Philosophy and Medicine

Important Notice
Regarding the Spring 2002 APA Newsletter on Philosophy and Medicine

This is the corrected version of the Spring 2002 APA Newsletter on Philosophy and Medicine. The version included in the Spring 2002, volume 01, number 2, issue of the APA Newsletters contained a number of significant errors that were introduced subsequent to submission of the articles to the APA. We ask that no citations be made to that earlier, flawed version. The APA National Office apologizes for the problems that occurred in production and for the inconvenience this problem has caused the authors, editors and subscribers.
THE AMERICAN PHILOSOPHICAL ASSOCIATION
NEWSLETTERS ON PHILOSOPHY AND MEDICINE

Volume 81, Number 2 REVISED  Spring 2002

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FROM THE EDITORS

Rosamond Rhodes & Mark Sheldon

At the December 2002 meetings of the Eastern Division, the APA Committee on Philosophy and Medicine invited four panelists to address the question of whether bioethics represents a challenge to ethical theory. This issue begins with Heidi Meld’s response. The Fall 2002 issue will contain additional replies. This Spring’s issue includes contributions on a variety of additional novel and thought-provoking issues. Together, they make this another worthwhile Newsletter.

Preventive medicine has received a great deal of response from the public because of floods of product advertisements and media attention. Exercise! Take vitamins! Eat natural foods! More oat bran! Here’s a minicourse annually! Get your full body CAT scans here! We are all familiar with the implicit and explicit promises that lifestyle changes and screening programs save lives. But, these claims have hardly been examined. In “Do This. It Could Save Your Life!” and “Other Problematic Claims in Preventive Medicine,” Heidi Meld raises the kinds of issues that others overlook and that philosophers are challenged to notice. She examines the banal representations of preventive medicine and identifies a variety of hardly trumpeted problems that accompany adherence with the broadcasted recommendations.

In “Genetic Ancestry and American Indian Identity,” Susan Parr and Carl Elliott analyze the implications of using genetic testing as the basis for a determination of ancestry. Decisions on whether, what, and how to use genetic evidence can be particularly important when a group has an individual’s claims to rights or privileges turn on some particular ancestral line. Yet, genetic evidence can be ambiguous, misleading, and misleading. To illustrate the stakes and the problems of reliance on genetic evidence, Parr and Elliott describe the plight of the Lumbee Indians, a group that has not been, but would benefit from being classified as Native Americans.

Robert Baker’s piece, “The Co-Evolution of Bioethics, Computing, and Cyberspace: An Archaeological Perspective,” shares the layers of debris that he uncovers as he packs up his old office for a move to Union College’s new Biodynamics Center. The inventory documents the simultaneous development of bioethics, computing, and cyberspace and Baker’s account provides interesting anecdotes and curious links.

The book review section offers thoughtful comments of some important books. Leonard Fleck reviews Premeditated Testing and Disability Rights, edited by Erik Parens and Adrienne Ach, a very useful contribution to the literature on disability. For Fleck, the collection is a model of careful attention to a difficult private case and the envisioned social implications of that case. Matthew Rottnek contributes a review article of Joel Halpern’s From Detached Concern to Empathy: Humanizing Medical Practice. Halpern is trained as a physician and a philosopher and Rottnek, trained as a philosopher, is now training to become a physician. Rottnek finds the book to be uniquely valuable because Halpern effectively uses philosophy (both the analytic and continental traditions) together with psychoanalytic theory and cultural criticism to offer a rich account of how physicians can more effectively provide care to their patients. Meg Smith reviews Nursing Ethics: Controversies in Dialogue. She is especially impressed with the insights in the applied chapter on Feminist Ethics. Richard T. Hull’s review of Gina Kolata’s Flu: The Story of the Great Influenza Pandemic of 1918 and the Search for the Virus That Caused It, combines some personal reflections with his comments on an interesting and informative book.

We want to remind you to please send along your annotations, letters, papers, case analyses, poetry, and stories. Directions for formatting your submission can be found at the end of the Newsletter volume. Please feel free to contribute your book review. Your contributions and quotes should be sent to Rosamond at the address below. Please include your phone and fax numbers and email address if you have one.

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Adventures at the AMA

Despite its many shortcomings, the traditional academic career can boast at least one unalloyed blessing: the sabbatical. Having been marooned for more than 20 years on a remote Pacific island, I was able to spend 2001-02 in Chicago as the American Medical Association’s first Visiting Senior Scholar. Here is a report from the front.

Representing almost 300,000 physician-members, the AMA struggles with these distinctive identities. It is a corporation with a range of profit centers and a focus on the bottom line. It is a trade association for doctors, advocating powerfully on behalf of their interests. And it is a professional association with a selfless commitment to medicine’s distinctive goods. About 1000 staff work at the AMA’s building on State Street. The eighth floor, where I have my cubicle, houses the Professional Standards Sections, the unit with lead responsibility for the third identity.

A few feet from my desk is the office of the Council for Ethical and Judicial Affairs (CEJA), which issues the AMA’s codes of ethics and its “Judicial Opinions.” The Council itself consists of nine AMA members, mostly practicing physicians, who are elected to seven-year terms following nomination by the AMA president. CEJA’s canonical ethics texts include a one-page AMA “Principles of Medical Ethics”—a set of nine axioms to live by—and a slightly longer “Fundamental Elements of the Patient-Physician Relationship”—a set of six specific norms. There are also approximately 180 discrete CEJA “Opinions,” that, in general, treat questions pertaining to professional practice. Issues include the reporting of spouse abuse, genetic counseling, organ procurement, sports medicine, advertising, fee splitting, gifts from industry, caring for the poor, and so on. Finally, there are the “Reports” that lay out justifications for many of the Opinions. Taken together, these four components are the AMA Code. The first three are easily obtained in an AMA publication entitled Code of Medical Ethics: Current Opinions.

As it happens, I have never used the Code in teaching medical ethics nor am I aware of anyone who does. Despite much more intense analysis in these materials, there are reasons for passing on pedagogical use. First, the Code is often inconsistent. While the Council and its staff do conscientious work on the Opinions, each is drafted separately. What is said this year can conflict with language in an opinion drafted a decade ago. Second, the Opinions are narrowly focused: they are not intended as a comprehensive set of norms nor are they accompanied by a background conception of the profession’s responsibility to society. There is no big picture. Third, the older opinions often fail to reflect the best thinking in the current medical ethics literature.

Though CEJA members are far better informed than the representative physician, it is rare for them to be "specialists" in medical ethics, and the staff can only do so much to bring them up to speed during their two-day orientations every other month. In my opinion, CEJA functions, in part, as what advertisers call a “focus group.” Its processes generate what may be a fairly accurate reflection of the collective moral judgment of America’s better-informed physicians; a judgment that is, to some extent, authoritative within medicine despite dozens of other codes governing medical practice in the United States. (See, for example, Medical Ethics: Analysis of the Issues Raising by the Coders, Opinions, and Statements by Brody, Rodin, McCullough and Boltoski.)

Godly that I am, I have been pressing the point that the medical profession suffers from a damaging disconnect between the processes by which it articulates what authoritative ethical standards it has, and the processes by which it inculcates ethical standards in its novices and initiates. Those who are teaching medical ethics in colleges and universities who are following and contributing to the pertinent literatures, are distinct from those who are busily hammering out professional guidelines for practitioners.

I have been urging that these two stakeholders be brought together to generate responsible ethical guidance that can somehow be incorporated into medical ethics pedagogy even as it can be authoritative endorsed by medicine’s leading professional organizations.

While — personally — it is a salutary welcome change to be able to see my field anew from this remarkable vantage point, there may be challenging work for other philosophers should formulae for cooperation be found.
“Do This, It Could Save Your Life!” and Other Problematic Claims in Preventive Medicine

By Heidi Malm
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At a recent API symposium sponsored by the APA Committee on Professional Standards, four panels, including myself, were asked to address the question of whether bioethics represents a challenge to ethical theory. The question seemed to be ambiguous, but the answer was obvious otherwise. That is, if the question is asking whether the problems raised by medical practice and bioethics are so intractable, so unwieldy, or open to theoretical analysis and resolution that they show ethical theory to be a sham or devoid of pragmatic relevance, then the answer is certainly “no.” For even if we could get by at the level of clinical practice with a purely casuistical or particularistic mode that is devoid of any theoretical claims or commitments (sadly I don’t think we can), because even the identification of the goal of a clinical encounter (e.g., health, or longevity, or preference satisfaction) requires some theoretical commitment), quite a bit of bioethics has to occur at the level of policy. For example, there must be hospital policy regarding the sorts of services that will be made available, social policy regarding the funding of research and the distribution of resources, legal policy defining one's rights and duties in the medical arena(s), and governmental policy overseeing all of the above and more. Most, if not all, such policies involve a prescriptive element and thereby involve a theoretical component.

On the other hand, if the question is asking whether medical practice and bioethics represent a challenge for ethical theory by creating new problems which need the aid of theoretical analysis, or by exposing problems in existing theories, whether more deeply entrenched, or new distinctions, or even by showing that therefore consistent theories are now inconsistent in practice and need to be revised, then the answer is an inconceivable “yes.” Anyone who recognizes bioethics as a satisfactory discipline has to recognize that advancements in medical science and technology continue to create problems that need ethical analysis in many levels, including the purely practical level where policies have to be implemented, the level of applied ethics where policies are developed and defended, the level of normative ethical theory, and even the level of moral ethics at which we test and refine the concepts used at the other levels. Moreover, the practical necessity of bioethics mandates that the problems be at least conditionally resolved. Since laws often hang in the balance we cannot be content with mere proposals, postulations, agreements to disagree, and idealist answers, as we might be with purely theoretical concerns. Indeed, resolutions must be implementable in the imperfect real world.

Given the above, the second interpretation of the question seems far more interesting than the first and I’ve chosen, then and now, to direct my attention to challenges that advance in medical practice and technology create for ethical theory. I’ll focus on three such challenges and propose some of the relatively overlooked challenges that arise in the area of preventive medicine. I’ll first focus my attention on that aspect of preventive medicine that aims to protect individuals from health by encouraging people to “take this screening test,” “avoid that food,” or “take this drug” as a means to protect their own health. I’ll only marginally touch on preventive health measures that involve transmissible disease. Thus, my focus is on such common preventive practices as encouraging all women over 40 to have mammograms to detect breast cancer, encouraging all men over 50 to have PSA tests to detect prostate cancer, encouraging all adults to be checked for high cholesterol and initiate drug therapy for those in the top quartile, and encouraging specific dietary changes as a means to avoid particular diseases.

An informal review of over 20 bioethics textbooks—I look up the kind written or edited by philosophers—revealed that none devoted a section to the problems of preventive medicine in general, and only two included a section on the narrower concern of testing and screening for contagious diseases such as AIDS. Some included individual articles within each section, such as articles about pre-natal screening or the morality of conceiving when there is a high probability of passing on a genetic impairment within sections on other sections, such as articles about pre-natal screening or the morality of conceiving when there is a high probability of passing on a genetic impairment within sections on other issues. Most, if not all, such policies involve a prescriptive element and thereby involve a theoretical component.

Perhaps this relative lack of attention is due to an assumption that the issues of preventive medicine are not significantly different from those of traditional medical practice and thus not in need of a separate analysis. Or perhaps we are assuming that the issues of preventive medicine, at least those that are not substantive under discussions of traditional medical practices, are not ethically problematic, especially when compared to such things as cloning and organ sales. After all, preventive health recommendations merely aim to protect future health by diagnosing and treating disease in its pre-symptomatic stages and by preventing risk factors from developing into disease, and they aim to do this in relatively harmless and cost-effective ways. How could there be a problem with that? But those assumptions are mistaken. There are a number of serious differences between preventive medicine and traditional medical practice that preclude us from simply assuming that the problems of preventive medicine do not need their own ethical treatment.

Moreover, most of the presumptions of preventive medicine, as it is currently practiced, have not been subject to the kind of ethical scrutiny that would expose their various problems.
And even if the underlying assumptions were to be tested and found to be O.K., the task of doing the testing is one of our jobs as philosophers. In what follows I will develop these points as they arise in connection with efforts to justify preventive health recommendations and efforts to use the recommendations in for-profit marketing. My aim here isn't to resolve each of the problems I raise, but rather to expose them and encourage attention from philosophically trained ethicists.

Under what conditions are physicians, hospitals and various health-advocacy groups (such as the American Cancer Society) ethically justified in encouraging asymptomatic individuals to take screening tests, adopt drug regimes, or make dietary changes as a means to avoid particular diseases (or the debilitating effects thereof)? The general answer to this question is easy to discern: when the recommender reasonably believes that the recommended action will be good for the recipient, all things considered. (All things considered) takes into account the probabilities of benefits and harms as well as the magnitude of those benefits and harms. The particular answer, on the other hand, one which specifies the conditions for such reasonable belief, is not so easy. And the source of the difficulty is the combination of the following two facts: First, preventive health recommendations and the procedures to which they lead are not risk free. (The risks of the follow-up procedures and treatments are standard included among the risks of the preventive recommendation because the risks would not have been serious were it not for the recommendation and the point of the recommendation is to respond to suspicious results.) Space limitations preclude a detailed account of the various sorts of risks but they include: (a) the very minor risks of the tests themselves (e.g., discomfiture, inconveniency, loss of time and money, exposure to low-dose radiation, etc.); (b) the much more serious risks of additional procedures, including surgery, performed in response to a suspicious but ultimately false positive result; (c) the wide-spread risks of overtreatment, that is, treatment that the patient would never have received had she not been screened and treatment from which she gained no benefit (because, for example, the treatment was either ineffective or harmful, or treated a disease that would never have progressed to clinical relevance); (d) the risks of overly aggressive treatment, that is treatment that, although it was the best available at the time it was given, was later shown to be more aggressive (i.e., with more debilitating side effects) than was actually needed; (e) the risks that treatment for one problem will increase the risks for another; and (f) the risks of various psychological changes that happen when people begin to see themselves as patients rather than persons, see their bodies as a threat, and forgo basic pleasures in the hope of avoiding disease.

Of course, the presence of such risks doesn't show that preventive health recommendations should never be issued. It is quite possible that the benefits of the recommended tests and dietary changes will be enough to outweigh the risks. But this brings us to the second fact, namely, that the best evidence as to whether the benefits of a given preventive practice are worth its risks and harms comes from randomized controlled clinical trials on the use of the test or drug as a preventive measure. For only those trials can tell us how much the recommended treatment reduces one's overall risk of death and if what cost it in terms of harms and side effects. And such trials take a very long time to complete, typically a decade or more. Thus we have to determine whether and under what conditions health care professionals and advocacy groups are justified in encouraging apparently healthy people to take the test or drugs, or to make the dietary changes, in the absence of clear evidence indicating that doing so would be beneficial for the person, all things considered.

