive Health Planning Act to the 1999 Balanced Budget Amendments. Intellectual energy of health policy analysts has tended to focus on explaining the “why” of rapid growth in medical expenditures rather than the “what” these billions of dollars were buying (Weisbrod 1991). Now a new line of health services research has launched a rigorous assessment of “value for money.” Initial results are encouraging: more money can indeed buy better medical care and, in some cases, much better care.

That is the principal message from a conference sponsored by the Brookings Institution and the American Enterprise Institute (AEI) in 1997 as reported in *Measuring the Prices of Medical Treatments*. A seemingly narrow and technical question provided the conference focus: Is the consumer price index (CPI) a reliable measure of change over time in health care purchasing power? However, in addressing that question, conference participants offer a wide-ranging set of information and ideas and examples of contemporary health services research at its best.

Consider the CPI. Like the Dow Jones closing average, the CPI is a figure we hear every day without giving much thought to its underlying construction or measurement validity. Conference participants remind us

that a consumer price index is fundamentally a tool for gauging consumer welfare over time: a rise in the price index means that a fixed income will buy a smaller bundle of goods, leaving consumers worse off. However, if higher prices are accompanied by qualitative improvement in the bundle of goods, consumer welfare may remain constant or even increase, depending on the ratio of change in price to change in underlying value (i.e., utility as a function of consumption).

Now we have a theoretical construct for the main line of research presented at the conference. Select a clinical condition and related treatment intervention. Construct a price index by calculating the ratio of change in price to change in “value” derived from the therapy over a period of several years. Contrast that ratio with the equivalent medical care price index as calculated by the federal Bureau of Labor Statistics (BLS).

Using this approach, researchers who examined treatment for heart attack calculated a quality-adjusted price index of roughly -1.0 to -0.5 percent per year—falling prices compared with the comparable BLS estimate of a 3–4 percent annual price increase (64). Another team applied similar methods to examine treatment of major depression. Between 1991 and 1995, the BLS prescription drug CPI rose by almost 18 percent while the medical services CPI climbed 27 percent. By contrast, the synthetic price index for episodes of depression treatment (which rely on medical services, drugs, or both) *declined* by some 20 to 30 percent (96).

The clear implication of these results, echoed by discussants, is that analogous studies of other medical therapies would likely produce similar findings. On that basis, the policy implications are clear: apologize to the doctors and administrators who have taken a beating as the villains in medical cost inflation and give the BLS the task of implementing a quality adjusted medical care price index. But wait! Life isn't quite that simple.

While appropriate use of health care technology can be remarkably effective, there is widespread evidence that many people do not receive optimal care. A case in point is the major depression price index study presented at the Brookings-AEI conference. Only 20 to 40 percent of observed episodes of depression care conformed to guidelines established by the Agency for Healthcare Policy and Research (85). Review of other medical interventions may reveal similar lack of compliance with widely accepted treatment guidelines. Thus, without evidence to the contrary, it is not safe to assume that the surge in medical expenditures as documented by the conventional CPI has been efficiently deployed.

Creating a quality-adjusted medical care price index is hardly a simple

task. Just measuring the fair market value of medical services and procedures is in itself extremely complex. Market prices are almost nonexistent in health care due to pervasive third-party payment. Billed charges are an unreliable gauge of transaction prices while adjudicated claims data may be distorted by negotiated payment mechanisms. The BLS has recently devoted substantial effort to constructing indexes that track the price of medical service bundles such as a hospital stay for a circulatory disorder. These represent a great improvement over previous indexes based on lists of discrete services such as daily hospital room rates or laboratory fees (103). However, the index still captures only components of treatment rather than the cost of a complete episode of care.

Devising a practical mechanism to track change in the *quality* of a service bundle over time is even more complex. The heart attack price index described at the Brookings-AEI conference relied on change in mortality as a measure of quality. While certainly an important outcome, survival alone fails to capture the spectrum of treatment goals for many costly conditions such as chronic disease. By contrast, the major depression price index study relied on conformity with published guidelines—the treatment *process*—to establish quality of care. Outcomes research purists would fault this as a “halfway measure” that ignores patient preference. In fairness to the researchers, health insurance administrative claims files, which are the source of data for both the heart attack and depression studies, offer minimal insight on the outcomes of treatment.

