

# APA Newsletters

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APA NEWSLETTER ON

# Philosophy and Medicine

Rosamond Rhodes & Mark Sheldon, Co-Editors Fall 2001

Volume 01, Number 1

## FROM THE EDITORS

### Rosamond Rhodes & Mark Sheldon, Co-Editors

Our Fall issue demonstrates the unique place and potential for novel use of the *Newsletter*. In addition to information about the activities of the Committee on Philosophy and Medicine, our new Chair, Kenneth Kipnis, invites us all to interact and communicate through an internet link that the APA is helping us to establish. Please contact him to subscribe to the Philosophy and Medicine (P&M) electronic bulletin board. [Email to [kipnis@hawaii.edu](mailto:kipnis@hawaii.edu) with "P&M subscribe" as the subject line.]

"Letters to the Editor" always provide an opportunity for an exchange of ideals. This issue provides an arena for a lively debate about the nature of criticism in bioethics. Letters from Wesley Smith's and John Donnelly's reply to Leonard Fleck's last column, "From the Chair," and Len's letter replies to Wesley.

Bernard Gert and Charles M. Culver are in the process of revising *BIOETHICS: A Return to Fundamentals* (Oxford University Press, 1997). Over the next couple of years, their paper for this issue, "What Information Should Physicians Be Required To Know?" will probably become a chapter for that new volume. In the paper they explore the importance of physicians having a clear and full view of what they should know in order to provide information to patients and solicit their consent to treatment. Gert and Culver welcome comments on this work in progress. Comments should be submitted to this *Newsletter*. We will pass them on to the authors and also publish a selection of comments in a future newsletter along with replies from Gert and Culver.

Philosophers have been working in the field of bioethics for more than a quarter of a century. Some of the people who joined the field at its beginning actually shifted their careers from academic philosophy to the more "applied" clinical realm. We invited Gregory Pence, Mary Mahowald, Tom Tomlinson, David Thomasma, Daniel Dugan, and Mark Sheldon to reflect on their experiences and to share them with *Newsletter* readers. This issue includes narrative accounts of their motivation, their expectations, and what they encountered. The contribution by Mark Sheldon, "Experience and Reflections," also introduces him as this *Newsletter's* new co-editor.

The book review section includes discussions of two books written by physicians and a disputatious discussion of

a controversial thesis. *When the Body Speaks its Mind: A Psychiatrist Probes the Mysteries of Hypochondria and Munchausen's Syndrome*, by Berney Goodman is reviewed by psychiatrist Jorge R. Petit. *Dying: A guide for helping and coping* by Martin Shepard is reviewed by Daniel Fischberg a geriatrician who specializes in palliative care. *Is There a Duty to Die? and Other Essays in Medical Ethics*, by John Hardwig with Nat Hentoff, Dan Callahan, Larry Churchill, Felicia Cohen, and Joanne Lynn and also *Is There a Duty to Die?*, a collection of papers edited by James M. Humber and Robert F. Almeder are reviewed together by Felicia Ackerman. Her review essay of the papers in two books that make a case for there being a duty to die provides incitive and creative arguments to challenge that thesis.

As always, please continue to send along your announcements, letters, papers, poetry, stories so that they can be shared, used, and enjoyed by all. Directions for formatting your submission can be found at the end of the *Newsletter* volume. Feel free to volunteer a book review. Contributions and queries should be sent to Rosamond at the address below. For ease in communication please include your phone and fax numbers and email address if you have one.

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## FROM THE CHAIR

**Kenneth Kipnis**  
*University of Hawai'i*

If you are reading this column, there is a decent chance that you are a part of the constituency of the APA Committee on Philosophy and Medicine. The task of the P&M Committee, as I am trying to conceive it, is to advance philosophical work in health-related contexts on behalf of scholars who are probably very like yourself. The assets we have at hand are (1) this semiannual segment of the "APA Newsletters" (ably co-edited by Rosamond Rhodes and Mark Sheldon), (2) the designated sessions at the APA's division meetings, (3) the members of the Committee (see below) and (4) the good will of the APA: its officers, board and staff. In addition there are former Committee members who have been of service. Chief among these is Len Fleck, the past Chair, who has been admirably helpful as I have entered into what was formerly his office.

The salient problem faced by the Committee is the gossamer linkage we have to our constituency: we do not know who you are, where you are, what you do, and what might help you to do it. I took up this matter with Richard Bett and Jerry Schneewind in San Francisco: we have asked for a mailing to solicit expressions of interest in our Committee. The APA staff has since agreed to include such an inquiry in the packets containing its annual dues notices.

It might well be a good idea to have a P&M electronic bulletin board. Such an asset would facilitate the exchange of ideas and the rapid dissemination of information. I am asking that you respond to the APA request in your dues packet; or email me at [kkipnis@hawaii.edu](mailto:kkipnis@hawaii.edu) (put "P&M" at the beginning of the subject line and "subscribe" at the beginning of the Message Text); or write to me at Kenneth Kipnis, APA P&M Committee, Department of Philosophy, University of Hawaii at Manoa, Honolulu, HI 96822. Please let us know who you are and how we can best reach you.