On one side of the equation are all the harms and deaths that we could prevent if we recommended the promised but unproven test now, and on the other side are all the harms and death we will have unjustifiably caused if the recommended tests prove not to be beneficial overall.

The preceding problem may not seem very different from the general problem of determining when a physician or other professional is justified in recommending any medical course of action and thus not in need of independent analysis. But there are at least two main differences between preventive medicine of the sort we are discussing and traditional medical practice which show the need for independent ethical analysis and argument. The first main difference can loosely be described in terms of the origin of the physician-patient interaction. In traditional medical practice, the prospective patient comes to the physician or other health professional seeking help or advice for a particular concern. The physician or other does her best to provide the best possible care and treatment (even a recommendation to do nothing). But in preventive medicine as it is currently practiced, the recommendation for a given preventive procedure comes from a third party, that is, physicians, hospital administrators and advocacy groups confront people who have no reason to believe they are sick (at least not in the relevant way) and say "do this" to better protect your future health. The physician-patient interaction is thus a consequence of the recommendation instead of the recommendation being a consequence of the interaction. This difference is important because when we take into account both our general theory of moral responsibility that entails that the more one is responsible for the occurrence of an event, the more one is responsible for the outcome of the event, and the medical imperative to do no harm. It becomes even more important when we recognize the power or authoritative weight that people attach to medical recommendations. Although people have been trained to be skeptical of the recommendations of used car salesmen and other retailers, they have been socialized to trust health care recommendations and to believe both that the recommendation would not have been made had the recommended test not been tested and shown to be both safe and effective and that the motive for the recommendation is the well-being of the recipient. Furthermore, with respect to preventive medicine (and unlike traditional clinical practice) there is no imperative to make a
recommendation either way. Bruce Charlton puts the point this way:

When physicians ask a doctor for help because they feel ill, can they expect the doctor to do only his or her best. Responsibility is, in a sense, shared between the patient and the doctor as long as the doctor is acting in good faith. But the ethics that govern preventive medicine must be different. When a doctor initiates contact with a person who is not ill then doing his or her best is not good enough.4

The reason is it is not good enough that the clinical imperative that "someone must be done," which applies to patient-initiated encounters and may be satisfied by something as simple as "listening and responding appropriately" does not apply to programs of preventive medicine. Since it is not the case that a recommendation of some sort must be made, then, before one makes a preventive recommendation one needs solid ground for thinking that the recommended procedure will in fact be beneficial or safe, all things considered. We could express this point in legal terms by saying that when a patient initiates the contact, the recommended treatment must be supported by a demonstration of the available evidence indicating that the treatment is likely to be beneficial for the patient, all things considered. But when the health care professional initiates the contact—when she seeks out persons who believe themselves to be healthy and offers to "optimize their health"—then the evidence must justify a higher standard. There must be clear and convincing evidence of, or, even stronger, evidence showing it to be beyond a reasonable doubt that the recommended procedure will be good for the patient, all things considered (that is, taking into account the probability and magnitude of the benefits and harms). These stricter standards assess not just the weighing of the available evidence but also whether the available evidence is of a sufficient quality or kind to justify encouraging apparently healthy people to undertake any activity with more than trivial risks, especially when encouragement comes from a trusted professional or organization.5 Unfortunately, some of our current screening recommedations fall to satisfy even the weaker preponderance standard.

A second main difference between preventive medicine and more traditional medical practice focuses on the odds that a given person will actually benefit from the recommended procedure. This difference is most noticeable in the case of screening recommendations. That is, according to the very nature of screening, the vast majority of people screened will not have the disease in question and thus not be able to gain any benefit from the recommended procedure (other than the minimale benefit of being told that one does not have a disease that one had no reason to think one had in the first place). Yet they are still subject to many of the mentioned harms. In contrast, persons who are already symptomatic and rely on traditional medical help are much more likely to be sick. They thus have a greater probability of benefiting from the recommended treatments, and more room for benefit (they are already symptomatic and thus start in a worse position than persons who are screened, (then the symptomatic people who turn out not to be sick can gain the benefit of knowing that the suggestive symptom was nothing to worry about.) This difference in the probability of benefit can greatly affect the reasonableness of encouraging the attending risks. For according to probability calculus, the smaller the probability of benefit, the greater must be the size of the benefit, if it occurs, in order to justify the risks. Thus, risks that are very reasonable to take when one is already known to be sick may be quite unreasonable to take when the probability is that one is healthy.

In short, the key differences between preventive health recommendations and recommendations in traditional medical practice—differences relating to the origin of the physician-patient interaction, the probability of benefit, and whether a recommendation of some sort has to be made—can work together to create substantial differences in the quality and quantity of evidence needed to ethically justify the recommendation. In turn they help show that some of the common defenses for the practice of having preventive health recommendations prior to the acquisition of clear evidence indicating that the recommended measures will actually be good for people, all things considered, are ethically quite problematic. (By the way, I'm not claiming that all preventive health recommendations are ethically questionable. Some are backed by evidence from well-designed randomized clinical trials showing a statistically significant mortality reduction from the recommended measure and others are the disease where detection and treatment is the first step toward resolution of the disease.) To cover these such defenses.

First, some people attempt to defend our current screening practices by maintaining that it is intuitively obvious, or that it just stands to reason, that early detection is good for people and thus that recommendations for screening are ethically justified. But the preceding points help show the absurdity of this "commonsense" view. First, it is wrong to simply assume that very early detection through screening is beneficial. For some diseases it affords no benefit at all because the disease is not treatable at all. It can also be worse for the patient than later detection because it can lead to ever treatment, overly aggressive treatments, and simply knowing for many more can work together to create substantial differences in the case. Second, and more importantly, even for diseases for which we know that very early detection allows a treatment benefit over somewhat later detection (e.g., after symptoms appear) that isn't can't justify a screening recommendation. The reason is that the common sense view that early detection saves lives is therefore good for people focuses solely on the benefits to the sick. Yet screening recommendations are given to vast numbers of persons who don’t know to be sick or healthy but who are statistically more likely to be healthy. Thus, the relevant question isn't whether latent sick people will benefit from screening (which is the question addressed by the "common sense" view), but whether "sick" persons that is, any given person in the target population will be better off being screened now when she has no symptoms of disease, or better off waiting
and being treated only if and only when symptoms appear. Answers to that question have to take into account the risks and harms to the healthy as well as the benefits and harms to the sick. And when the risks of detection and treatment are more than trivial (as they are for diseases such as cancer), good faith or even great effort to early detection saves lives is not enough to justify a screening recommendation. We need to know that the size of the benefit that the sick person will gain—that is, how much it reduces her risk of death and is what (non-monetary) cost—worth the myriad risks that harms that we apparently healthy person will endure in an effort to determine whether she is in fact latently sick. That sort of maximization can't come from "common sense" or intuitive reasoning.

(Consider this prophylactic appendectomy would also save lives, but we don't consider that to be an adequate justification for encouraging asymptomatic people to have them. One might respond that appendectomies are major surgeries whereas screening is not, but note that screening tests can lead to major surgeries. Moreover, prophylactic appendectomies guarantee that one will not die from an acute appendicitis while cancer screening only reduces one's risk of death. This greater certainty of benefit would balance the greater cost of gaining the benefit if such a benefit were a sufficient justification for encouraging asymptomatic people to have the appendectomy or screening. But isn't rational decision making requires that we take into account the probability that a given person will fall into a certain class (i.e., the class of persons whose appendix will rupture sometime in the future or the class of persons with asymptomatic cancer) and not just the benefits that will accrue from a particular procedure to persons who happen to be in that class? Simply, we know that the lotteries turn out some people into millionaires. But a financial advisor who used that fact as grounds for encouraging her client to spend his paycheck on lottery tickets, without knowing the odds that he would win or whether he could afford the loss, would be in violation of her fiduciary duty.)

Another problematic justification for our screening recommendations relies on partial evidence about the benefits of screening, such as evidence showing an increased survival rate for persons whose disease is detected through screening. We don't want to answer the question of whether or when health care professionals are justified in encouraging asymptomatic individuals to submit to various preventive measures that the test would result in a certain number of lives being saved across the population. Such evidence is more readily obtained than evidence from randomized clinical trials, but this approach is problematic in that it builds an ill-fated. It sacrifices the smaller harms of the many for the greater benefit of the one. It says that we are justified in encouraging lots of people to undergo an activity in which we know that many of them will be harmed in small to moderate ways because we also know that a few of them will be benefited in much greater ways. Yet when we are talking about non-contagious diseases such as cancer—diseases for which one person's probability of benefit from a given test or treatment is not at all affected by the number of other people who take the test or treatment—such inter-personal balancing of benefits and harms seems inappropriate and unfair. For non-contagious diseases, the only thing that should determine whether person X is encouraged to take the test is whether the benefits that X is likely to gain outweigh the risks and harms that X is likely to suffer. We can't know that just by looking at the number of lives saved across a population.

In summary, each of the above Justifications for our "Do this, it can save your life" recommendations suffers from a myopic focus on the benefits of the sick while ignoring the risks and third justifies by asking us a question that would result in a certain number of lives being saved across the population. Such evidence is more readily obtained than evidence from randomized clinical trials, but this approach is problematic in that it builds an ill-fated. It sacrifices the smaller harms of the many for the greater benefit of the one. It says that we are justified in encouraging lots of people to undergo an activity in which we know that many of them will be harmed in small to moderate ways because we also know that a few of them will be benefited in much greater ways. Yet when we are talking about non-contagious diseases such as cancer—diseases for which one person's probability of benefit from a given test or treatment is not at all affected by the number of other people who take the test or treatment—such inter-personal balancing of benefits and harms seems inappropriate and unfair. For non-contagious diseases, the only thing that should determine whether person X is encouraged to take the test is whether the benefits that X is likely to gain outweigh the risks and harms that X is likely to suffer. We can't know that just by looking at the number of lives saved across a population.

The second main area of critical concern that I'll discuss focuses on the use of preventive health claims in for-profit marketing. It is difficult to watch TV, read magazines or newspapers, or go to the mall without seeing multiple ads either touting a preventive procedure (for example: "Cure in for your annual screening test at the clinic conveniently set up at Northtowns, or "Take this drug to lower your cholesterol") or using a preventive health claim to sell an everyday product (for example: "Our bagels have oat bran which can lower your risk of colon cancer" or "Our margarine can lower your cholesterol count by 15"). Of course, there is nothing inherently wrong in a caplitalistic society with encouraging healthy behaviors or using accurate claims to promote one's product. But problems arise when (a) the
claims aren't backed up with good evidence showing an overall benefit, or (b) the claims are easily misunderstood by laypeople, and (c) the claims are used by companies adopting wide business practices ("Come, use our product!") but are researched by a public that still assumes that the ricey behind a medical recommendation is the welfare of the patient and not the profit of the company. Although we have moved far away from the paternalistic model of medicine, we have not moved as far as we'd like in the opposite direction. And the problems are more acute in the case of preventive medicine than in traditional medicine because (a) the relatively large target audience for preventive health claims creates more incentives for companies to exploit the claims, and (b) preventive health claims are currently subject to less government oversight and regulation than are traditional health claims.

At least four issues of ethical concern arise in connection with the for-profit marketing of preventive health claims. I'll cover each one briefly. 1 The first sort of problem arises in connection with the for-profit promotion of screening tests, especially those that have not yet been established to be beneficial, all things considered. As things currently stand, the advertisers are allowed to promote the tests without listing the potential harms. They can, for example, that mammography is the best tool we have for early detection of breast cancer and that early detection saves lives without listing the risks of a false-positive diagnosis and the corresponding risk of unnecessary surgeries. For are they required to explain that the tests that one will benefit (for example, in the case of a one-decade or annual mammogram for women in their forties, a full one-third to one-half of the women will be subject to the costs, stresses, and harms of additional tests, treatments, and surgeries, while only one out of two or three thousand will have the actual disease). Thus one ethical question that needs to be addressed is whether and to what degree advertisements for preventive health measures such as screening tests ought to be subject to the same truth-in-advertising regulations as advertisements for drugs and other traditional medical procedures (through the latter seldom get marketed).

A second ethical issue is whether the truth in advertising requirements that we do have in place ought to be sharp enough to help prevent the use of factually correct but easily misunderstood health claims as a means to promote business. For example, promoting a drug or test in terms of its relative risk reduction as opposed to its absolute risk reduction may misleadingly put people to thinking that the test or drug will confer a far greater benefit than it actually will. (A 5% risk reduction in one's risk of death from X may sound like a huge benefit but be, in fact, a minute benefit if the initial risk of death was already low.) Similarly, false inferences by lay people may result from the use of incomplete statistics. For example, hospitals have promoted the use of their testing facilities with are noting that 4 out of 5 men whose prostate cancer is detected through presymptomatic screening survive the disease. The likely inference by lay people is that the screening is beneficial. But what the ads don't state is that 4 out of 5 men whose cancer is detected through screening also survive the disease because 4 out of 5 men with prostate cancer die of something else before the cancer has time to significantly affect their lives.

Other ads make use of the claim that women have a 1 in 8 "lifetime risk" of getting breast cancer as a means to encourage women to use a particular radiological facility for a mammogram. Lay women might reasonably assume that means that 1 out of every 8 females born in the U.S. will get breast cancer, or even more alarming, that 1 out of every 8 women will have her own life affected by breast cancer. We now in this respect have a 1 in a chance of getting breast cancer, but most of them will die with the disease and not from it.) Similarly, makers of cereal, mattress, pasta, bagels, and extremal now tout the fact that their products do or do not contain certain ingredients—oct, trans, cholesterol, etc.—and allow consumers to infer that the product is thereby good for them. (The inference is aided by the consumer's knowledge of generally promoted preventive health claims.) But the makers don't have to note that the evidence of an actual benefit is scant or limited to a narrow class of people. In summary, these statements can still be quite misleading and we need to determine whether, with respect to health claims, people should be protected from this problem or taught to be more cautious consumers.