Ideally, a system would be put in place to characterize every intervention in terms of a universal measure of patient preference for treatment outcome such as quality-adjusted life-years gained (QALYs) (Gold et al. 1996: 308). But measurement of QALYs is in its infancy. Robust figures for QALYs gained by specific interventions are scarce and may never be widely available. A surrogate measure of change in health care purchasing power, advocated by one conference participant, would track change in the annual premium for a health insurance policy with a fixed benefit package. Surveys of consumer willingness to pay for specified additional benefits would establish the relative value of qualitative improvement in the treatment bundle (197).

Unlike many conference reports, especially those dealing with a rather dry subject, this book reads well. Chapters presenting the research projects reported at the conference are punctuated by the insights of knowledgeable commentators who are not shy about poking holes in methods or findings. Several audiences will find this book especially valuable. Health services researchers will see examples of interdisciplinary research

at its best, integrating clinical medicine and economics in an outcomes research framework. Health economists will appreciate the tutorial on price index theory and its application to cost-benefit analysis. Students of health policy will debate whether “the fundamental premise of health policy over the past decades has possibly been fraudulent” (111).

Expansion of Medicare to include pharmacy benefits is on the horizon. Recent history predicts that expenditures will rapidly exceed budget projections and the urgent quest for cost containment will begin anew. Oscar Wilde (1991: act 3, lines 451–455) defined a cynic as “a man who knows the price of everything and the value of nothing” and a sentimentalist as “a man who sees an absurd value in everything and doesn’t know the market price of a single thing.” Our society needs a health policy process that is neither cynical—focused solely on stemming rising prices—nor sentimental—equating more care with better care. Research presented at the Brookings-AEI conference is an important step in that direction.

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References

- Gold, M. R., J. E. Siegel, L. B. Russell, and M. C. Weinstein, eds. 1996. *Cost-Effectiveness in Health and Medicine*. New York: Oxford University Press.
- Weisbrod, B. A. 1991. The Health Care Quadrilemma: An Essay on Technological Change, Insurance, Quality of Care, and Cost Containment. *Journal of Economic Literature* 29(2):523–552.
- Wilde, O. 1991. *Lady Windermere’s Fan*. In *Plays, Prose, and Poems*, by Oscar Wilde. New York: Alfred A. Knopf.

Stefan Timmermans. *Sudden Death and the Myth of CPR*. Philadelphia: Temple University Press, 1999. 256 pp. \$59.50 cloth; \$22.95 paper.

Speculating about what he would do if he were to come across someone in cardiac arrest, Stefan Timmermans writes: “If no relatives or friends are present, if I have no personal ties with the person dying, if I do not know the person’s wishes, and survival is not a near certainty, I would

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follow the advice I once heard a paramedic give a colleague: 'If I were to collapse suddenly, close the door and check back in twenty-five minutes.' I would chose not to start CPR, and I would make the decision in good conscience. I would decline to subject a dead person to an invasive and traumatic intervention" (186). It's a brave claim, made on a bold argument. I am almost convinced but not quite.

Let me be clear: *Sudden Death and the Myth of CPR* is a very good book. It is scrupulously researched, skillfully written, careful in its arguments. In taking on out-of-hospital CPR and the entire structure of emergency medicine that has grown up around it over the past three decades, it extends in an important new direction the criticisms that many social scientists have made about the treatment of in-hospital death. It is a book very much worth reading. If I disagree with one of Timmermans's conclusions, even one of his most important conclusions, it should be altogether clear that I do so on the basis of evidence and argument that Timmermans himself supplies.

The Myth of CPR is divided roughly into two parts. The first is a history and assessment of resuscitation techniques. The second is based on field research in the emergency departments of two different community hospitals in a Midwestern town. Each part is convincing. But, in my reading, they lead to somewhat different conclusions.