Members of the Committee met on March 30, 2001, at the Pacific Division Meetings in San Francisco and tentatively agreed to the following topics for the 2001-2 APA sessions. Rosamond Rhodes will organize a session at the Eastern Division meetings on "Does Bioethics Represent a Challenge to Ethical Theory?" Mark Sheldon will organize a session at the Pacific Division meetings on "Medical Exigency and the Prescription of Nonstandard Therapies." Finally, with the help of Lainie Friedman Ross, I will organize a session at the Central Division Meetings on "The Limits of Parental Authority in the Clinical Setting." We hope to be able to provide -- perhaps via email -- additional details concerning these programs. Stay tuned.

### Members of the Committee:

Kenneth Kipnis (Chair), University of Hawaii  
Micah Hester, Mercer University  
Glenn McGee, University of Pennsylvania  
Lainie Friedman Ross, University of Chicago  
Rosamond Rhodes, Mount Sinai School of Medicine  
Mark Sheldon, Indiana University

To register for the P&M electronic bulletin board, email the P&M Chair at [kkipnis@hawaii.edu](mailto:kkipnis@hawaii.edu). Please put "P&M" at the beginning of the subject line and "subscribe" at the beginning of the Message Text.

## LETTERS TO THE EDITOR

**TO: Editor, *Newsletter on Philosophy and Medicine***  
**FROM: Wesley J. Smith**  
**DATE: July 2, 2001**  
**RE: From the Chair**

I was amused to read Leonard M. Fleck's diatribe against my book, *Culture of Death: The Assault on Medical Ethics in America* (From the Chair, Spring 2001). How clever and mature of him to call me "Weasley." And here I thought academic discourse was supposed to be proper and dignified.

Dr. Fleck is certainly free to dislike my book (which was named Best Health Book of the Year at the 2001 Independent Publisher Book Awards), but he should not be free to criticize me for something I did not write. Specifically, he accused me of writing that bioethicists "are nothing but whores for the pharmaceutical industry."

Not true. What I did write was that the IRB system is not doing an adequate job protecting vulnerable human subjects. I am certainly not the only critic to hold this opinion. Indeed, I quote some very prominent bioethicists who have leveled the same criticism.

Dr. Fleck is also upset that I charge bioethics with rejecting the sanctity and equality of human life. But do not most bioethicists accept the premise of the born human who is not a person based on quality of life criteria? Once quality of life rather than equality of life became the bottom line of bioethics, the entire enterprise headed down the path that leads directly to invidious discrimination.

It seems to me that discriminating in health care against the so-called human non-person is as bigoted as discriminating in health care against someone based on race, sex, sexual orientation: there are merely different victims. Indeed, health care rationing, the current cause celebre of the bioethics movement is merely a polite term for health care discrimination based on quality of life. Lamely defending himself to his son, Fleck claims that I "probably only interviewed a bunch of Hollywood hip-happy High Priests of Bioethics" (whoever they might be) in researching my book. In actuality, I support my theses with more than 500 citations, including interviews with and/or quotations from the writings of the likes of Callahan, Veatch, Caplan, Childress, Beauchamp, Fletcher, Jonsen, Arnold, Youngner, Harris, Frey, Hardwig, Glover, Singer, and many others. Perhaps Dr. Fleck's real gripe is that I didn't quote him.

**TO: Editor, Newsletter on Philosophy and Medicine**

**FROM: Leonard M. Fleck**

**DATE: July 6, 2001**

**RE: Letter from Wesley J. Smith**

I have a favorite passage from Shakespeare's *Merchant of Venice* that I like to quote when I am about to participate in an orgy of self-pity. It is Shylock's speech, Act III, Scene I.

SHYLOCK. ...He hath disgrac'd me and hind' red me half a million; laugh'd at my losses, mock'd at my gains, scorned my nation, thwarted my bargains, cooled my friends, heated mine enemies. And what's his reason? I am a High Priest of Bioethics. Hath not a High Priest of Bioethics eyes? Hath not a High Priest of Bioethics hands, organs, dimensions, senses, affections, passions, fed with the same food, hurt with the same weapons, subject to the same diseases, healed by the same means, warmed and cooled by the same winter and summer, as a Wesley J. Smith is? If you prick us, do we not bleed? If you tickle us, do we not laugh?

Old "Weasley" is much annoyed by the nickname that I have attached to him, regarding this as a serious lapse of academic etiquette. However, he fails to remind the reader that his use of the phrase "High Priests of Bioethics" to tar a whole class of individuals with his own distorted ideological misconstruction of the field is more than a lapse of etiquette; it is a perfect example of irrational rhetorical zeal run amok. A taste of his own medicine must be bitter indeed.

If old Weasley had confined himself to just this one bit of rhetorical excess, he could be excused. But this is a deeply engrained habit. He repeatedly promulgates the broadest generalizations on the slimmest possible evidential base. The interested reader may consult the following Web site for the text of an interview Smith did on his book with a radio talk show host named Geoff Metcalf.

Some samples: The host of the show says, "That guy [Peter Singer] is a wacko." To which Smith replies, "Peter Singer epitomizes the movement I'm talking about." Nothing subtle about that connection. A little later in the interview the host says, "I'm absolutely flummoxed that people could even waste a moment listening to that jerk Singer." to which Smith replies, "He is more tactless than some of the others. However, he is not an aberration. He epitomizes the movement."