A third area of concern covers the medical and legal problems that can result from directly consumer marketing of preventive health measures. For example, during the 80's the National Prostate Cancer Awareness Week was heavily promoted by the company that made the PSA tests and products used in follow-up procedures. The promotion was so successful that most men (and women) were put into the testing arm and the researchers had to contend with the fear of contamination—that is, that men in the control arm will have the test done and study, which is both unethical and problematic. It is that we now have a test with known substantial risks and no proven benefit in part of the governing standard of care against which malpractice is assessed, and although the physician who decides not to recommend the test because she believes (is scientifically unwarranted can try to avoid a malpractice judgment by citing the doctrine of the questionable morality, the risk of harming a jury trial, as well as just the useless of fighting such a charge, can be enough to motivate some physicians to recommend the test even though they believe that it is not medically justified. This practice further establishes the test as part of the governing standards of care and exacerbates the problem.

The last type of problem I'll discuss arises primarily (but not exclusively) with respect to preventive health recommendations that are promoted through the media and carried out by individuals without physician involvement, such
as dietary recommendations to eat oat bran to avoid colon cancer, to avoid alcohol to reduce one's risk of breast cancer, and to limit salt intake to avoid the risk of hypertension. The risks associated with the dietary changes seem quite small when compared to the risks associated with screening tests (e.g., the fonging of favorite foods vs. the risk of unnecessary surgery). This would suggest that it will be easier to justify dietary recommendations than screening recommendations in the absence of clear evidence of a material benefit. After all, no one loses much if the recommended dietary changes prove in effective. But this view ignores what I have elsewhere referred to as news communication risks. For example, when preventive health recommendations are promoted through the media and carried out by individuals acting on one's own, we run the risk that the prohibition on the recommendation didn't properly understand it. They might mistakenly assume that they are in the target population when they are not. Or they might be unaware that the means to reduce their risk of death from one disease can increase it from another (as appears to be the case with alcohol, breast cancer and heart disease). Or they may read too much into the recommendation and assume, for example, that if a low sodium diet is recommended, a very low sodium diet must be ideal. (It isn't, and it can actually be harmful.) This risk of misunderstanding isn't as worrisome in the case of screening and other preventive measures that have to be carried out in an office or laboratory because the clinical encounter provides an opportunity to correct the misunderstanding.

Another type of mass communication risk is the risk of harm that arises when, as accurately understood and implemented dietary recommendation is later shown to be ineffective or, worse, that promotes worsening the problem. Once the public begins to question the effectiveness of the recommendation, it is hard for the public to distinguish among all the dietary recommendations, even those that are well supported. This latter risk should make us very cautious about making dietary recommendation prematurely.

The final type of mass communication risk I'll discuss combines elements of the first two and focuses on the fact that preventive health recommendations can be used and misused by non-medical companies to promote their products. Labels proclaiming "Low salt!" "No cholesterol!" "Now with oat bran!" are seen on all sorts of products. I'm not claiming that providing this information is wrong or necessarily a bad thing. The concern is that the labels contribute to what some social scientists call "availability cascades." The key idea is that in the absence of complete information, people will tend to judge the seriousness and significance of these issues based on the degree to which information about that risk is available to them—how much they see it around them. Thus repeated exposure to advertisements noting that a product is low in sodium, or high in fiber, or lacks cholesterol, combined with a background familiarity of preventive health recommendations, increases a person's fear of disease and increases perception of the risk of getting it. As these people share their worries with each other ("only use egg-substitutes, how about you?") and in turn demand more specialized products to quell their fears, an availability cascade occurs in which products 'fly off the shelf' as each other and the awareness of the risk becomes widely exaggerated. And once these availability cascades get going they can be very difficult to reverse. In the case of screening, for example, the particular dietary recommendation, turns out to have been misguided. Moreover, fears focused on one risk may distract our attention from another risk even though the other may actually be more risky. For example, women are more afraid now of breast cancer than heart disease (and younger women wildly overstate their risk), even though heart disease kills far more women than breast cancer. (This should make us wonder whether women who avoid alcohol because they've been told that it increases their risk of breast cancer are actually doing themselves a harm given the protective value that alcohol has against heart disease.)

Once again, I'm not claiming the this or any of the mass communication risks provide sufficient grounds for prohibiting the use of preventive health claims in for-profit marketing. Instead, my point is that the presence of these risks establishes a need for effective regulation. Once these institute the use of explicit statements such as "margarine is just as bad as butter" and "eggs don't raise your cholesterol level," simply banning claims of "no cholesterol" for a long, long time can foster distrust in all dietary recommendations, even those that are well supported. This latter risk should make us very cautious about making dietary recommendation prematurely.

Notes
1. The other panellists were John Delph, Bernard Gent, and Daniel Brock. The symposium was arranged by Rosamond Rhodes.
2. Although in practice preventive health measures such as cancer screening are often extremely expensive on a per-person basis, the saved, and do not save money when compared to treating cases that are discovered through traditional investigation.

4. Thus small probabilities of great benefit can outweigh moderate probabilities of small harms netting to a balance in which it is good for the person, all else considered.

5. For a detailed explanation of these and other risks, as well as specific examples of how these risks can interact screening programs for breast cancer, prostate cancer, and high cholesterol, see my "Medical Screening" at 31-32.

6. This risk of obtaining a false-positive and then undergoing further test when studies later show that the very early treatment conferred no benefit when compared to some other later treatment, appears to be the case with screening-detected prostate cancer in asymptomatic men.

7. Actually, even that information doesn't fully answer the question because we have to evaluate the degree of mortality reduction in terms of what it costs (non-minimally) the patient. A 50% increase in one's risk of death from X may not mean much to the patient if her risk before the test was quite low and the efforts needed to gain that reduction would significantly impact her life for the worse.


9. Ibid. p. 32.


11. I develop these points in more detail in "Preventive Health Recommendations and the Burden of Proof: Whose Does Your Health Industry Accept Your Business?" Unpublished. Also, the standards need not apply where the recommended procedure is identified as experimental and the patient consents to it as such.

12. Another defense of this type alludes to justify a recommendation to a population (e.g., women in the United States) by citing evidence of a benefit in another population (e.g., women in their forties). But if the incidence of disease differs between the groups they even if the benefits in the two groups are equally well from the presymptomatic treatment, we can't assume that asymptomatic women would get the same benefit. Screening-detected cancer is thus, in my view, if it is equally reasonable for them to accept the risks.

13. I am ignoring factual counterexamples in which the people with the disease are merely lightly given fatal treatments. In such cases, screening would not necessarily increase the average length of time one lives after diagnosis.


15. Nor do they note that men with screening-detected prostate cancer appear to have the same five-year survival rate regardless of the treatment they receive, including no treatment.


18. I discuss Rosenau's Rhodes for this point.

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Genetic Ancestry Tracking and American Indian Identity

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Last year saw the launch of a new Internet service called Family Tree DNA. A commercial firm sponsored by Genealogy by Geneticists Inc., Family Tree DNA advertises itself as "America's First DNA-driven genealogical testing company." For fees ranging from $210 to $485, the company offers genetic testing to subscribers who wish to trace their genetic ancestry. Among the special services and projects on its menu are genetic tests for Jewish and Native American ancestry. The headline on the Family Tree DNA website declares, "Genealogy by Geneticists is the greatest addition to Genealogy since the creation of the Family Tree!"

Commercial genetic ancestry tracing may be new, but the techniques it uses are not. Scientists working in population genetics and genetic anthropology are using Y chromosome and mitochondrial DNA testing to trace the genetic ancestry of populations all over the world. In 1996, geneticists used Y chromosome testing as a means of corroborating and denying the status of Americans who claimed to be the descendants of Thomas Jefferson and his slave mistress Sally Hemings. Rick Kitts of Howard University provoked controversy in 2000 when he began using mitochondrial DNA and Y chromosome testing to attempt to trace the ancestry of individual African Americans to the areas of Africa from which they were captured and brought to America as slaves. A number of research groups have used similar techniques to detect evidence of Jewish genetic ancestry in groups whose cultural or oral history suggests a Jewish heritage that has been lost or forgotten — most famously the Lemba, a black African tribe in southern Africa.

For the past year, a multi-center research group funded by the National Institutes of Health and based at the University of Minnesota has been exploring the philosophical implications of genetic ancestry tracing for concepts of social identity. The Genetics and Identity Project asked the question: how might new ways of mapping genetic variation change the way a given individual or group conceptualizes its identity? Historically, the meaning of genetic constitution has played an important role in the construction of various political structures, and this is often still true today. The one-drop rule in the Jim Crow South; the fact that many counties still base citizenship on "blood"; the issue of who is allowed membership in tribal bands of aboriginal peoples, or who is allowed access to affirmative action: all these questions have been subject to a kind of informal genetic assessment, which new techniques of gene mapping have the potential to alter, undermine or reinforce. But gene mapping also has the potential to alter conceptions of identity beyond the political. It might alter conceptions of ethnic identity (who counts as African American or American Indian) or religious identity (who counts as Jewish) or family identity (who counts as a member of the Jefferson family). All of these various aspects of social identity overlap in complex ways, and genetics is
only one part of the mix. But clearly there is great potential for confusion when new knowledge of genetic markers conflicts with other kinds of markers of group membership, like a shared culture or historical narrative. In a person any one of whom, a Cherokee, a Cree, a Japanese, a Jewish or his/her identity is corroborated by a genetic marker?

Geneticists often emphasize that the techniques used to trace genetic ancestry are very limited and offer only a glimpse into the ancestry of any given individual. Two main techniques are currently in use. The first type traces genetic markers (polymorphisms) on the Y chromosome. The Y chromosome is only passed from father to son. Thus the Y chromosome of any given man will be a copy of the Y chromosome of his father, which will be a copy of the Y chromosome of his own father, and so on. Tracing the Y chromosome offers any given man knowledge about one — but only one — of the many genetic lines in his ancestry. Any man has four grandparents, two of whom are his grandfathers, but Y chromosome tracing will connect him to only one of those four people. Similarly, any man has 128 great-great-great-great-great-grandparents, but Y chromosome tracing will track his genetic lineage back to only one of those ancestors.

For women, the story is slightly different. Women generally do not have Y chromosomes, of course, but they do have mitochondrial DNA, which is passed down through maternal lines. Mitochondrial DNA is present in both men and women, but only women pass their mitochondrial DNA on to their children. Like the Y chromosome, mitochondrial DNA includes markers that geneticists can use to trace maternal genetic lineages. Thus any person, male or female, can trace his or her ancestry through his or her mother, his or her mother’s mother, and so on. This kind of ancestry tracing is subject to limitations similar to those of Y chromosome tracing, in that it offers knowledge about only one of many genetic lines. A person whose mitochondrial DNA is traced back 9 generations will get information about his or her links to only one of 512 genetic ancestors.

This is perhaps good news for those who wish for a better understanding of their genetic background. For instance, if a person were to trace his or her mitochondrial DNA, he or she would be able to see which groups of people he or she is related to, and perhaps even get a sense of where his or her ancestors were from. This kind of tracing can be very useful for understanding one’s family history and for connecting with distant relatives.

Genetic ancestry tracing such as that offered by Family Tree DNA offers the lure of hard, scientific corroboration of American Indian ancestry, which could in turn be used to confirm or deny access to government services and participation in government programs. Should American Indians continue genetic ancestry tracing? If they do, how might this impact the relationship between Indians and government bodies? Ultimately, the question of whether to use genetic ancestry tracing is a matter for American Indians themselves to decide. What we can observe are some of the broader issues at stake in the debate, as well as a cautionary note about the ways that genetic ancestry tracing might be misused.

Genetics and the Bureau of Indian Affairs

Who counts as an American Indian? The answer is complicated. The most influential statement of American Indian identity, the Indian Reorganization Act of 1934 (IRA), defines "Indian" as follows:

All persons of Indian descent who are members of any recognized tribe now under Federal jurisdiction, and all persons who are descendants of such members who were, on June 1, 1934, residing within the present boundaries of any Indian reservation, and shall further include all other persons of one-half or more Indian blood.

Blood quantum is an enormously complicated issue because it is used in so many different ways. The federal government has two main types of relationships with American Indians: those with individual American Indians and those with tribes. In determining whether a tribe receives federal recognition (and is thus able to claim rights to federal financial support and sovereignty), the federal government does not use blood quantum explicitly. However, federal recognition is based on seven mandatory criteria (25 CFR Part 83), two of which refer to membership and ancestry. 83.7(d) requires that groups petition for federal recognition describe membership criteria and how they are applied, while 83.7(c) requires that current members of the petitioning group descend from a historic tribe or amalgamated tribes. Blood quantum thus plays an implicit role here, in that tribes determine their own membership criteria and these criteria vary greatly among tribes. Some tribes require that members trace their ancestors as a basis for tribal roles; others require anything from 1/32 to 1/2 "blood" of that tribe.

Even more complicated is the role of blood quantum in the relationship between the federal government and a state government and an individual American Indian. Many Bureau of Indian Affairs (BIA) regulations governing the administration of federal "in Kind" programs rely on one-quarter or one-half blood quantum requirements: e.g. the Indian Hiring Preference, Vocational Training for Adult Indians, and Educational Loans and Grants. Other programs require blood quantum and proof of tribal enrollment. Because these regulations vary so greatly, it is possible for a given individual to qualify for federal benefits, for example, but not employment benefits.

Despite great variations in how "American Indian" is defined, most definitions include some mention of ancestry and many refer explicitly to blood quantum. The amount of debate and disagreement here is high, in part because there

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The documented history of the Lumbee Indians begins in the early 18th century when Scottish settlers described encountering a "native tribe practicing a 'European culture.'" The Lumbee Indians have no remaining language or distinctive cultural practices, although some tribal officials were never a reserved people, and have no treaties with state or federal governments. The name "Lumbee" was adopted only in 1953. Most scholars agree that they are an amalgamation of at least several tribes and other individuals. Unlike most American Indian tribes, they have defined "their identity primarily in terms of shared ideas about themselves as a people," rather than genetic ancestry.

The Lumbee Tribe has made many petitions for federal recognition that includes full financial benefits. In 1985 the Bureau of Indian Affairs produced a final Determination that the Lumbee Nation does not exist as an Indian Tribe. In that document the Assistant Secretary determined that the Lumbee failed to satisfy five of the seven mandatory criteria and further that because of the group's mixed and uncertain ancestry, the geographical dispersion of its continuity, and the group's lack of inherent social and political cohesion and continuity, the Lumbee failed to satisfy federal requirements. But rejection by the federal government has not changed how the Lumbee Indians view themselves; members carry an overwhelming sense that "we know who we are." Despite this strong sense of self-preservation in the face of diversity, there is also a strong sense within the Lumbee Tribe that the federal government has treated the tribe unjustly.