In the first part, Timmermans documents two centuries' worth of efforts to develop effective resuscitation techniques. He shows, in particular, how claims for resuscitation accompanied (and helped shape) a modernist transformation of death—a transformation of death from something understood as God's unalterable work to something to be fought against, denied, even reversed. With deft irony, Timmermans traces a series of innovations in out-of-hospital CPR, each promising dramatic success, but ultimately contributing more to the development of unrealistic expectations than to actual improvements in survival rates. Indeed, the survival rates are the key to his argument. (One of the many virtues of the book is a willingness to engage with highly local quantitative studies of health outcomes, a willingness absent from the work of many social scientists with ethnographic inclinations.)

The available data, as Timmermans shows, are neither consistent nor very convincing. Reports of survival rates for out-of-hospital CPR range from under 1 percent to 30 percent (in Seattle and its King County suburbs). Apart even from real regional differences in the speed of response systems, the interpretation of these results is complicated by differences both in what is counted as an arrest and what is counted as survival. Thus

since the 1991 Utstein, Norway, consensus conference most studies of survival rates exclude all conditions resulting in resuscitation efforts *except* those with an underlying cardiac etiology. As a result, as many as three-quarters of out-of-hospital resuscitation efforts (weighted heavily to those conditions with the lowest chance of survival) are excluded from the calculation of survival rates. Moreover, there is considerable ambiguity as to what counts as a survivor. Little or no follow-up data suggest what sort of neurological damage is done even to the small minority of patients who are eventually discharged from the hospital after an out-of-hospital arrest and even fewer data follow their long-term survival rates. Timmermans seems fully justified, then, in his conclusion that meaningful survival rates for out-of-hospital CPR are likely between 1 and 3 percent. More important, he also seems equally justified in his implication that this survival rate does not warrant the massive effort and expense (perhaps a half-million dollars per survivor) required to produce it.

Timmermans's fieldwork, however, suggests a somewhat different conclusion. To be sure, he is often and effectively critical of the way resuscitation efforts are conducted in hospitals. He points, convincingly, to the authority of physicians in the emergency department as an instance of medicalization and regrets the exclusion of family and friends from attendance at the resuscitation effort. Along with other sociologists who have studied the practice of medicine in the age of informed consent, he shows that patients' wishes, even those certified by advance directives, are often ignored. And he argues that physicians' efforts are driven by their own moral hierarchy, rather than by purely medical considerations. In particular, while the intensity of effort in emergency departments is no longer driven by the race or apparent class position of patients, as it may have been in the past, physicians and nurses are still likely to carry on their efforts for "tragic cases"—younger people and occasional local celebrities—well beyond the point where they would have "called the code" for others.

To this we might add the strains that CPR creates for medical personnel. Physicians, nurses, and emergency medical technicians are, by both training and inclination, activists. Their very occupational identities are based on the ability to save lives. The constant failures of the emergency department are a reproach to their activism, a threat to their identities. It is little wonder, then, that the legal obligation to treat patients who cannot be revived weighs heavily on medical personnel. And it is little wonder that they become cynical or that they try desperately to develop technical criteria for evaluating the success of a code, in which the survival of

the patient is at best a bonus, at worst, irrelevant. None of this, I need hardly add, is very good for morale.

These are all important observations. They are, however, subverted by another, more powerful consideration.

CPR does not, in Timmermans's fine phrase, save living so much as it saves dying. Regardless of the inability of CPR to save as many lives as it promises, it nonetheless transforms the experience of dying. CPR is a ritual. A resuscitative effort, as he points out, "takes some of the suddenness of sudden death away" (110). CPR may not deny death. CPR may not even postpone death. But CPR does provide a brief reprieve from the acknowledgment of death and an opportunity for family (and, at times, staff) to come to terms with it. CPR is also a community event. "The act of putting one's mouth on the mouth of a relative or stranger and massaging that person's chest creates a close bond between rescuer and victim" (111). It is not only a heroic act but a ritual enactment of our obligations toward each other. Most important, CPR, the swift appearance of an ambulance, the frantic activities of the emergency department, all reassure family and friends that "everything medically possible has been done to revive their loved one" (*ibid.*). As a ritual, CPR celebrates our society's commitment to saving lives. And, in a roughly secular society, particularly in a sector of that society committed to rationality, the ability to mount an effective ritual is no small accomplishment.