The conversation continues about how bioethicists have insinuated themselves into the corridors of power, various presidential commissions and task forces. Smith notes that the president of Princeton, the same university that hired Singer, is the head of the President's bioethics commission [NBAC], which elicits from the host the comment: "So it's an incestuous little club." And Smith replies, "You have a very elite group." He ticks off several elite universities in the US involved in the training of bioethicists, and goes on to complain that these individuals believe that some individuals have higher moral value than others, yet "because they are from the elite universities and part of the intelligentsia, people seem to think its OK." The host then chimes in with a comment about "this small collection of arrogant, pretentious academicians who are now dictating how medicine will be practiced." To which Smith replies, "It's because we have a

bad case of expert-itis in this country." So Smith is making a blatant appeal to the raw anti-intellectualist currents in our political life, yet in the same conversation he complains that hairdressers need to be licensed but bioethicists (presumably the ones with doctoral degrees from prestigious universities) do not need to be licensed. I stand by my attribution of the sobriquet "Weasley" to Mr. Smith.

In the remainder of the interview Weasley rants about rationing and futile care theory. At one point he says, "Under Futile Care Theory, doctors are giving themselves, like Napoleon crowning himself emperor, the authority to say no. That if they think the quality of your life isn't worth the expending of the money and resources, they can say no and unilaterally refuse it." In this passage there is a tiny speck of truth, but that speck is totally obscured and distorted by the rhetorical baggage all around that, all of which is aimed at inflaming rather than informing and engaging a broader public in the discussion of the complex ethical and policy issues that are at the core of bioethics today and central to our lives as patients and as citizens. I would remind the reader that this last point was the real focus of my essay. Reading Mr. Smith's letter would give the impression that he was the focus of my essay. He simply provided a timely example of the sort of rhetorical excess and distortion that undermines our capacity as a society to engage in more rational public deliberation about these difficult issues.

Finally, Smith writes that I am upset because he charges bioethics with rejecting the sanctity of life ethic and accepting a quality of life ethic. That latter ethic he associates (in his book) with the worst forms of discrimination against the disabled, including the practices of Nazi Germany (the not so subtle implication being that the vast majority of bioethicists are closet Nazis). This sort of inflammatory distortive rhetoric deserves anger. A much more representative example of the kind of careful moral argument and analysis that characterizes the discussion of disability issues within bioethics may be found in the excellent collection of essays edited by Eric Parens and Adrienne Asch under the title *Prenatal Testing and Disability Rights*. When Mr. Smith shows a capacity to appreciate the essays in that volume I will happily withdraw the nickname "Weasley" from him. In the meantime I will withdraw to my pity party, ashamed that I was not quoted by him because I must be no more than a demi-high priest of bioethics.

## ARTICLES

### ***What Information Should Physicians Be Required To Know?***

**Charles M. Culver, MD, Ph.D.,**  
*Barry University, Miami Shores, Florida.*

**Bernard Gert, Ph.D.,**  
*Dartmouth College, Hanover, New Hampshire*

There is a general consensus in bioethics, in health law, and in medical practice that neither treatments nor diagnostic tests should be administered to a patient without the patient's valid consent, and an important part of the valid consent process is the disclosing of information to the patient about the suggested intervention.<sup>1</sup> One way of characterizing the scope of the required disclosure is to say that there is an ethical duty to give the patient that information that a rational person would want to know before making a decision.<sup>2</sup> Here too there is a general consensus that at a minimum three specific kinds of information should be disclosed, namely, the significant harms and benefits that might follow the suggested intervention; the significant harms and benefits that might follow any plausible alternative intervention that could be employed; and the likely course of events if no intervention were used at all. Patients cannot decide rationally whether they should consent to or refuse a treatment without knowing these three kinds of information. The so-called "reasonable patient" standard that some courts (not all) have adopted as the standard of care that should apply to the consent process uses a similar criterion. For example, in one of the landmark cases in the consent area, the *Canterbury v. Spence* court declared that, "The patient's right of self-decision shapes the boundaries of the duty to reveal."<sup>3</sup> The court explained that there is a duty to disclose "material" information and the definition of "materiality" is whether the information would likely be important to the rational patient in making a decision.<sup>4</sup>

Since the criterion for what must ethically be disclosed is "what a rational person would want to know before making a decision," there are at least four additional kinds of information about particular medical interventions that should be disclosed. These kinds of information are increasingly available and rational persons would want to know them before consenting to or refusing a treatment. If physicians know these kinds of information, there is no doubt that they have a duty to disclose that information to their patients. The only question about these four additional kinds of information is the extent to which competent physicians have the duty to learn about them. Until there are standards concerning what a competent physician has to know, standards concerning what a physician must disclose have significantly less value.

#### **Information About Suggested Interventions**

As information about the nature of medical practice has grown, there has come to be available certain kinds of additional data about particular medical interventions that would be useful to many patients who have to make decision

about whether to consent or refuse a suggested treatment. These four kinds of additional information "would likely be important to the rational patient in making a decision," often as important as the three kinds of information about the possible harms and benefits of the suggested treatment, alternative treatments and no treatments at all.