It is not hard to imagine the prospects of genetic ancestry tracing for a group like the Lumbee Indians. These techniques promise new ways to document ancestry. Although current techniques are not perfect, some imagine improvements that would allow members of the Lumbee Tribe to use genetic testing to help settle the question of whether they are descendants of the Cherokee or Eastern Sioux Tribes. Testing could also be used to determine the ratios of genetic variation among Tribe members. Databases could be constructed that might link the Lumbee to other American Indian groups. Genetic ancestry testing could finally give the Lumbee Indians the "proof" of Indian ancestry they need for federal acknowledgment and benefits. But would it be worth the risk?

The Risks of Genetic Ancestry Tracing

One obvious risk of a genetic test for ancestry is that it will fail to corroborate an ancestry claim. The results of a test may never be known in advance. Any group or individual stating a claim of a genetic test runs the risk that the results will be reasonably interpreted in a way that runs counter to the interests of the individuals or group being tested. It is also important to remember that genetic ancestry testing has different implications for individuals than it does for groups. For individuals, genetic ancestry testing can be used to corroborate claims of a genetic relationship to a particular group, and it can fail to corroborate these claims, but it cannot be used to define such a relationship. If an individual Lumbee Indian were to get mitochondrial DNA testing, he or she might find that her mitochondrial DNA is
contained markers tracing back to one of the five Native American 'haplogroups.' This might be taken as evidence corroborating his or her ancestry claim. Yet, it would be inaccurate to assume that one (out of hundreds) of his or her maternal lineages tracked back to Europe. All of the others may trace back to the origins, but those would not be detected by the test.

Genetic ancestry tracing could play out differently for groups. For example, if mitochondrial DNA and Y chromosome testing were performed on a representative group of volunteers that identified themselves culturally and historically as Lumbee, the results would likely show that a certain percentage of the group had markers tracing back to one of the Native American haplogroups. If they were a high percentage, then federal authorities might be inclined to accept this as evidence that the Lumbee were "real" American Indians (and not, as the BIA put it, a group with "mixed and uncertain ancestry.") Yet what would count as a high percentage? Any figure would be meaningless without some point of comparison. High compared to whom? Other Native Americans? Other American Indian tribes? How should a group's ancestral profile be interpreted? And who should decide what percentage of a particular ancestry is sufficient for identity claims?

Most importantly, however, there is a real danger that the widespread adoption of genetic ancestry tracing will elevate genetics to a position of authority at the expense of other, arguably far more important aspects of identity. Membership in an American ethnic community may have often been tied to genetics, but it has never been solely genetic. For a person to be an "authentic" American Indian or Jew or African-American has never been solely a matter of a person's physical appearance or blood ties, but of all manner of other cultural forms, from language and history to music and food. If a simple genetic test comes to be seen as a way of adjudicating identity claims, it will threaten to overwhelm all of the other, less easily recognizable cultural forms that constitute an identity — such as shared values, languages, history, religion, social institutions, and worldview.

Can Elliott's research funded by the National Institute of Health, grant R01-HD02156-01, Ethnicity, Citizenship, Family: Identity after the Genome Project

Susan Parry's research funded by the University of Minnesota's Consortium on Law and Values in Health, Environment and the Life Sciences

Endnotes
1. See http://www.familysearchDNA.com, accessed 12/19/01.
7. For more information on genetics and scientific background see "Scientific Background" and "Resources" sections of Genetics and Identity Project website.
15. Ibid., 14-15.
16. Ibid., 16.
The Co-Evolution of Bioethics, Computing and Cyberspace: An Archaeological Perspective

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The Office as an Archaeological Dig

Moving offices is an exercise in autobiographical archeology. I have been a bioethicist since before bioethics came to be called "bioethics"—which was well before the advent of the personal computer. So, although it was only a matter of descending three flights of stairs from a Philosophy office occupied for over a quarter of a century to a newly established Bioethics Center, the materials unearthed in the process document the birth of bioethics and its co-evolution with computing. In this essay I use the "data" revealed by my recent move to explore this co-evolution, touching on the impact of computing and cyberspace on bioethics—including such recent innovations as e- or distance learning and consulting—while reflecting on bioethics' initial struggles for realization.

The world divides into pilers and flers. I am a habitual piler. The lower levels of some of my piles were clearly demarcated by artifacts of arcane BCE—before the Computer Era—carbon, dittos, and mimeo, notebooks and note cards. The earliest computer era (CE) artifacts in my office are printout sheets from the 1970s—remnants of the period of central computing, when faculty workstations were scarce and printing (for a campus of 2,000 students and 200 faculty) was concentrated at a single campus location. Twelve-inch Displaywriter disks—remnants of two desk encompassing dedicated word processing machines (IBM Displaywriters) that, together with a single printer, were leased to serve the 40 faculty members resident in the Humanities Center in the late 1970s—are the first indicators of "personal computing." My first personal computer was a 1981 Digital Rainbow that actually fit on and under my desk, in my own office, and used disks that were merely five inches. The Rainbow has since been replaced by a variety of ever-smaller machines, IBM clones, Macintoshes and Palm Pilots. My current computers—a four-pound Titanium G4, and a four-and-one-half-inch four-point-nine-ounce Palm M-500—have shrunk to notebook and notepad size, and yet even the Palm holds more information than the IBM Displaywriter or the Rainbow. The first artifacts of true cyberspace appear in the early 1990s in the form of Telnet printouts of library catalogues and reference materials. As computing evolved into cyberspace, however, indicative artifacts evaporated into information that is itself stored in cyberspace.

Evolving into a Bioethicist

The BCE artifacts relating to early bioethics suggest that recent portrayals of the birth of bioethics fail to capture the initial turmoils of the enterprise. "Bioethics" is now a secure sub-field of philosophy. Philosophers designate themselves as "bioethicists" in much the same way that might call themselves "epistemologists." Yet, until recently, even my journals discarded the term. The earliest run of a journal denoting itself "bioethics" that I own is the eponymous Bioethics—a 1986 British publication. Curious, I decided to see what the new field they were attempting to found, neither a typical philosopher working in the field, nor the books and journals in his library, were initially receptive to the concept of the emergence of "bioethics"—until the 1990s. This exercise in autobiographical archeology raises three questions. Why did philosophers eschew the term bioethics? Until the 1990s? Why does bioethics become the standard designation for the field? And, finally, to touch on a minor methodological point, if the field first came to be called "bioethics" in the 1960s, can computing be said to co-evolve with "bioethics" prior to bioethics' emergence, or vice versa?

My files/piles suggest some answers. One reason why those involved in bioethics from the beginning were reluctant to use the term was that the legitimacy of our teaching and scholarship depend upon peer acceptance. Yet the documents in my office indicate that my peers in philosophy were initially reluctant to recognize any area of "applied ethics" as properly philosophical—including bioethics. To cite one minor example: in 1972 I listed participation on an American Psychiatric Association panel on psychosurgery in my annual report of professional activities. The Chair of the Philosophy Department where I was teaching asked me to "correct" my report by deleting that line. Displaying the innocent, albeit principled obstinacy of a young academic, I refused. The matter went before a dean, who resolved the issue by surveying philosophy chairs. None of the chairs consulted considered my activity philosophical. In the early days of applied ethics, therefore, a praxis concern for professional survival dictated a strong emphasis on the philosophical nature of one's work. Philosophy and Sex, which was published
three years later, contains 'philosophy' in the forefront of its title for precisely this reason.

I had deeper reasons for eschewing the label 'bioethicist.' The 'ist' suffix, with its association with 'logies' and 'ics' imminently a level expertise that made me feel uncomfortable. Archeologists are experts in archeology, biologists in biology, and physicists in physics. Thus to accept the designation 'bioethicist' would seem to imply a claim to expertise in bioethics, comparable to bioethicist's expertise in biology. Such claims afforded my intellectual heritage. Like most analytic philosophers who came to bioethics in the early days, my teachers held that 'ethics' was really metaethics, or, at worst, ethical theory. They disclaimed 'normative ethics,' dismissing it as beyond the bounds of professional philosophy. My ethics teacher, for example, used a very popular ethics textbook that closed with the following thought.

Moral philosophy is a practical science; its aim is to answer questions in the form 'What shall I do?' Yet ... no general answer can be given to this type of question.... [It] is a dangerous task to undertake... [for] the sort of life that will in fact be satisfactory to a man will depend on the sort of man that he is... The questions 'What shall I do?' and 'What moral principles should I adopt?' must be answered by each man for himself; that is, at least, part of the connotation of the word 'moral.'

Bioethics, of course, is precisely the attempt to address the questions "what shall [clinicians/medical researchers] do?" Yet, even as I rejected the notion that it was part of the meaning of 'moral' that each person, clinician or researcher, should decide each question for herself/himself, my teachers' intellectual prejudicesingered. Only in the 1990s—after two decades of work in clinical contexts—did I become comfortable with the 'ist' suffix and its implications of expertise. I found, moreover, that my knowledge of clinical and professional ethics extends well beyond that of a (true I say "mere") metaethicist or an ethical theorist. They are comparatively untutored in the languages of the clinic and the biomedical sciences; the liticacies of professional codes of ethics often elude them, as do the rules and unwritten roles of the clinic and the laboratory. Not surprisingly, therefore, although their presentations on the ethical aspects of biomedicine sometimes display the virtues of talented amateurs, more often than not they seem amateurs. Yet, if I consider them amateurs, I could not object to designations implying my expertise. In the 1990s my reservations about the designation 'bioethicist' vanished.

Other philosophers must have undergone a similar transformation. Until the mid-1980s the term 'bioethics' was notably absent from the names and the publications of the major societies in the field: the American Society of Law, Medicine and Ethics (founded by physicians and lawyers in 1911) and The Society for Health and Human Values (SHHV, founded by physicians and theologians working in medical contexts in 1969). By the 1980s, however, philosophers began to play an active role in professional societies. They played a leading role in founding the Society for Bioethics Consultation (SBC) in 1983, and the American Association of Bioethics (AAB) about a decade later. In 1998, the (approximately) 600-member AAB, and the 150-member SBC, banded together with the 850-member SHHV, to form the 1500-member American Society for Bioethics and Humanities (which now has almost 3,000 members)—making 'bioethics' the official name for the field. Organizations founded by philosophers: thus catalyzes the move to denounce the field 'bioethics.' Perhaps not surprisingly, during this period, philosophically oriented discourse systematically displaced the more theologically oriented 'human values' language of theology and ethics. In the space of a few decades, some philosophers, perhaps philosophical, philosophers became more willing to accept the designation 'bioethicist,' and—to return to autobiographical archology—the books, journals and other artifacts of my office "dig" reflect that transformation.

Now to the methodological issue: if philosophers are newly minted "bioethicists" who did not accept the designation until the 1990s, is reasonable to discuss the co-evolution of computing and bioethics in earlier periods? As happens, the language of evolution is Whiggishly ideological. The evolution of human aspiations, for example, includes our non-human precursors. So, if one takes care to recognize the evolving nature of both computing and philosophers' changing attitudes toward assumptions of expertise, the term 'bioethics' can be applied to earlier proto-bioethic decades.

The Impact of Computers and Cyberspace on Bioethics Publishing and Research

Judging from the evidence offered by the various stratas in my office, computers and cyberspace had the same impact on the field that was to become bioethics as it did on the rest of academia. Lower strata bear witness to the incessant struggle with the fault of the physical page that defined and plagued academic publishing before-era—cutting, pasting, stapling, multiple pre-publication galley and page proofs, prolonged correspondence over edits, and so forth. Word processing liberated writing from the fault of the physical. Cutting and pasting were soon supplanted by metaphysically analogous computer operations, freeing writers from a bondage that had been made invisible by its universality. The page vanished, and we could focus on the text.

Word processing freed some of us from other limitations. Spell check, for example, meant that poor spellers, like me, could now circulate our writings to wide and wide with confidence. From an editor's perspective, however, e-mail—especially the "attach file"—was as important as word processing itself. The physicality of the page and the slowness of the post held editorial processes to a small pace, leaving a lengthy paper trail in its wake. Editorial correspondence and related materials for the first edition of Philosophy and Sex (1975) filled a small filing cabinet. By contrast, materials relating to the latest edition (1998)—a text 2 3/4 in—fills only a few folders, the rest is on my laptop computer's hard drive. The editorial preparation process itself was reduced from three years to a bit over one. This transformation occurred relatively recently. Most of the texts for the four volumes that I edited or co-edited between 1990 and 1995 were transcribed via
intermediate technologies: diskettes mailed through the post supplemented by phone, fax and email. After 1995, however, e-mailed files became the primary means for transmitting manuscripts. Virtually all of the chapters commissioned for The American Medical Ethics Resolution (1999) were sent by e-mail as attached files. The diskette, once the epiphenon of progress, is now so obsolete that many computers no longer have disk drives. The result of this transformation is that complex volumes can now be edited expeditiously and less expensively. Yet, ironically, as the acceleration of the process becomes commonplace it is taken for granted, and what once seemed rapid in editing now feels like a delayed response.

Cyberspace has some real limitations. Although I share editorial comments via cyberspace with my co-editor, A History of Medical Ethics, Lawrence McCullough of the Baylor College of Medicine, we still meet in person on a regular basis and we are in constant phone communication. We also launched the history project and our more recent collaboration, the Cambridge Dictionary of Bioethics, the old-fashioned way—via conferences in Houston and Schenectady at which contributors and editors met face to face, in the flesh, to explore new ideas in non-virtual reality. Nonetheless, meeting fellow scholars in non-virtual reality is time consuming and expensive (the launching conferences would have been impossible without generous funding from such organizations as the Greenwall Foundation and the National Endowment for the Humanities). Whether our need for personal contact is not a psychological limitation of mature scholars—like Larry and me whose expectations and scholarly habits are rooted in the pre-computer past. For the present, however, I cannot envision launching projects at this level of complexity entirely in cyberspace. Person-to-person non-virtual interaction and cross-fertilization seem essential—perhaps even essential.