Even for physicians and nurses, CPR has powerful and positive meanings. During my own research in intensive care units—one end point of the process whose beginning Timmermans reports on—I saw many patients brought in after out-of-hospital arrests who might have been better left to die quickly without the extended agonies of invasive treatments. But the occasional dramatic "save"—the patient who did leave the ICU healthy after an out-of-hospital arrest—also occupied the symbolic center of the unit. Such patients contributed the success stories that justified—to physicians and nurses, let alone to families and a more diffuse public—the entire enterprise of medicine.

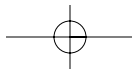
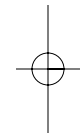
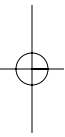
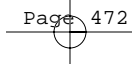
How can we balance such weighty matters as the financial costs of CPR, the additional strain on an already overtaxed medical system, and the disappointment of hopes falsely raised with something as ethereal as ritual? Apparently Timmermans thinks that we cannot. I'm not so sure.

If we were to evaluate out-of-hospital CPR on the basis of survival rates and cost-benefit analyses alone, we might well come to the conclusion that it isn't worth the effort. But this is to accept more or less exclusively medical criteria of what is worthwhile. It is altogether to

Books **471**

Timmermans's credit that he provides us with another, more social, way of thinking about what CPR does, even if he does not weigh these considerations as heavily as I might like. Even if CPR is only a ritual, and there are instances when it is considerably more, that may be enough. The tough questions, as the author himself realizes, are what kinds of rituals do we want. But without CPR, indeed even without the myths that surround it, death would be far more difficult to manage. We are very much in debt to Timmermans's excellent book for raising these questions.

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Books Received

Comparative Studies of Health Care Delivery, Politics, and Policy

Public Health Policies in the European Union. Walter Holland and Elias Mossialos, eds. Burlington, VT: Ashgate, 1999. 408 pp. \$89.95 cloth.

Economics and Finance

Costs of Occupational Injuries and Illnesses. J. Paul Leigh et al. Ann Arbor: University of Michigan Press, 2000. 323 pp. \$49.50 cloth.

GPs and Purchasing in the NHS: The Internal Market and Beyond. Bernard Dowling. Burlington, VT: Ashgate, 2000. 276 pp. \$69.95 cloth.

Health Care Delivery

Community Health Needs in South Africa. Ntombenhle Protasia and Khoti Torkington. Burlington, VT: Ashgate, 2000. 260 pp. \$74.95 cloth.

Health Data Quest: How to Find and Use Data for Performance Improvement. Jill Lenk Schilp and Roy E. Gilbreath. San Francisco: Jossey-Bass, 2000. 252 pp. \$45.95 cloth.

Psycho-Economics: Managed Care in Mental Health in the New Millennium. Robert D. Weitz, ed. New York: Haworth, 2000. 165 pp. \$39.95 cloth; \$19.95 paper.

Remaking Health Care in America: The Evolution of Organized Delivery Systems. 2d ed. Stephen M. Shortell et al. San Francisco: Jossey-Bass, 2000. 357 pp. \$42.95 cloth.

Women, Work and Care of the Elderly. Elizabeth A. Watson and Jane Mears. Burlington, VT: Ashgate, 1999. 214 pp. \$64.95 cloth.

474 Journal of Health Politics, Policy and Law**History and Humanities**

Beriberi, White Rice, and Vitamin B: A Disease, a Cause, and a Cure. Kenneth J. Carpenter. Berkeley: University of California Press, 2000. 296 pp. \$40.00 cloth.

Brush with Death: A Social History of Lead Poisoning. Christian Warren. Baltimore, MD: Johns Hopkins University Press, 2000. 376 pp. \$45.00 cloth.