**1. Volume-outcome studies.** There has been much interest in recent years in studying the variability in outcomes associated with various medical and surgical procedures. For example, volume-outcome studies have frequently been performed in which the incidence of in-hospital morbidity and/or mortality associated with a particular surgical procedure is correlated with the frequency with which that hospital performs that kind of surgery. Gordon, et al. note, "The relationship between volume of surgical services performed by surgeons and hospitals, and positive outcomes of care, has been well documented."<sup>5</sup> An illustrative study was reported by these authors<sup>6</sup> in which the outcomes of all 501 Whipple procedures (pancreatico-duodenectomies, a complex, fairly high-risk procedure, usually carried out for cancer of the pancreas) performed in the state of Maryland between 1988 and 1993 were examined. More than half of these procedures (271, or 54.1%) were performed at Johns Hopkins Hospital (JHH) while the remainder (230, or 45.9%) were performed at 38 other hospitals in the state, no one of which performed more than a total of 20 during the 5.5 years of the study.

The outcome of the procedure was significantly different between JHH and the rest of the hospitals, even after the two patient groups (JHH vs. all other hospitals) were statistically matched for age, gender, race, source of payment, source of admission, and extent of comorbid processes. In-hospital mortality was more than 6 times higher at the low-volume hospitals than at JHH (13.5% vs. 2.2%,  $p < .001$ ).

Even among the 38 low-volume hospitals there was a significant linear monotonic relationship between volume and mortality. The 38 hospitals were divided into four groups based on the frequency with which they had performed the procedure. Twenty hospitals had performed a total of 1-5 Whipple procedures between 1988 and 1993, 9 hospitals had performed 6-9, 6 hospitals had performed 11-15, and 3 hospitals had performed 16-20. Their respective in-hospital mortality rates were 19.1%, 14.3%, 13.0%, and 8.9%.

Thus among the 20 hospitals in Maryland (more than half the total number of hospitals) that performed only between 1 and 5 procedures, the chance of dying in the hospital was almost 9 times greater than at JHH (19.1% vs. 2.2%). This represents almost a one-in-five versus a one-in-fifty chance of dying. Even among the four hospitals that performed 16-20 procedures, the chance of dying was four times greater than at JHH (8.9% vs. 2.2%).

These are substantial differences, not merely statistically significant differences of limited practical importance. Unless they had strong reasons for not doing so, any person trying to make a rational decision about treatment would choose to have the Whipple performed at JHH rather than at a local, low-volume Maryland hospital. Absent such reasons, it would be seriously irrational to choose to have the surgery in a low-volume setting. And of course there is no reason to believe that this volume-outcome relationship in performing Whipple procedures is limited to Maryland.<sup>7</sup>

Studies have been emerging with regularity in recent years showing similar volume-outcome relationships with respect to other surgical procedures and medical treatments.<sup>8</sup> Most if not all of these studies have produced information that rational patients making decisions about treatment would want to know if they realized that it existed. Thus they satisfy the “rational person would want to know” criterion and yet, so far as we know, no official medical group has suggested that physicians have a duty to learn this information so that they can disclose it to involved patients. We believe that at a minimum specialists in a field do have a duty to learn and to disclose volume-outcome information.

**2. Geographical variation studies.** A related but conceptually distinct body of research has consistently shown large differences in the frequency with which certain surgical procedures and medical treatments are performed in different geographical areas of similar demographic characteristics. The phenomenon is especially apparent in the so-called “discretionary” procedures (for example, carotid endarterectomy, radical prostatectomy, and back surgery). Relatively “non-discretionary” procedures (for example, colon resection for colorectal cancer, cholecystectomy, and hip fracture repair) show less geographical variation.<sup>9</sup>

The magnitude of these geographical differences is often large: a 6-fold to 10-fold difference in incidence between closely matched areas is commonly seen. For example small-area variation studies in New Hampshire, Maine, and Iowa showed that among different areas closely matched for demographic characteristics there were broad variations. In one area only 20% of women, by the age of 70, had a hysterectomy; in a matched geographical area, 70% had one by that age. Similarly, in one area, by age 85, only 15% of men had a prostatectomy; in a matched area, 60% had one. In another study it was found that among women with early breast cancer who, according to practice guidelines, could reasonably choose either to have a lumpectomy or a radical resection, there was wide geographical variation in the choices made. The extremes: in one small town, 48% of women had lumpectomies and 52% had radical mastectomies; in a closely matched small town, only 1.4% of women had lumpectomies while the remaining 98.6% had radical mastectomies.

The reason for these geographical differences is not entirely clear. Chance variation can be shown to cause no more, at most, than a very small part of the differences observed.<sup>10</sup> An unlikely explanation for the discrepancies seen between different areas is that they reflect a difference in what patients in the different localities, adequately informed, would actually prefer. It seems extraordinarily unlikely that half of adequately informed women in one geographical area would opt for a breast-sparing lumpectomy while almost none of the women in a closely matched area would make the same choice. The women’s “choices” are almost certainly reflecting their doctors’ “recommendations.”