Larry and I are exploring even newer ways in which bioethicists can collaborate on complex scholarly works via cyberspace. The editorial process for the Cambridge Dictionary of Bioethics is a case in point. The Dictionary will be a 600,000-word, 750-page, global dictionary of bioethics, involving an editorial board of over 50 bioethicists and hundreds of contributors (who will be invited to contribute via e-mail). Our aim is to produce a comprehensive but concise one-volume international dictionary. The project is challenging both because of its international scope and because bioethical language is as rooted in the informal argot, the "shop talk," of the laboratory and the wards, as it is in the formal discourses of medicine, law, theology, and philosophy. Thus, in addition to definitions of the biological medical, legal, theological and philosophical terms used in standard bioethical discourse, the Dictionary will include acronyms and informal usages (who will eventually be invited to contribute via e-mail). Our aim is to produce a comprehensive but concise one-volume international dictionary. The project is challenging both because of its international scope and because bioethical language is as rooted in the informal argot, the "shop talk," of the laboratory and the wards, as it is in the formal discourses of medicine, law, theology, and philosophy. Thus, in addition to definitions of the biological medical, legal, theological and philosophical terms used in standard bioethical discourse, the Dictionary will include acronyms and informal usages (who will eventually be invited to contribute via e-mail).

Meeting the three great challenges of dictionary creation expeditiously would have been impossible outside of cyberspace. Dictionaries require a headword list—and thus a method for determining which terms will be included or excluded from the headword list—a panel of experts to define the headwords, and a vetting process to check the accuracy of the definitions. Since there is no precedent for a comprehensive international dictionary in bioethics, had we pursued this project by traditional means, completion would take at least a decade, probably longer.

Given the pace of bioethical innovation, the volume would be doomed to obsolescence before its publication date. Yet, by scanning through newsletters, journal abstracts and indices we were able to generate a sample of bioethical discourse in under a year; combining this raw data with a new dictionary-editing software that we are developing for our purposes, we should be able to engage hundreds of bioethicists in a collaborative process of selecting, defining and editing the hundreds of entries in the comparatively short period of a few years. By drawing on the collaborative possibilities inherent in cyberspace we will thus be able to publish the Dictionary before it becomes obsolete—presumably a minimal condition for its success. Cyberspace, or, more accurately, a website devoted to the Language of Bioethics, will also enable bioethicists to report new usages to us, allowing us to make updated list of definitions available to the international bioethics community in a timely manner.

Problems in Cyberspace

Having lauded the virtues of computers and cyberspace, I want to underline some problems: the instability of cyberspace and computer media, technological obsolescence, and our collective dependency on government maintained databases. Cyberspace and computer technology are in perpetual revolution and revolutions, by nature, are unstable and destructive. The fluidity of paper and print, resilient though they may be during the process of creation, becomes a singular virtue in matters of preservation. As the piles and files in my office demonstrate, typescripts, printed pages, books, even hand written manuscripts, are inherently stable media whereas, to reiterate, cyberspace is not. Computer problems (often virus induced) plagued both editors and many authors throughout the editing of A History of Medical Ethics. Assuming a modicum of probity in editorial communications, a surprisingly large number of contributors still lose material on their computers or in cyberspace—frequently without the protective redundancy of "back ups." Viruses are also an on-going threat to the Dictionary, and, despite multiple precautions, I have nightmares about a cheaply dormant virus or a worm undoing weeks, perhaps even years of work.
use of cyberspace, like freedom everywhere, requires eternal vigilance in protecting it.

Computer dependency is also problematic because of the rapid obsolescence of computer technologies. A unified intersection of human facility and bureaucratic procedure, for example, led to the destruction of thousands of tons of notes on ICU decision-making that Had collected during the 1980s. They had been stored on mainframe computer tapes, and destroyed during the College's conversion from a Hewlett Packard to a Digital VAX cluster. (It happened when I was away on sabatical and so never filled out the requisite form.) Computer technology is constantly being upgraded, and data and texts not transferred from older media to new media quickly become inaccessible. When the last diskette drive becomes a museum piece, whatever has not been transferred to its storage medium of the moment will become inaccessible and will degrade from information to artifact. On a somewhat deeper layer, in the late 1970s, André Heffner, the inspirational force behind the Kennedy Institute of Ethics, urged Jeffrey Wheelers and others at the Institute to work with the National Library of Medicine to create a research tool for the nascent field that they envisioned. The result was Bioethicsline, a site of the art research tool, linked with Medline and designed to facilitate the needs of bioethicists. Like physicians, therefore, bioethicists enjoy one of the earliest and best computer-based bibliographical resources in academe. What government gives, it can retract. Sadly, in the name of economizing, Bioethicsline has now been integrated into the National Library of Medicine's PubMed and Lycosregal search engines (see http://www.georgetown.edu/research/verch). The integration has not only slowed the rate at which material is entered into the system, it removes journals from full-text, and it strips out the MESH headings that made Bioethicsline a self and supple tool for sorting through the literature. Where bioethics once enjoyed one of the best and most advanced computer search systems in academe, it must now be content with mediocrity. The sensitivity of our on-line search instrument has been degraded, and while it remains to be seen whether this will affect the quality of bioethics research, it has radically decreased the availability of up to the minute information needed for expedient clinical decisions. Dissatisfyingly, the downsizing of a government program has provoeced no discomfit public outcry from the ASIB or any other bioethics society.12

Distance Education and Cyber Consulting in Bioethics

Among the verdicts littering my office was a set of Digital Authoring System manuals. For five years (1980-1985) it was my misfortune to be a computer education pioneer. I directed CUC (Computer Humanities Undergraduate Classroom) one of the earliest efforts to bring Computer Assisted Instruction (CAI) into the humanities. The $1.4 million dollar DEC-Mellan project brought a new Digital VAX cluster and, perhaps more important still, 12 faculty computers and a Computer Classroom to the humanities departments at Union. Sadly, this faculty effort needed to create a single CAI lesson exceeded that required to teach an ordinary (40 hour) course, and, although we did some of the research that established the virtues of work processing in higher education, we also demonstrated that CAI was unworkable; at least as it existed in those early days.

Computing has changed since those days and, as faithful readers of these pages know, computer assisted instruction in bioethics is flourishing at the Medical College of Wisconsin, Milwaukee. In his thoughtful APA Newsletter article Mark Kuczewski13 discussed at length the virtues and problems of bioethics distance teaching and learning. My own experience with the time-consuming but delightfully student-centered medium of education is essentially similar. The Albany Medical College-Union College Distance Learning Masters in Bioethics Program that I co-direct with Wayne Seligman (http://www.bioethicsunion.edu), however, differs from MCCV's program in origins and emphasis. We formed a distance education consortium at the behest of members of hospital ethics committee members would preclude their participation. Cyberspace is perhaps the only place that could accommodate their needs.

Like the masters program itself, our curriculum responds to the perceived needs of health care administrators and clinicians in the tri-state area. We designed a three-year program that could be taken, one course at a time, by working professionals that also considers the standards set forth in the 1998 ASIB Core Competencies for Health Care Ethics Consultation report.13 Three founts of our courses are e-courses: a mix of core courses (Bioethics, Clinical Ethics, Health Law and Health Policy), electives (Ethics and Reproduction, being taught by Bonnie Steinbock this semester), thesis supervision, and on-line practica. Yes, for three summer months, our students are required to participate in on-site seminars and practices (either at Albany Medical College/University College, or the Mount Sinai or U of Rochester Program that I co-direct with Wayne Seligman is an 80-hour intensive introductory on-site seminar taught by Jane Greenlaw, Susan Leiderer, Lawrence McCulloch, Wayne Sherrill, Robert Veach and I) designed to familiarize administrators and policy makers with clinical contexts, and to provide overviews of the field of bioethics. We also use the initial fortnight to teach our students to navigate our on-line instructional system, Blackboard (www.blackboard.com).

The advantages of e-instruction for this program are obvious. Cyberspace can unite those divided by physical space and/ or temporal distance. Anytime/anywhere electronic instruction facilitates the formation of a real community of e-learners who bond and collaborate by means of the Web. Cyberspace also offers special advantages. Consider clinical consultations. Like clinical encounters, they need to be insulated from external scrutiny. On-line practice and e-consultation, however, open ethics consultants to semi-public but still confidential peer and professional scrutiny.

As the example of online consulting suggests, e-instruction is not a second-rate imitation of the on-site original.
It is different in kind of instruction, suffering some drawbacks, but still offering significant advantages, especially for applied and bioethics. In addition to the virtues of asynchronicity, distance bridging and the creation of an on-line community of otherwise isolated individuals, e-instruction offers instantaneous grading and direct feedback on examinations, on-line grade books that permit every student to see their grades instantly and in confidence, well-attended virtual office hours (via an instant messaging chat room) that permit multiple students access to an asynchronously typed, and a discussion board format in which no student can excite him from participating.

The resources available via the Web are also extraordinary. For example, in the pages discussing the birth of research ethics I provide links to the complete Nuremberg trial transcripts http://www.yale.edu/lawweb/avalon/int/ b19.htm and additional information about Nazi psychology http://members.aol.com/polotboyd29/naril1.htm http://remember.org/edurate/medexp.html http://www.aangshutz.dk/doctors.htm http://www.aangshutz.dk/Bullenhuser.htm http://auschwitz.dk/Mengelevid17.htm Student evaluations to date have literally been rave reviews about on-line instruction — although, it is important to emphasize, we restrict all courses so 15 or fewer students; above that number, the extent and quality of participation degrades precipitously.

Yet, although e-instruction is ideally suited to the tri-state area and to other regions where practitioners find masters programs inaccessible (our next class will include students from Florida and Michigan), there are significant costs that should give anyone pause. Perhaps the most daunting is the enormous capital investment in computer equipment (we maintain our own server) and support personnel. Our startup cost was over a quarter of a million dollars, which is down significantly from the 1.4 million dollar CHIC experiment, but still a substantial investment. Moreover, the personal investment required to produce a single week of e-learning remains outrageously high. So one should enter the world of e-education who is not prepared to devote enormous amounts of time and energy to the project (reread Kurekewich from this thread). Since I am operating as a consortium, however, we hope to share our costs and burdens by inviting other Northeastern institutions to join our consortium and to explore the opportunities that cyber-space offers for bioethics education and research. Two other New York bioethics centers (at Mount Sinai School of Medicine and the University of Rochester) have already joined, and we shall soon seek other partners.

There are substantive drawbacks to distance learning. As with all e-media, students feel an insistent need for face-to-face contact in non-virtual reality. Students (a physician from Rockaway, New York, in fact) have driven over four hours to share an end-of-term drink with classmates and instructors. A somewhat deeper problem arises in clinical ethics instruction. As David Rothman emphasizes in his aptly entitled, Strangers at the Bedside (1993), bioethics are, in part, because as physicians became estranged from their patients. Philosophers, formerly strangers, arrived at the bedside to fill the communication gap between clinicians and patients. One primary function of clinical ethics has been to legitimate the patient's role in medical decision-making. For decades, long before narrative ethics became vogue, clinical ethicists understood the significance of patients' narratives. To underscore this point I have my students analyze one of my favorite cases (a bioethics case with a happy ending): the case of "the woman who would rather die.") One of the lessons that I draw from the case is that the staff narrative is just one amongst many: problems identified by the staff may not coincide with those actually felt by patients...therefore ethicists should try to view the problem from the public's perspective as well as the staff's." Yet when we engage in e-consults the only narrative that we have access to is that of the clinician-student-narrator. E-consultation thus tends to undermine one of the major functions of clinical ethics. For the moment, I have not worked out a strategy for overcoming this problem—except to require our students to participate in supervised e-ethics that focus on the importance of the patient's narrative and perspective.

Bioethics and Cyberspace
One of the artifacts of the BSE era that I unearthed in my office was a typescript, composed on an electric typewriter—a once advanced but now arcane technology—defending the idea applied ethics. Western philosophy was instead a footnote to the remarkable teacher-student trio of Socrates, Plato, and Aristotle (who was, of course, tutor to the house of Philip and Alexander of Macedon—then rulers of the Western world). Socrates engaged ordinary people in the market place, Plato critiqued the status quo and drafted utopian blueprints, while Aristotle presented practical guides for moral education and governance. Applied ethics, I argued, follows this precedent, reawakening moral philosophy to its traditional goal of challenging, criticizing, and mentoring the society in which it functions. The rest of the manuscript is an overly detailed diatribe against the metalethical preoccupations of the day. Thankfully, I never submitted the piece for publication. The underlying idea, however, was that because applied ethics deals with real problems, it prevents the extermination of substantive ethics through a preoccupation with technique. In the same thread. This observation has been validated by the history of bioethics over the last three decades. When Arthur Caplan writes newspaper columns querying whether a rich man should be allowed to buy a pancreas, he is engaging ordinary people in moral debate in the Socratic tradition. So too is Peter Singer, when he forces our students to consider the morality of munching hamburgers. As cyberspace becomes a dominant medium of communication for the twenty first century, if we, as bioethicists, are to continue to engage that world, we must follow it into cyberspace, ignore cyberspace threatens disengagement and even retreat back to the all too academic, intellectually arid, substantively desiccated form of moral philosophy that I rebelled against as a young philosopher.
Prenatal Testing and Disability Rights, edited by Erik Parens and Adrienne Asch (Georgetown University Press, 2000), xvi + 372 pages

Reviewed by Leonard M. Fleck, Ph.D.
Michigan State University

There can be no doubt that we will increasingly have the ability to control the genetic endowment of future generations of human beings. As I write this review the Washington Post (Feb. 27, 2002, at A1) reports the story of a thirty-year-old woman who recently gave birth to a baby whom they know is free of a familial Alzheimer’s gene. That gene is associated with the onset of dementia in the fourth decade of life, a very rare form of the disease. These had a 50% chance that any child carried by this woman would be born with this gene. But because she used IVF and preimplantation genetic diagnosis (PGD), which involved genetic analysis of a number of eight-cell embryos she had produced, she was able to avoid the risk and the burden of this disorder. Prima facie, this appears to be a very highly effective use of preventive medicine. Still, there has been significant criticism of this effort. Several of these eight-cell embryos were discarded. This would be cause for much outrage by advocates for a Sanctity of Life ethic. Why were they discarded? Advocates for the rights of persons with disabilities would say they were discarded because they were flawed and imperfect embryos. They see this as a form of invidious discrimination, not just directed at embryos with genetic mutations likely to very adversely affect the lives of future possible persons, but directed at all persons who currently live in our society with disabilities. They see such actions as expressing the message, “We do not want people like you living in our society.”