Law and Biomedical Ethics

Endings and Beginnings: Law, Medicine, and Society in Assisted Life and Death. Larry I. Palmer. Westport, CT: Greenwood, 2000. 161 pp. \$39.95 cloth.

Intensive Care: A Doctor's Journal. John F. Murray. Berkeley: University of California Press, 2000. 310 pp. \$27.50 cloth.

Margin of Error: The Ethics of Mistakes in the Practice of Medicine. Susan B. Rubin and Laurie Zoloth, eds. Hagerstown, MD: University Publishing Group, 2000. 384 pp. \$29.95 paper.

The Ritual of Rights in Japan: Law, Society, and Health Policy. Eric A. Feldman. New York: Cambridge University Press, 2000. 233 pp. \$64.95 cloth; \$23.95 paper.

Speaking for the Dead: Cadavers in Biology and Medicine. D. Gareth Jones. Burlington, VT: Ashgate, 2000. 288 pp. \$89.95 cloth.

Xeno: The Promise of Transplanting Animal Organs into Humans. David K. C. Cooper and Robert P. Lanza. New York: Oxford University Press, 2000. 295 pp. \$30.00 cloth.

Medical Anthropology

The Female Circumcision Controversy: An Anthropological Perspective. Ellen Gruenbaum. Philadelphia: University of Pennsylvania Press, 2001. 235 pp. \$55.00 cloth; \$24.95 paper.

Venus on Wheels: Two Decades of Dialogue on Disability, Biography, and Being Female in America. Gelya Frank. Berkeley: University of California Press, 2000. 299 pp. \$50.00 cloth; \$19.95 paper.

Politics and Policy

After the Cure: Managing AIDS and Other Public Health Crises. Martin A. Levin and Mary Bryna Sanger. Lawrence: University of Kansas Press, 2000. 276 pp. \$35.00 cloth; \$16.95 paper.

America's Health Care Safety Net: Intact but Endangered. Marion Ein Lewin and Stuart Altman, eds. Washington, DC: Institute of Medicine, 2000. 299 pp. \$42.95 cloth.

Books Received 475

Analysing Health Policy. Alison Hann, ed. Burlington, VT: Ashgate, 2000. 205 pp. \$64.95 cloth.

Is the Fetus a Person? A Comparison of Policies across the Fifty States. Jean Reith Schroedel. Ithaca, NY: Cornell University Press, 2000. 238 pp. \$29.95 cloth.

License to Steal: How Fraud Bleeds America's Health Care System. Updated ed. Malcolm K. Sparrow. Boulder, CO: Westview, 2000. 303 pp. \$26.00 cloth.

Medicaid and the States. Paul Offner. New York: Century Foundation, 1999. 46 pp. \$9.95 paper.

National Health Reform American Style: Lessons from the Past, a Twentieth-Century Journey. Norbert Israel Goldfield. Tampa, FL: American College of Physician Executives, 2000. 187 pp. \$38.00 paper.

Public-Private Policy Partnerships. Pauline Vaillancourt Rosenau, ed. Cambridge: MIT Press, 2000. 262 pp. \$19.95 paper.

The Shadow Welfare State: Labor, Business, and the Politics of Health Care in the United States. Marie Gottschalk. Ithaca, NY: Cornell University Press, 2000. 298 pp. \$45.00 cloth; \$18.95 paper.

Under Attack, Fighting Back: Women and Welfare in the United States. 2d ed. Mimi Abramovitz. New York: Monthly Review, 2000. 182 pp. \$15.00 paper.

Miscellaneous

Dollars and Democracy: A Blueprint for Campaign Finance Reform. Association of the Bar of the City of New York, Commission on Campaign Finance Reform. New York: Fordham University Press, 2000. 237 pp. \$27.50 cloth; 19.95 paper.

Social Science in Government: The Role of Policy Researchers. New ed. Richard P. Nathan. Albany, NY: Rockefeller Institute, 2000. 226 pp. \$38.95 cloth; \$16.95 paper.