The most likely explanation is that the differences represent different professional practice patterns that have evolved in different localities. The procedures that show the greatest variation may be those procedures in which it usually would be rational either to consent to the surgery or to refuse it (or to have a mastectomy vs. have a lumpectomy, etc.), as the term “discretionary” implies. However although both choices may be rational, particular individuals, adequately

informed, may nonetheless strongly prefer one to the other if they knew that such a choice was often chosen by patients in other localities. Thus, they should be provided with full comparative information so that they can make the choice dictated by their personal values.

Rational persons would often want to know about geographical variation data. A woman with breast cancer, whose gynecologist was urging her to have a radical mastectomy, might be quite interested to know that in her city such operations were carried out 34 times (48% vs. 1.4%) more frequently than in a neighboring city, with no known difference in the nature and incidence of breast disease between the two locales. These data would not mean that it would be irrational for her to have a radical mastectomy in these circumstances, but she might be motivated to consider the lumpectomy option especially seriously if she realized that in a neighboring locale it was chosen much more frequently than in your locale. However, despite the pertinence of geographical variation data, few doctors include data about geographical variations during the consent process. Here too, as these data become increasingly available, specialist physicians have a duty to learn about them and disclose them to their patients.

**3. Number needed to treat measures.** As noted above there is widespread agreement that physicians should tell patients, as part of the consent process, the expected efficacy of any treatment that they are suggesting. There are several ways in which physicians can impart information about efficacy; some are relatively uninformative or even misleading, while others are more useful.<sup>11</sup>

One way in which a physician can describe efficacy is to assure the patient that the treatment has been found to be effective in research studies. While this may be true it communicates relatively little information. If experimental studies are conducted with large groups of subjects it is possible to achieve statistically significant differences between experimental and control groups that are based on relatively small mean differences in efficacy. Thus while a suggested treatment may be statistically superior to doing nothing, or to employing some older treatment, the degree of superiority may not be large in absolute terms. Whether an adequately informed patient would elect the suggested treatment might depend on many factors: the absolute degree of superiority of the suggested treatment, its cost and side effects, the noxiousness of simply continuing to have the disease (for example, some version of “watchful waiting” in mild to moderate prostatism), and so forth.

A second common way of describing efficacy is to use relative frequency data: “this drug will cut your chance of having a heart attack by 50%.” This is a kind of efficacy description not only used by some doctors but also by many journalists. It can make a treatment sound more remarkable than in fact it is. For example suppose a treatment is expensive and has many unpleasant side effects. Suppose further that without the treatment the patient has a 1 in 100 chance of having a heart attack over the next five years but that with the treatment the rate is cut to 1 in 200. That would be a 50% reduction but it might not impress some patients, who might think the five-year bother and unpleasantness associated with the treatment outweighs the rather small gain the treatment confers. Thus telling patients only about relative risk reduction gives them incomplete information and in many cases is actually misleading.

There is an alternative statistic that has become more widely used in recent years, called the Number Needed to Treat (NNT). The NNT tells how many persons need to be subjected to a treatment before one person would benefit from the treatment who otherwise would not have benefited. The lowest possible NNT would be 1, if there were a treatment that benefited everyone who took it and no one would receive that benefit who didn't take the treatment. Some antimicrobials and some orthopedic procedures may approach an NNT of 1, but NNT's this low are rare in medical or surgical practice.

The NNT is easily calculated. Here is an example: if 2/3 of all patients with a DSM-IV diagnosis of Major Depressive Episode improve significantly within two months of beginning to take antidepressant medication, while 1 out of 6 persons improve significantly without any medication, then:

- if 100 patients take the drug, 67 will recover,
- if 100 patients don't take the drug, then 17 will recover,
- therefore the drug will benefit 50 patients who would not be benefited without the drug,
- thus 2 patients need to be treated in order to benefit 1 patient who would not otherwise be benefited (100/50). Thus the NNT is 2.

Here is another example, based on an actual study. A group of hypertensive patients took part in a randomized clinical trial studying the effect of a particular regimen of drugs on the frequency with which they experienced either heart attacks or strokes over a three-year period. It was found that 4.0% of the experimental group (the patients taking drugs) experienced a heart attack or stroke but that 9.8% of a control group (taking a placebo) had one of these maladies. What was the NNT? It can be calculated using the method shown above:

- if 100 patients take the drugs, 4 will have a heart attack or stroke,
- if 100 patients don't take the drugs, 10 (rounding off) will have a heart attack or stroke,
- thus 6 persons will be benefited from the drugs who otherwise would not have been benefited (100/6). Thus the NNT is about 17.<sup>12</sup>

It would be possible for a physician, confronting a hypertensive patient, to describe these results in several ways. He might say simply, "These drugs have been shown in scientific studies to be effective and I recommend that you take them." Or he might use relative risk data and say, correctly, "These drugs will lower your risk of having a heart attack or stroke by 60%." (That is, going from 10 to 4 involves a 60% reduction.) Or he might say, "These drugs can be beneficial but not everyone is helped. If 17 people take the drugs, one person will avoid having a stroke or heart attack who otherwise would have had one. For 16 people it will not make any difference."