Let me confess the reader, allow me to mention haste that this book is not about PGD. It is about prenatal genetic testing and the choice to abort fetuses that are found to be “defective” from the perspective of potential parents. I mention the example of PGD because some might be tempted to think that what was most morally troubling and socially objectionable about prenatal testing is that it sets up the need to make a decision for abortion relatively late in pregnancy. The virtue of PGD is that the decision of embryos occurs so shortly after conception that few reasonable people would be deeply troubled by this option, especially in relation to the alternatives. However, this is not a conclusion that would be embraced by most of the contributors to this volume. On the contrary, Adrienne Asch, who is blind, identifies herself as pro-choice. But she would object as vigorously to the prophylactic use of PGD as she would to the use of prenatal genetic testing. In both cases her primary concern is that the decision to embrace these interventions, either by society at large or individual parents, is rooted in a morally objectionable and (she would add) empirically flawed belief about the worth and quality of life of individuals with a range of disabilities.

This volume grew out of a two-year conversation sponsored by The Hastings Center among a number of philosphers, bioethicists, attorneys, law professors, and health professionals around the moral and policy issues raised by prenatal testing in a world awash with stereotypes and misperceptions about being with disabilities. This is a remarkable volume, and, having read the essays, I regret not having been part of the conversation that generated them. But my impression is that the spirit of those conversations is captured in the range of the essays.

Three large questions served as a focal point for these discussions. First, is there something strongly morally objectionable about selective abortion of fetuses diagnosed with some range of disabling conditions? That is, does such a practice represent a form of discriminatory behavior analogous to racism or sexism? Second, how ought health professionals and policymakers respond to this practice? If we were talking about the practice of "redlining" neighborhoods or denying jobs to individuals on the basis of race or gender, the answer to this second question would be obvious. That is, we would quickly put in place laws and professional norms aimed at ending such behavior. But in the context of reproductive decisionmaking we are treading in the territory of permissive liberty. Our political traditions and professional norms would both speak against intrusion into an arena of intimacy. To be sure, we do "invade" family life when children are abused. But the moral status of the fetus is a matter of intense moral and societal controversy. Further, parents in such circumstances may have a variety of reasons for seeking against certain embryos. Some parents may have legitimate self-regarding reasons and others will have reason rooted in what they judge to be best for their future possible child. That brings us to the third critical issue. Is there a way of distinguishing morally and politically tolerable uses of prenatal testing from morally and politically intolerable uses of such testing? Would an effort to answer that question in a road well-trodden yield a social compromise that all could live with, even if they felt there was something not quite right about the compromise?

Parens and Asch report that consensus was not achieved on any of these questions. As nearly as I can judge, they do not report this with a sense of regret. To my mind there is little value in papering over deep value disagreements with consensus conclusions on some seductively ambiguous and abstract concept. On the contrary, the value of this volume in a health care ethics course is that the debates that inflame it are very much alive. At one time the debates around cases such as Quintanilla or Cruzan were intense and real. But a kind of "reflected wisdom" has emerged with regard to these cases that makes ongoing debate seem forced and rhetorical. There is nothing forced or theoretical about the disability critique at the heart of this volume. These are the kinds of issues that need to be the focus of respectful social dialogue in our society. Our students need to see that such dialogue is
possible, that we do not have to reduce ourselves to shouting and ideological shouting, as we often find in the abortion debate. Providing students with the resources they need to appreciate this social insight is a clear strength of this volume. In the remainder of this review, let me walk the reader through some of the essays so that you can better appreciate the rich diversity offered here.

Parens and Asch provide a long and excellent introductory essay. The price of the book is worth it for that alone. They yield that the three major ones I mentioned above. For example, reasonable people might be tempted to say that they can readily appreciate the concerns of disability rights advocates about societal expectations for "perfect children." But surely, they continue, parents who are concerned about "serious" disabilities in a fetus should 'without doubt' have the unimpeded right to choose abortion if the fetus is judged positive for such a disability. However, Parens and Asch point out (citing the work of Dorothy Wertz, another contributor) that there is considerable societal and professional disagreement about what should count as a "serious" disability. Down's Syndrome would be an excellent example of that problem.

More generally, one of the points emphasized in the Parens/Asch introductory essay is the threat of numerous kinds of social science research for purposes of informing these debates. That is, there is no neat or clever moral or philosophic arguments, or careful conceptual analysis, that can somehow resolve the moral and policy issues around prenatal testing. All manner of stereotypes and misconceptions about various disabilities circulate in our society, and sometimes shape the way In which information is presented by health professionals to potential parents who are concerned about having a child with some disabling condition. Among other things, this includes the potential for disruption of family life. What kind of moral judgments and policy judgments are most appropriate in a world like that? The essay by Ferguson, Gartner, and Lipsky attempts to address these issues. Their general conclusion is that many families are amazingly adaptive and resilient in caring for children with disabilities. This is clearly something that needs to be better known. But that leaves open the question of what a society ought to allow in the way of parental choice when a couple knows pretty well that they are unlikely to be among the adaptive and resilient couples of the world.

There is the familiar point made by disability rights advocates that disability is socially constructed, that the way we organize social life in specific respects results in individuals being disabled with respect to certain life projects. This is an obvious truism when we consider the worlds that have become accessible as a result of social commitment to redesigning buildings. But Bonnie Steinbock in her essay notes that this is far from being the whole story. If it were the whole story, then we would not work as hard as we do to use the resources of medicine to cure or ameliorate or provide functional equivalents for various disabilities with which individuals are afflicted.

There are two wonderful personal essays in this volume, one Mary Ann Baily under the title "Why I Had Amniocentesis" and the other by Eva Kittay. Eva has owned for a very seriously disabled child for more than twenty-five years, her daughter Sabra. She does not regret taking the risks she has made, but she neither does she deny others the right to make very different choices, even if they are in a situation very similar to her own. These personal narratives add a very important dimension to the data science and moral analysis that are otherwise the core of this discussion. Students need to appreciate this as well in thinking more carefully about these issues.

The core argument of the disability critique is what is labeled as the "expansionist objection." The main point is that individuals who choose to abort fetuses on the basis of what they learn from prenatal testing are really sending a message to society at large, and to persons with disabilities in particular, that they are not wanted or valued in this society. They may see themselves as simply making an agonizing personal private decision, but the expressive argument is that this decision, to some extent at least, sends this message and provides strong moral grounds for social policies and practices that would severely limit or prohibit abortion in these circumstances. Mark Feldman is a powerful spokeswoman for this argument in her essay while Jim Nelson critically assesses this argument in his nicely crafted essay. Finally, Both the attempts to do the sort of line-treading we alluded to earlier, in effect saying there ought to be some range of circumstances in which it would be morally and politically unacceptable to perform prenatal testing and abortion, and others where we could put in place legal and professional restrictions. He offers a set of four criteria for accomplishing this task. But his critics vigorously object because they see this as transforming what could be construed as a purely personal decision into a decision that has been socially legitimized, and therefore, legitimates the devaluing of the lives of individuals with some range of disabilities.

In conclusion I reiterate the point made earlier. Students need to be exposed to these sorts of ongoing social debates. Students need to see that civil discourse about such controversial issues is both possible and necessary. This volume provides an excellent model of how such discourse ought to occur.

Reviewed by Matthew Rottnek
Mount Sinai School of Medicine

Ms. G., a 56 year old woman with diabetes and subsequent kidney failure, has just undergone her second above-knee amputation and is now receiving dialysis — even though she has grown accustomed to dialysis three times per week and knows that with it she will die in a matter of days; even though she'd come to the hospital voluntarily for surgery; even though she had recovered from her first amputation quite well, although, initially depressed, bad, with psychiatric treatment, regained her optimism and energy, continued her work as an artist and returned to an active social life; even though her post-surgical prognosis is promising. What's different this is: her husband has just announced that he could never be attracted to her with her amputations and other medical problems; he is in love with another woman and has moved in with her during Ms. G.'s hospital stay. When no safe amount of morphine seems to relieve her suffering, the treatment team calls for a psychiatric consultation (Halpern), but Ms. G. refuses to speak to her. The surgeon, the internist, the supervising psychiatrist, and the ethicist concur that because Ms. G. is not cognitively impaired, because she's been made aware of the consequences of her decision, because she has the legal right to refuse treatment, and because attempts have been made to establish a therapeutic alliance, she's making an informed decision and her right to refuse treatment ought to be respected. A decision is made to keep her as comfortable as possible and to honor her choice to die, which she does soon after.

If we accept the current norm of "detached concern" in medical practice, Ms. G.'s case, "although tragic," was handled correctly. Her decision was not irrational because she was aware of all the logical dilemmas involved in her options; each of her beliefs about the present and the future was justified based on the facts at hand. Given her self-awareness and her cognitive capacity, the treatment team was respecting her autonomy in honoring her decision to refuse treatment. But for Halpern, this case, which serves to frame her inquiry into the role of emotion in the options-physician relationship, highlights the impoverishment of "autonomy" as it is currently construed in medicine and the inadequacy of the norm of detachment in caring for patients.

Traditionally, Halpern reminds us, "autonomy" refers both to an ethical ideal of individual self-determination and to a psychological capacity to make decisions that reflect one's own goals. But the term has evolved within medicine to describe a set of patient's rights — to determine what happens to one's body, to give informed consent, to refuse treatment, to participate in medical decision-making — which, for the most part, have emerged in response to a long tradition of physician paternalism and, unfortunately perhaps, through lawsuits. We are left with a norm of negative autonomy — autonomy as freedom from interference — grounded in a legalistic conception of persons as an independent agent who should not have treatment imposed by others. And under the current bureaucratic, marketplace, and legal influences in medicine, physicians are faced with a legal obligation to respect such autonomy.

While autonomy-as-resistance has certain social and political advantages and (therefore ought to be institutionalized as a legal point), it neglects the emotional distress, compromised sense of self, and loss of perspective that often accompany serious illness. Indeed, it fails to recognize the distinct experience of suffering and acute grief and is therefore inadequate in the context of serious illness.

In cases such as that of Ms. G., Halpern asserts, the norm of suffering is not so much the body as a biological entity as the person as an existential being facing a loss of agency and purpose. One's sense of value and agency is undermined. Life-goals are fractured, and the ability to form new ones feels drastically compromised. Mental freedom is impaired because the very foundations of practical reasoning — options, priorities, agency — have become meaningless. For Halpern, these disruptions to the self constitute a loss of psychological autonomy and signal the need for a reconceptualization of autonomy as it is used in medicine.

To this end, Halpern suggests a return to the Kantian notion of deliberative freedom — revised to include emotional and interpersonal elements. In Halpern's view, the core of autonomy is the liberty to generate ends and goals as the result of practical and emotional reasoning. And in order to do this, one must be able to assume that one's future is not wholly determined, that one's deliberation matters, that the world is sufficiently responsive to one's own agency, and that few can enlist the participation of others in achieving one's own ends.

For Halpern, whose thinking is shaped by her training in psychiatry as well as in philosophy, reconfiguring a sense of psychological autonomy can be achieved only through an intense and sustained interpersonal process, one that restructures the developmental attainment of self-efficacy. And like a child's need for emotional integration and recognition, recovering psychological autonomy relies on a socially and emotionally-situated reasoning with others. In order to imagine a future that has been altered by illness, patients need to feel that their future is not bound by the experience of illness, that they can imagine new goals which have meaningful influence in their medical decisions, and that they can be effective in ensuring the participation of physicians and others in making their decisions. It is here that the practice of empathy enters into patient care.

Drawing on the writings of Edmund Husserl, Martin Heidegger, Theodore Lips and others, Halpern presents empathy as a form of emotional reasoning which makes use of one's own associations, resonances, and moods to provide a context in which to imagine the experience of the other, as a form of knowledge in its situatedness. Guided by an engaged curiosity about the human predicament.
the other faces and aware of common human possibilities not necessarily actualized in similar experiential histories or present emotional states, the empathizer allows his/herself to be affected by the experience, so that the empathizer's own emotions organize his/her understanding and direct his/her participation in the interaction. In this way, empathy provides a first person, internal point of view—a kind of experiential or subjective knowledge—which can give insight to what it is like to be in the other's situation.

Applied to medical practice, empathy can help discern the behavior meaningful to a symptom or disease has for a patient, elicit greater disclosure, produce fuller histories, bridge differences that might otherwise serve as impediments to care, and, most fundamentally, help patients who are suffering overcome states of emotional irrationality and regain a sense of psychological autonomy.

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Before beginning her residency in psychiatry, Halpern completed a Ph.D. in psychology in which she focused on the following question: What precisely is involved when one person attempts to grasp another's subjective experience, and does this require some form of emotional engagement? Convinced that subjective or experiential knowledge plays an important role in understanding other people, Halpern returned to medicine and served as a psychiatric consultant for patients who refused treatment or who were otherwise at odds with the medical team. In repeated consultations like the one with Ms. G., Halpern found that physicians often lacked insight into the emotional dynamics of their relationships with patients: physicians who extended the detachment needed to perform emergency procedures to their general interactions with patients risked missing important cues about what patients were thinking and feeling, and physicians' own unacknowledged emotional reactions to patients often contributed to clinical difficulties by introducing cognitive distortions or incorrect assumptions about patients. This led to miscommunication, inefficiency, and ultimately interfered with patient care—in the form of misdiagnoses, patient noncompliance, and incomplete or inaccurate understanding of patients' values. But Halpern also found that, when invited to reflect on the emotional complexities of their relationships with patients, not only were physicians able to do so but also this brief exercise often resolved the clinical problem. This persuaded Halpern that it was practical for physicians to learn more about emotional communication and to use this knowledge to empathize more effectively with patients.

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In their effort to avoid judging Ms. G.'s situation in an emotional manner, the treatment team, Halpern suggests, actually participated in Ms. G.'s "emotional irrationality," i.e., her unexamined, intractable, and inescapable conviction that her future was hopeless. Unaware of her own emotional reactions, they responded with various states of sympathy ("Wouldn't you want to die if you were in her situation?") or detachment ("You can't take her home with you, so leave her alive."). They unknowingly allowed the outward resonance of Ms. G.'s tortured inner state to influence them more than the three (facial) positive prognostic indicators: her previous recovery, her underlying vitality, her supportive network of friends. Both Ms. G. and her physicians accepted her hopelessness as a fact rather than as a potentially alterable state of mind.