Consider the two statements, "These drugs reduce the risk by 60%," and, "Only one person in 17 who takes the drugs will be helped." To many persons these seem at first blush such disparate statements that they sound incompatible — as if they must be descriptions of two different drugs. This is because of the often misleading connotation engendered by relative risk data. This misleading connotation may arise from an unreflective and false assumption that the risk of having a stroke or heart attack is 100% and that the drugs reduce the

risk to 40%. That would indeed be a powerful effect but of course that is a different situation than having a 10% risk that is lowered to a 4% risk. Unless the drugs were extremely unpleasant or dangerous, it might be irrational not to take them if they reduced the risk of stroke or heart attack from 100% to 40%. However not taking drugs (for three years) with an NNT of 17, especially if the drugs are expensive and/or accompanied by significant unpleasant side-effects, need not be irrational at all.

NNT's are now rather widely available and even exist in lists that can be downloaded (and frequently updated) on to a hand-held computer that the physician can conveniently have with her at all times.<sup>13</sup> NNT's are also increasingly being reported as the key dependent variable measure in randomized clinical trials investigating the efficacy of medical treatments. Specialist physicians have a duty to learn about the NNT's of those specialized treatments they prescribe and disclose them to their patients, along with more traditional kinds of information about harms and benefits.

**4. Departure from Practice Guidelines.** In recent years there been created many medical "Practice Guidelines." These are sets of recommendations about the best way to manage and treat various maladies; for example, the best way to treat an acute myocardial infarction, or a patient suffering from a manic episode. Usually the guidelines have been created by groups of specialists in a field who have relied on the best evidence that is available, from randomized clinical trials and from meta-analyses of randomized clinical trials, about optimal treatment strategies.

The guidelines are meant to be prescriptive. The group writing the guidelines is claiming that the particular strategy outlined has been shown to be superior in its results to any other strategy that has been tried and studied in a particular clinical situation. However the guidelines are not meant to be absolute. Frequently there is good reason, based on the circumstances of a particular case, not to follow a particular guideline but to take some other action instead. The burden of proof is always on a physician who departs from a particular guideline to justify the departure, but departures are not only sometimes permissible, they are sometimes obligatory. Departures should not be capricious or based on inexplicable hunches: the physician making the departure must be willing to argue that in any future cases with relevantly similar characteristics to the case at hand, the guideline should be departed from in just this way. In fact some future, fuller edition of the Practice Guidelines might say not only: "Do X," but add as a corollary, "In case of Y, do not do X but instead do Z." The exception becomes a publicly defensible (sub)guideline itself.

Any rational person suffering from a condition for which there exists a professionally accepted set of Practice Guidelines would want to know about these guidelines. Because there is good research evidence that by following these guidelines her chances of recovery are greater than they would be if another treatment strategy were followed, she generally would want her physician follow these guidelines. However, she might want her physician to depart from the Guidelines if he were able to plausibly argue that the departure was justified.

There is now good research evidence that patients whose depression has been successfully alleviated by the use of antidepressant medication should continue to take the

medication for four to six months after their mood has improved. If patients prematurely stop the medication soon after they feel better, there is a significant and non-trivial chance they will suffer a depressive relapse and need to take the medicine for another full course. This fact has been recognized for years and has been incorporated into the Practice Guidelines for treatment of Major Depressive Episodes that have been published by the American Psychiatric Association. Any psychiatrist who undertakes to treat depressive episodes should be aware of this fact and should explain to patients the reason for continuing the medication. A psychiatrist who does not follow this guideline and does not tell patients of its existence is subjecting his patients to the possibility of a good deal of avoidable future suffering. If the psychiatrist has some reason not to recommend that a patient continue with medication for several months after the patient's depression has lifted, he should explain to the patient why he is making the recommendation that he is.

The existence of Practice Guidelines should not be kept a mystery to patients. In fact the content of the guidelines should be an essential and central part of the information given to the patient during the consent process. A cardiologist might say, "There is good evidence that you have suffered what appears to be a mild myocardial infarction, or heart attack. The set of treatments that I suggest we follow that has been shown to maximize the chances that you will make a good recovery from what has happened. They are, in fact, incorporated in the Practice Guidelines for treating your kind of case. These Guidelines have been developed by the leading experts in the field. Let me tell you about them. (Sometimes a physician might add, "Let me tell you why I think we should depart from them in this one aspect.") You can ask any questions you want about what I tell you."

Given the current existence of professionally-agreed upon, research-based guidelines, one might expect that physicians would know about them and follow them scrupulously and that patients would generally be informed of their existence. Neither expectation seems to be true.<sup>14</sup> In fact Practice Guidelines are so commonly ignored that there is emerging a literature investigating the question of why this should be so.<sup>15</sup> With respect to any specialist interventions they suggest, specialist physicians have an ethical duty to learn about and disclose the relevant Practice Guidelines to their patients and inform them when they are departing from these Guidelines and why they are doing so.

### **The Duty of Physicians to Learn and to Disclose**

All physicians have an ethical duty to disclose to patients the first three kinds of information mentioned above: the significant harms and benefits that might follow the suggested intervention, the significant harms and benefits that might follow any plausible alternative intervention that could be employed, and the likely course of events if no intervention were used at all. The strong emphasis on the duty to disclose this information has resulted in less attention on the duty of physicians to know this information. No one doubts that, except in extraordinary circumstances, physicians should disclose to their patients all of the information that they have about the possible harms and benefits of the suggested treatment, alternative treatments and no treatments at all. However, although it is clear that physicians have a duty to know some information about these matters, it is not clear

how much information they have a duty to know. It would be useful to establish some level of knowledge that would count as the minimum level required for specialists and primary care physicians to be competent.

The four additional kinds of information discussed above, volume-sensitivity, geographical variation, NNT's, and Practice Guidelines, have the same status as the first three kinds. If physicians have this information they have a duty to disclose it to their patients, and they have a duty to know some of this information. Rational patients would want to know these additional kinds of information because they could significantly affect the outcome of their decision-making. We recognize that the four kinds of additional information are not always as available in the medical literature as are the first three kinds. However a great deal of information is already available, much of it obtainable on the internet, and it seems a safe prediction that before too long NNT's and Practice Guidelines, for example, will exist for the vast majority of medical treatments.

For all of the treatments they suggest in their role as specialists, specialist physicians have a duty to know all of the available information of the four additional kinds. Knowing this information should be required of all competent specialist physicians. Having the same requirement for primary care physicians would put too heavy a burden on primary care physicians who suggest a wide variety of treatments for a multitude of ailments. It is appropriate to expect a competent urologist to know the Practice Guidelines for treating mild to moderate prostatism and the NNT for a transurethral resection of the prostate performed for that condition. However to expect a family physician to know these kinds of information about every condition he or she might encounter seems excessive. But the family physician should be expected to know some of this additional information. For example, any physician prescribing antidepressants should be expected to know that the drug should not be abruptly discontinued one week after symptomatic relief.

Perhaps specialty groups should themselves publish what they believe to be the level of knowledge and disclosure that should be obtained and carried out by primary care physicians who practice in a specialty area. For example, psychiatrists might decide that primary care physicians who treat depressive episodes need not know that the antidepressant drugs typically have an NNT of about 2 (especially because the NNT is so low and thus favorable) but should know the practice guideline about when to discontinue medication after a patient's return to a relatively normal mood.

People writing about informed consent have concentrated on the duties of physicians to disclose all of the information that a reasonable patient would want to know. All physicians have the same duty to disclose everything they know that is relevant to rational patients' decisions. It is not clear how much physicians have a duty to know about the information they would have a duty to disclose if they knew it. It also seems that not all physicians have a duty to know the same amount of this information. How much of this information a competent specialist should know, and how much a general practitioner should know are significant questions that have not yet been seriously considered. It is important that these questions be given serious consideration by specialty groups of physicians as well as by those who write in bioethics.

## Endnotes

1. It is also necessary that no coercion be used in obtaining the patient's consent, and that the patient be fully competent to consent. The precise meaning of the concepts of "coercion" and "competence" requires explication; see Gert, Bernard, Charles M. Culver, and K. Danner Clouser, *Bioethics: A Return to Fundamentals*, New York: Oxford University Press, 1997, Chapters 6 and 7.
2. See Gert, et al., op cit., pp. 152-156.
3. *Canterbury v. Spence* 464 Fed Rptr 2d 722 1972 DC.
4. This standard is in comparison with the "reasonable physician" standard, held by some courts, that the standard of disclosure should simply be what physicians generally do tell patients about the likely outcomes of a particular treatment.
5. Gordon, Toby A., et al. The effects of regionalization on cost and outcome for one general high-risk surgical procedure. *Annals of Surgery*, 221 (1995), 43-49.
6. Gordon, et al. op. cit.
7. At least two other studies have found similar volume-outcome relationships with the Whipple procedure: Birkmeyer, et al. Effect of hospital volume on in-hospital mortality with pancreaticoduodenectomy. *Surgery*, 1999, and Simunovic, et al. Relation between hospital surgical volume and outcome for pancreatic resection for neoplasm in a publicly funded health care system, *Canadian Medical Association Journal*, 1999.
8. For example, see Begg, et al. Impact of hospital volume on operative mortality for major cancer surgery, *JAMA*, 1998; Hannan, et al. Coronary angioplasty volume-outcome relationships for hospitals and cardiologists, *JAMA*, 1997; Lavernia & Guzman. Relationship of surgical volume to short-term mortality, morbidity, and hospital charges in arthroplasty, *J Arthroplasty*, 1995; Tu, Austin & Chan. Relationship between annual volume of patients treated by admitting physician and mortality after acute myocardial infarction, *JAMA*, 2001, 3116-3122, and others.
9. For an extensive summary of geographical variation data, see *The Dartmouth Atlas of Health Care*, 1999, Center for Evaluative Clinical Sciences, Dartmouth College. Also see Wennberg, John E. "Understanding geographic variations in health care delivery," *NEJM*, 1999, 340, 52-53.
10. It is easy to calculate confidence intervals for the observed differences and, since most of them are based on large groups, the probability that the difference is a chance phenomenon is extremely small. And of course there are many such observed differences so that the probability that all or any substantial proportion of them are due to chance is vanishingly small.
11. There is much anecdotal and some empirical evidence that physicians often do not even attempt to give information about efficacy, but simply "assign" a patient to a treatment. ("It looks like you have an enlarged prostate. Here's what we're going to have to do.") This simply abrogates the consent process.
12. A somewhat quicker but completely equivalent way of making the calculation is to realize that the NNT is the reciprocal of the absolute difference between the percentage outcomes of treatment vs. no treatment. Thus in the above example: 10 minus 4 equals 6; 100 divided by 6 equals about 17. (NNT's are conventionally rounded off to the nearest whole number.)
13. See, for example, <http://www.library.utoronto.ca/medicine/ebm/glossary/nnts.htm> .
14. One of us teaches a didactic course on evidence-based medicine to Physician Assistant students immediately after their 12-months of clinical rotations in area clinics, hospitals, and medical practices. Most students say they have never heard the term "Practice Guideline" mentioned during their year-long exposure to 8-10 different physician preceptors and resident staffs.
15. See Cabana, et al. "Why don't physicians follow clinical practice guidelines?" *JAMA*, 1999, 282, 1458-1465.