For Halpern, Ms. G.'s apparently logical justification was actually a defensive strategy to shield her from alternative considerations that she could not entertain for emotional reasons: she was unable to reason about her emotional responses to her husband's incoherence, unable to consider that she might feel differently with time, and unable to imagine a future living without him. Her decision to die was the rationalization of a strong, unprocessed emotional state. Patients in the throes of catastrophic emotion—strong states of hopelessness, fear or anger—are often unaware of their own irrational inner states, and the only way they reveal them is through the impact they have on others, a phenomenon psychoanalysts call "projective identification." In such instances, Halpern explains, the physician's own emotional reactions to the patient can serve as clues to the patient's otherwise unresolved emotion. And because in unconscious emotional communications patients are "treat open to their physicians' influence, these instances are opportunities for therapeutic intervention—that is, the projected emotion is empathetically received. If a patient is able to see the impact of his/her unacknowledged, projected emotional state reflected in another, then there is an opportunity not only to recognize the emotional state in him/herself but also to see that it is merely a state, i.e., one that he/she is experiencing from a particular emotional perspective, and that alternative perspectives exist.

Had Ms. G.'s physicians recognized that she was in an irrational state of fear and anger and that her projected emotions may have been a kind of primitive effort to communicate, they may have been able to empathize with her. In turn, she may have been able to recognize her projected emotional state and thereby realize that her thinking was colored by a very powerful point of view. Rather than allowing her catastrophic emotions to become a concrete concern about her future, she may have been helped to process her grief and to consider alternative perspectives on the future, perspectives informed by the facts at hand—her previous recovery, her good post-surgical prognosis, her supportive friends, and her underlying vitality.

Patients also often need to know that their physicians are both sufficiently affected by their experiences and still reliable. They may, for example, need to provoke their physicians in order to Initiate their physicians' inaccessibility. When a suffering person feels that his/her physician is affected by his/her grief, fear, anguish, etc., and yet can see that the physician is not overwhelmed and remains involved, then the patient may gradually become able to face the loss and regain a sense of security. If Ms. G. had been able to express her anger about her husband's abandonment while finding that she was not abandoned by her physicians, she may have come to view her own emotions as less-threatening and the
may have regained the capacity to consider a future without her husband.

"Medical practice," Halpern writes, "involves more than merely physical bodies: It involves healing emotional states, but the challenge to discern where emotional healing is needed is a formidable one, even in ordinary medical encounters. Emotional receptivity is needed if physicians are to acknowledge the pain and suffering that patients do not, and sometimes cannot, put into words. This is because suffering is, by definition, difficult to bear, and thus is denied, hidden, or otherwise kept out of awareness."

Despite the recent emphasis on the emotional aspects of the patient-physician relationship, despite research demonstrating the role of emotion in healing, and despite the fact that primary care physicians are now encouraged to provide holistic care, the norm of detachment has a strong historical precedent — grounded in reaction to the ancient tradition of sympathy.

A rather long tradition from Hippocrates through Thomas Percival to Worthington Hooker emphasized a central role for sympathy and compassion in medical practice. Rather than taking emotional detachment as a requirement for unclouded judgment, the Hippocratic writers prescribed a balance between compassion and clinical accuracy. And according to Hooker, physicians' effectiveness and reliability depended upon their emotional understanding of human nature and their emotional interactions with patients. He therefore advised fostering a certain skepticism about emotional reactions to patients — in order to avoid being overly idealistic or judgmental. In this tradition, the emotional component of the patient-physician relationship and physicians' awareness of their own emotional reactions functioned to help underwrite patient morale, in effect allowing physicians to stay motivated to care for patients without resentment or despair, and to promote healing.

When early 20th century progress in physiology, microbiology, and chemistry heralded the possibility of medical diagnoses based on an objective understanding of the physical body, medicine as a profession was seen to emerge from a long history of superstition and subjectivity. Modern medicine was to be guided by a standard of objectivity derived from the physical sciences, and this standard was to extend to all aspects of patient care. Accordingly, and in line with an entrenched, rationalist philosophical tradition that defines reason and emotion in opposition to one another, emotions were seen as unscientific — not only unreliable but also disruptive to thinking and threatening to the modern ideal of "objectivity."

Led by Sir William Osler, the "father" of American medical practice and a pioneer of bedside patient rounds at Johns Hopkins Hospital, physicians came to wear white coats and to engage in detective-like diagnoses of illness. In pursuit of "objective" medicine, physicians were taught that they could avoid the conflict that arises from "over-involvement" with patients, circumvent emotionally-driven errors, preserve an objective understanding of patients' emotional states, exercise greater therapeutic influence, and care for patients in an equal, impartial way, if they cultivated an attitude of "detached concern," that is, a kind of professional, humane approach to patients devoid of their own emotional responses. The same detachment needed to dissect a cadaver without fear or disgust was apparently necessary to care for patients.

But, Halpern points out, this extension of "objectivity" into all aspects of doctor-patient interactions makes two fundamental assumptions — that a physician can be free from bias and that a patient's emotions are best observed from a "neutral" perspective, i.e., that a physician can see most clearly when he/she is not moved or affected.

The first assumption is unfounded, Halpern argues, because emotions are attitudes that influence people even when not erupting into consciousness. They can create bias or prejudice, lead to errors of judgment, and influence actions and decisions. The best one can do is make an informed effort to be aware of one's emotional reactions and their influence on interpersonal dynamics.

Halpern's response to the second assumption runs parallel to a well-established defense of the subjectivity of conscious states: observing that a patient is in a certain emotional state — even if all the factual information about a hitherto private has been collected — leaves something out. (Recall Searle's Chinese box.) Hypothesizing and data-gathering do not yield an understanding of the particular term of an individual's state of mind because they limited by an external, third-person perspective. Furthermore, a more scientific description of a patient's emotional state denies the emotional communication already occurring in the dynamic. The model of unilateral emotional influence underlying the norm of detachment denies the ongoing emotional interaction between patients and physicians. Physicians are biased in choosing the aspects of a patient's problems for attention, in weighing the risks and benefits of treatments, in adopting views of the patient's future. These biases, if left unacknowledged and uncorrected, have direct impact on the dynamic with patients. "Detachment does not make medicine more rational," Halpern writes, "rather, it forces irrationality underground."

The norm of detachment, in striving for "objectivity" in interpersonal dynamics, is rooted in the rationalist tradition in philosophy. Cartesianism defines emotions as mere subjective reflexes that have no cognitive value and cannot be influenced by reason. And according to Kant, feeling states, in contrast to sense perceptions, cannot be reliably-tracking points of view — cannot, that is, contribute to knowledge of objects. As merely subjective impressions, in line with the Cartesian view, emotions have no cognitive value. But that an emotional point of view is not immediately or ineffectively responsive to theoretical reason does not preclude a person from having the capacity to assess his/her own or another's state for its rationality or realism.

Psychological, sociological, and anthropological studies, Halpern points out, have shown that even the most biologically-determined emotional reflexes are subject to
interpretive consets and cognitive restructuring. Emotions are shaped by individual psychic dispositions and histories, but they become enriched and individualized in an associative context. It is because emotions arise spontaneously that they resonate with others (e.g., the ways in which joy or fear are contagious), that we, as humans, can assume ourselves to one another emotionally. We come to know ourselves, as we come to know others, by living in a social world and sharing our reactions to it.

In practice, if we recognize the characteristic ways that emotions connect ideas, if we appreciate their limitations, and, most fundamentally, if we are aware of their influence on our own perspectives and judgements, then the very properties of emotions that create risk of frailty can create opportunities for knowledge. By means of accurate emotional reasoning, physicians can learn to make increasingly realistic assessments of emotion, and by engaging emotionally they can become attuned to patients' subjective accounts of their illness, which is essential for empathy.

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Despite the prevailing norms of detachment, Halpern tells us physicians do, at times, empathize with patients, but often empathy is confused with sympathy, over-identification, and detachment—this because, to date, there has been no in-depth inquiry into what, exactly, clinical empathy involves. And in the context of managed care the urge to standardize empathy in an effort to make patient-physician communication more efficient has resulted in detachment with a veneer of generic tenderness. Such a neutral, standardizable, approach to patients' needs is experienced as insincere; it also denies patient individuality, as some patients need reassurance, some acknowledgment, some a more confident and authoritative style.

In contrast to the model of detachment, which emphasizes the physician's knowledge of typical emotions, the development of empathy is grounded in the cultivation of curiosity, that is, an ongoing awareness and attentiveness to what patients communicate both verbally and through body language, gestures, vocal tones. This kind of curiosity requires withholding judgment and tolerating uncertainty as one listens. To this end, Halpern promotes reform in medical education in order to provide a context for students to develop and maintain their curiosity (and uncertainty) about patients' distinct experiences—including patients with whom students might not readily identify or even like, due to differences in social status, race, culture, gender, sexuality, cognitive or physical abilities. In order to encourage empathic engagement, Halpern suggests various pedagogical exercises such as writing narratives of illness from the patients' perspectives, having physicians write narratives of their most troubling encounters with patients, recording histories using the patient's own words, and putting patients' nonverbal messages into words. Most fundamentally, accurate empathizing—avoiding the risks of emotional irrationality and errors such as projecting their own unacknowledged emotions onto patients—requires physicians to be self-aware. And because empathy is influenced by differences in language, style, and value, medical students and practicing physicians also need to be aware of their own prejudices as well as the social and cultural influences that inform medical practice.

From Detached Concern to Empathy is a sophisticated, perspicuous, and extremely well argued defense of emotional realism in the patient-physician relationship. Bringing philosophy (both the analytic and continental traditions), then, a psychoanalytic theory, and cultural analysis to the subject of emotion, Halpern's analysis is both encompassing and exact. Her demarcation of the impact of social forces, historical precedent, and economic factors on interpersonal dynamics within the structure of medicine, combined with an exploration of the underlying ideology recalls the richness and value of critical social theory. But more than a critical philosopher, Halpern makes a positive and practical development of empathic engagement with patients as a means to maintain humanity in medicine under the challenging organizational, political, and economic conditions physicians currently face.

As the physician-philosopher, with experiential knowledge of the issues debated in medical ethics, Halpern is the ideal medical ethicist. Her philosophizing is succinct and has direct application to practice. And as the philosophically sophisticated psychiatrist, she is particularly well-suited to tease-out the subtle ways in which intra- and inter-psychic phenomena influence patient care. Given the very high Halpern maintains throughout the book and the thoroughness and overall success of her argumentation, what is perhaps most impressive is Halpern's sensitivity to the vicissitudes of human nature—the kind of sensitivity, insight, and emotional attainment one would typically expect only from a psychoanalyst or an aged psychiatrist. A clinical anecdote from the preface: when a patient is scheduled to be discharged the following morning dies suddenly during the night. Halpern's hospital stay is shorter than that of a typical physician as she becomes the patient's physician. She tells him to inform the patient's wife that she is scheduled to be discharged the following morning and to speak to her as he would to any other patient. He leaves the patient's wife, stone-faced, receiving the news. Halpern recalls feeling grief and guilt for having spoken to her in such a matter-of-fact manner. She says she needed the burden of alleviating her concerns. This time, this awareness, this degree of attunement is sustained throughout the book—she is attuned to personal reflection to empirical observation to theoretical discussion.

It's often said that what made Chekhov both a great writer and a great physician was that he was without ideology, that he was, where he looked around the world he saw only human beings. There's a truth here that expands beyond Chekhov—about the opportunity of physician-writers to both attend to and capture the human in whom human care resides. William Carlos Williams, Richard Reynolds, Eliza Carin, Abraham Verghese, and others extend this tradition. Such people who are able to navigate both the human and the scientific realms, see the poetics of intersection, and communicate some universal truth are quite rare. Not only does Halpern show
herself to be one of these new individuals, but as a philosopher, in line with the work of Baudrillard, Derrida, and Marcia Cavell, and in the spirit of Richard Rorty's Contingency, Irony, and Solidarity (Cambridge University Press, 1989), she demonstrates that intention to the realm of emotion and the treatment of physical illness is inherently linked in the practice of medicine.

This is a formidable undertaking, given the hold that the traditional view of detachment has in medicine and the underlying belief that a physician, in fact, able to be neutral, given physicians' socialization into an atmosphere of autonomy-as-nonviolence, and given widespread conventional resistance to accepting the therapeutic efficacy of emotion. As recently as 1964, in a new preface to Becoming a Doctor (Viking Penguin, Inc., 1987), Melvin Konner, M.D., writes of medical school failure to produce physicians who are capable of humane as well as scientific medical care, who are able to attend to the emotional aspects of their patients, His anthropologist's account of the third year clinical rotations, "the year of socialization into the world of medicine," depicts an inhuman environment in which these failings seem to be passed down from attendings to residents to interns to medical students.

While a palpable distinction between medical science and the less technical aspects of patient care remains a feature of medical education, significant progress has occurred in the last 10-15 years. Medical ethics has been incorporated into many medical school curricula, the medical interview and communication skills are emphasized, and, in an effort to teach the human aspects of patient care, literature-in-medicine courses are offered. In this time of change, Halpern's analysis is well-needed.

To those physicians who have felt a longstanding tension between their commitment to patient care and the organizational environment of medicine, the arguments in From Detached Concern to Empathy may seem intuitively obvious, and the qualities of doctoring espoused inherent in the role of the physician. For these readers, this book will make sense of the tension between commitment to patient care and the organizational environment of medicine and give philosophical, sociological, and historical grounding to the discrepancies between the ideal and reality in medicine. To the committed rationalist, this book offers solid argumentation and extensive empirical evidence for the causal efficacy of emotion. And to others — the staunch traditionalist or the unworried scientist — for whom detachment remains the appropriate standard, Halpern offers an opportunity to see patients' experiences in a different way. For what, other than the practice of empathy, provides an internal perspective into suffering? What earns an individual to recognize the fragility of other human beings? Many writers are motivated, at least in part, by the need to overcome some past or current hardship and, in so doing, develop insight into others. Many people who struggle to overcome drug or alcohol addiction cultivate, through their struggle, a greater degree of regard for others and an appreciation of the importance of human connection. Similarly in medicine, a personal experience with illness, suffering, or loss can transform a technically proficient, if not removed, physician into a more related and caring healer. Perhaps it is just in the experience of suffering that we learn to appreciate the suffering of others. Short of this, there is the conscious practice of empathy.

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If there is a failure in this book, it is the extent of Halpern's idealism. Halpern's critique calls for not only the development of self-awareness, but also a general change in the atmosphere in which medicine is practiced and an organizational overhaul of a system dominated by managed care. The degree of self-awareness and emotional realism Halpern prescribes for physicians is remarkable: at times, the emotional sensitivity and analytic ability he suggests physicians develop seem akin to that learned in psychoanalytic training.

The demands of medical training are great. The average medical student is accepted at the age of 21 or 22 primarily on the basis of demonstrated proficiency in science, standardized test scores, and research or medical experience; the extent to which other considerations such as the personal statement and interview are weighed varies. The forces operating against the development of emotional realism might be felt as early as the application process — reveal enough, but not too much, be an individual, but not eccentric, be easy to work with, but not conforming, be socially concerned but not overly emotionally invested. Furthermore, the spirit of competitiveness among students develop in order to get into medical school doesn't shift automatically, upon acceptance, is one of cooperation — even in a pass-fail system in which group work is encouraged. Students are faced with an extraordinary, often anxiety-provoking volume of material to learn. Pressures to perform academically can gradually come to erode, or overshadow, or prevent the development of more human concerns.

In the clinical years, students are faced with the challenges of developing technical proficiency, learning to cope with illness, suffering, loss, and witnessing some of the worst examples of human behavior — child abuse, domestic violence, substance abuse, negligence, rape. These are extraordinary emotional demands, and in the face of such pressures, the development and maintenance of self-awareness and emotional realism — reflecting on motivations, commitments, strengths, weaknesses, anxieties — might easily feel like unaffordable luxuries.

Halpern's point, though, is exactly this: self-awareness, emotional realism, and empathic engagement with patients are not unaffordable luxuries; they are necessary — both for patient care and for the sustenance of the self. But still, one might wonder, how? In this vein, one could view Halpern's book as a precis to a practical guide to clinical empathy. And we would do well to hear more from her.

Reviewed by Meg Smirnoff
The Mount Sinai Medical Center, New York.

This is a thoughtful, introductory text appropriate for classroom teaching and self-study. It provides clear explanations of the basic Western ethical precepts and presents them in a historical-developmental context. The author offers an overhanded description of several ethical theories and leads the reader in “trying each one on” as they are learning. Throughout the text the role of community is emphasized. The author traces the communal nature of nursing ethics in the formulation of identity, the development of ideas, as well as from nursing as a moral community.

Volbrecht addresses nursing’s need to have a distinct ethic within the wider sphere of biocultural or health care ethics. Nursing is one of “a number of specialized communities that share the same moral purpose of promoting health and alleviating suffering with caring and compassion.” Each of these communities has its unique virtues as well as virtues shared with the others. Volbrecht differentiates nursing ethics from medical ethics by placing the “focus of mainstream medical ethics on the doctor-patient relationship as the locus of ethical decision making.” In contrast, she considers nursing ethics to focus equally on the nurse-patient dyad and on the collective responsibility and accountability to society. This difference in focus compels the nursing community to build its own practice ethic.

The volume is divided into eight chapters. The first chapter, which traces an historical overview of nursing ethics as a discipline, defines terms and general concepts and provides a framework for ethical analysis that is utilized throughout the text. In the next chapters, three major ethical theories are fully developed: rule ethics, value ethics, and feminist ethics. For each ethical perspective, basic theoretical concepts are presented in a separate chapter. An application chapter follows, in which the ethical framework is applied to paradigmatic cases. The final chapter presents an ethical dilemma, “care of the frail elderly” from the vantage point of each of these theories. Each chapter includes case studies and concludes with a summary of key points and questions for discussion and reflection.

The chapters on rule ethics discuss the foundation in Enlightenment thought and introduces utilitarian and Kantian principles. The basic rules of nonmaleficence, beneficence, justice and respect for autonomy are applied to examples of ethical practice. Volbrecht notes the criticism of rule ethics; that it “excludes important aspects of the moral experience of nurses” such as the contextual nature of moral judgments and the relational nature of nursing practice. She also acknowledges the strength of this perspective: within the ever-changing world of health care, rule ethics provides a clear framework for decision making and ethical language that promotes dialogue within and across disciplines.

The chapters on virtue ethics are the strongest and have the clearest nursing identity. “To be an effective nurse requires the development of character.” Joining a community whose members are distinguished by characteristic traits.” Classic nursing theories fit comfortably within virtue ethics and it resonates with familiar nursing tribute. That all nursing care is based on key virtues with an overarching value of the “provision of human flourishing” is essential Virginia Henderson. Volbrecht heavily references Barbara Fox’s model for the development of excellence in practice, practical reasoning and the development of moral character through mentoring. This demonstration of nursing’s intellectual history recommends the text as a candidate for a core course in nursing program.

The chapters of feminist ethics were the most innovative and they contributed new insights. Feminist thought is not usually highlighted in ethical discussions to nursing texts or professional journals. Feminist ethics is presented in its embryonic form as an “ethics of care” with the moral imperative to preserve and foster relationships between people. That would seem to make it a perfect fit as a professional nursing ethical standard. This emphasis contrasts with rule ethics, and in other, rights, and duties. The essence of feminist ethics is the historic and current deeply-rooted, societal wrong in the stigmatisation of women and other groups. Feminist ethics serves us to identify and correct oppressive imbalances of power. As it is present in this volume, it lacks the moral fiber of the other perspectives. The scenario given for analysis considers patient-centered clinical issues as well as professional issues.

Beyond pedagogy, Ms. Volbrecht effectively contaminates the volume by asking if “we are the nurses that we want to be?” In this time of staffing shortfalls and reengineering, she asks us to query are we, as a nursing community and as a society, are the virtuous person and the community we want to be.

Reviewed by Richard T. Hull
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I thought I was watching my father die.

Daddy Jack had retired at the age of 70 from his position as Administrative Assistant to the Executive Director of the Oklahoma City Chamber of Commerce. He and my mother had built a summer home in Colorado, and my young family and I had fallen into the happy habit of spending 2 weeks with them each year while they escaped the heat of the Oklahoma summer.

One July night in 1968, my mother roused us with a cry from the next room. Dad was thrashing from side to side, eyes closed, jaw clenched. I tried to restrain him; his strength repeatedly threw me off the bed. The seizure went on for perhaps fifteen seconds; he then became quiescent; his breathing slowed until it seemed about to stop. Yet his heart rate was normal; his eye pupils reactive.

We were 35 miles from the nearest hospital. An ambulance had been dispatched; all we could do was watch him and wait.

As the ambulance pulled in and the medics scrambled out, Dad suddenly opened his eyes, looked around at the gathered family, and said, “What are you looking at?”

We were looking at the echo of Dad’s fight fifty years before against the 1918 “Spanish flu” or “Flinders fever,” two of the inaccurate names attached to this world-wide pandemic that killed between 40 and 100 million in the space of a few weeks and dropped the U.S. life expectancy for that year from 51 to 39 years. Dr. Ralph Smith of Oklahoma City diagnosed Dad’s grand mal seizure as the result of a brain lesion produced by the high fever that accompanied his infection in 1918, together with the decrease in brain circulation that comes with advancing years.

But we thought this was a fluke, a special case with my father, certainly not the effect of something historic and important. Gina Kolata’s book, Flu, gives a much fuller picture to the horrors of the epidemic, and leaves me with a renewed sense of the way in which history can leave its stamp. It also places our current pandemic, Acquired Immune Deficiency Syndrome, in a perspective that makes its potential impact on our lives even more horrifying.

In a sense, we are lucky with H1N1: it is a virus whose spread can be controlled by precautionary steps that are well known and within the grasp of individuals. By contrast, the 1918 flu passed silently throughout the country, infecting some 28 percent of the entire population, killing its victims within 2 days of the first onset of symptoms. Yet, despite the fact that millions were dead in one year from that disease than from any of the wars in this country, before or since, the 1918 flu became a horror that was collectively forgotten, only recently being chronicled by historians.

Kolata’s book reports her study of this disease and how it has affected us over almost 80 years. For, while that strain of influenza has not, apparently, occurred again, a number of individuals have been prooected for nearly 8 decades with the identification of the guilty virus, development of an inoculation against it, and developing social and governmental policies to deal with it should it ever recur. The disease, fear of it, and its puzzles have been with us for much of those 8 decades, yet few Americans have been aware of its ubiquitous presence.

In her first chapters, Kolata conveys the horror of this pandemic in several ways. She describes its explosive spread and gives its pathology in stark terms: “It was twenty-five times more deadly than ordinary influenza. This flu killed 2.5 percent of its victims...And since a fifth of the world’s population got the flu that year, including 28 percent of Americans, the number of deaths was stunning. So many died, in fact, that the average life span in the United States fell by twelve years in 1918...”

“Within a month after the flu arrived in Philadelphia, nearly 11,008 people died from the disease.” At Fort Devens, dead bodies were “stacked about the morgue like cord wood.” “Katherine Anne Porter...nearly died of the flu herself. Her hands was killed by the illness. She wrote a novels about her experience, Mide Horse, Mide Rider...”

Thomas Wolfe’s novel, Look Homeward, Angel, contains a chapter that tells the story of his brother’s death: “...Ben’s thin lips were lifted, in a constant grimace of torture and strangulation, above his white nose with a dead looking teeth, as thin by inch he gasped, a thread of sal into his lungs. And the sound of this gasping—loud, harrow, rapid, unbelievable, filling the room, and orchestrating every moment in it—gave to the scene its final note of horror.” Up to 90% of Alaskan villagers were killed off in just a few days, creating a hoarde of orphans wailing and waiting for overwhelmed rescuers to bury their parents in the permafrost-hardened churchyards.

Much of Kolata’s book deals with the search for the virus and a way of preventing its infecting the healthy. In many respects, this is an exploration of how science is done: how it depends on dominant paradigm conceptions, how individuals seek to overcome fruitless paradigms with desperately creative ideas, but above all, how science, when done properly, is always testing its conclusions and subjecting them to the stern tests of attempts to replicate and attempts to falsify. The work is also a testament to the folly of doing science under the pressure of politics, and to the ease with which humans, even scientifically-trained humans, commit the fallacy of post hoc, ergo propter hoc (after the fact, therefore because of the fact).

The latter are shown in Kolata’s treatment of the 1976 Swine Flu vaccination effort. An outbreak of flu at Fort Dix, New Jersey, prompted public health officials under the Gerald Ford administration to undertake a rapid development of a vaccine with which to immunize the entire country. The belief
was strong that this could be a recurrence of the 1918 flu, and, under the slogan, "Better a vaccine without an epidemic than an epidemic without a vaccine," a national campaign to immunize all Americans against swine flu was undertaken. "The first Americans were immunized on October 1. Ten days later, the first deaths occurred." The media pounced in an orgy of hyperbolic scare stories, ordering every death within weeks of receiving a flu shot to the vaccine. President Ford and his family got their shots on television. Public jitters continued, but by mid-December, 40 million adults had received the shots.

But post hoc reasoning continued augmented by an error of re-collection by a Minnesota physician. Thinking he harbored an association of Guillain-Barré syndrome and swine flu vaccine from a medical education tape, the doctor reported a case of the syndrome in a patient who had gotten the flu shot to the Centers for Disease Control. Several more diagnoses surfaced in Minnesota, Alabama, and New Jersey, and the CDC initiated an investigation.

The problem, as Kolata shows, is that same sort of problem that prompts double-blind studies. Physicians who had been prompted to look out for such cases began diagnosing the syndrome with frequency, despite the disease being poorly described with no set criteria. Physicians began thinking Guillain-Barré whenever they encountered a patient with weakness in the legs, and asking such patients whether they had had a flu shot. The vaccination campaign was stopped, both because of these reported associations and because not a single case of swine flu had been reported outside of Fort Dix.

The penultimate irony of this story came when the medical education tape was unearthed during an investigation of the whole affair. It was as a lecture by Dr. Paul F. Wehrle. He had said, "Problems with diseases that may be confused or incorrectly interpreted as induced by influenza vaccine I think will occupy a lot of our time and a lot of our attention... I can assure you... that if someone is developing this (Guillain-Barré syndrome) and receives the influenza vaccine within about thirty days of the time of onset of that illness, this influenza vaccine will be blamed either for initiating it or making it worse." This, misremembered by the Minnesota physician, created an epidemic of association where, once cooler heads began to prevail, there was none.

The final chapters of Kolata's book explore efforts to isolate samples of the original 1918 flu virus from either samples that had been preserved in tissue collections of the National Museum of Health and Medicine at the Armed Forces Institute of Pathology, or samples taken from the corpses of Alaskan and Norwegian victims of the pandemic of 1918 that remained frozen in their graves under permafrost. Several efforts at the recovery of these cadaver samples are detailed with the reporter's attention to the biographies and motivations of the researchers who undertook their location.

Amidst these chapters is one devoted to the Hong Kong bird flu incident of 1997, during which a suspected link between bird viruses, swine viruses, and human viruses led to the killing of 1.2 million chickens in Hong Kong, Kowloon Island, and the New Territories. This massive, preventive effort may or may not have nipped a pandemic in the bud; now have called it a "dress rehearsal" for the next major worldwide pandemic.

In her last pages, Kolata sums up the efforts of decades of scientists' efforts: "In a sense, it is the ultimate frustration. Scientists have captured the mass murderer, the 1918 flu virus. But they still do not know its murder weapon...do not yet know how the murder was committed." Yet, she is reassuring: "It may not matter as much if the weapon is found. Medicine has armed doctors with tools that were not available in 1918 to fight a killer influenza strain. Now there are antibiotics that can thwart pneumococci-causing bacteria that swarmed into the lungs of flu victims who were too ill to fight back... And there are new drugs that can temper some influenza infections, possibly softening the blows of a killer flu." She ends, though, with a caution: "It is hard to be complacent... Perhaps, as we grow almost numb about influenza, that most quotidian of infections, a new plague is now gathering deadly force. Except this time we stand armed with a better understanding of the past to better survive the next pandemic."

That understanding, born of Kolata's evident belief that those who are ignorant of the past are doomed to repeat it, was the reason for this book: to remind us that the most deadly plague ever to hit the human race during recorded history occurred in this century, that influenza killed more Americans in a few months of 1918 than died in battle in World War I, World War II, the Korean War, and the Vietnam War, and "killed more humans than any other disease in a period of similar duration in the history of the world."

I found myself reflecting as I finished Kolata's book that my father's fortune in surviving the 1918 flu was a factor in my existence, for he had by then become engaged to my mother. And as I sat down to write this review, I noted that, in Canada, an outbreak of E. coli in the drinking water of a small town in Ontario has killed five, put nine others in critical condition, and caused hundreds to become ill. The book has left me with both an appreciation for the work done quietly by the microbiologists of the world, and also with a renewed sense that our future health requires eternal vigilance against these ubiquitous enemies.

This review was published previously, with slight alterations, in Pharmacological News 8 (no. 5) (2001): 76-77, and is reprinted here with the kind permission of the publisher.

— APA Newsletter, Spring 2002, Volume 1, Number 2 —