## Medical Ethics is Whatever You Say It Is

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In what seems like yesterday but was actually a quarter-century ago, I was standing in the office of the Dean of Medicine in the huge medical complex that exists in Birmingham, Alabama. I had just been told that I would henceforth have a job on both sides of the campus, a regular one in the Philosophy Department and a special one in the School of Medicine, teaching 165 students a required course once a year in Medical Ethics.

I was happy, but not because I had entered an exciting new area of interdisciplinary study. Instead, I was happy because I had any job at all connected to Philosophy. During the previous year, I had come very close to having a career in real estate in New York City.

After getting my PhD in 1974 working under Raziel Abelson and Peter Singer (who visited for a year at NYU), I tried in vain for two years to secure a tenure track job. Failing to do so, I quit philosophy. (Looking back and at statistics, I now realize that the market was flooded with new PhD's in those years.)

An unexpected opening brought me to Birmingham on January 1, 1976, when the Karen Quinlan case and trials were going on. The Dean of Medicine had been a philosophy major at Davidson and, partly because of the Quinlan case, thought that medical students should think about such issues before they practiced. So my position was created and I was hired.

After he offered me the job, I accepted and then asked, "By the way, a lot of people disagree about Medical Ethics. What do you think it is?" He laughed and responded, "It doesn't matter what I think. From now on, it matters what YOU say. You're going to teach the course and write the books. Good luck!"

That was not the whole truth by any means, but when it came to teaching the course, it wasn't far off. There were no textbooks. My first year, readings were patched together from the *Hastings Center Report*, theology journals, *JAMA*, *Time*, and *Philosophy and Public Affairs*. Moreover, rather than embracing an exciting new area of interdisciplinary study, most medical students resented having to take another course (they didn't know when they had it good: since then, four additional courses have been piled on them: medical history, nutrition, neuroscience, and soon, integrated problem solving),

During the early years, I longed for the safety of teaching traditional courses in Philosophy - at least my courses in graduate school had some relation to that! I sometimes longed for my office on the green side of campus — away from the hospitals, where for several months I did daily rounds in oncology and other specialties. What was most uncomfortable was not having a definite role to play in making these rounds (for I was there strictly as an observer, not to advise about ethics; I have never been an ethics consultant in a hospital, and based on my experiences in hospitals, never want to be one).

Until I taught in medical school or served on hospital committees, I had never realized the power a professor has in his mini-kingdom, his classroom, especially over the "serfs"

who need one's recommendation for medical or professional school. In a hospital or even a medical school, and especially in the early years, I often got the question, "What is a philosopher doing here?" I constantly felt I had to prove I belonged.

Over the years, I wrote a text (so I would have something to teach) and learned to like the constant challenges. Entirely unexpected issues kept arising, such as artificial hearts, AIDS, the Human Genome Project, and cloning. What I didn't like doing was trudging over to the medical library, or badgering physician-friends, to try to quickly learn some new field.

I now think Medical Ethics is today's most exciting academic field. I was very lucky to enter on the ground floor and to help create a field that so well matched my interests and personality. (I am not constitutionally suited to spending decades writing on criteria of justified true belief or on proving to skeptics why I am not a brain in a vat.)

The growth in courses in Bioethics in North America has been explosive. (I purposefully use the wider term "Bioethics" here rather than "Medical ethics" to include issues such as genetically-modified food and animal rights.) Each year, dozens of my medical and undergraduate students want to become bioethicists (some have done so). Their interest is both satisfying and alarming (can the world accommodate so many bioethicists?)

Last September, I attended the International Association of Bioethics meeting in London. What struck me was how Bioethics has spread across the globe and is being taught in colleges in places such as Saudi Arabia and Liberia. The meetings also taught me that new problems arise when one takes an international perspective, such as the costs of AIDS drugs and the protection of human rights.

In 1976, the quintessential bioethical issue was Death and Dying. (There were also some red herrings: psychosurgery, genetic engineering, and behavior control.) What no one could have predicted were the cultural shocks from Louise Brown's in vitro fertilization and birth in 1978, from the failure of *Roe v. Wade* in 1973 to end the abortion debate, from the introduction of artificial hearts and xenografts, from the creation of hordes of homeless people from deinstitutionalization in the 1980s, from surrogate mothers, from the discovery of genes for clinical disease, from thirty years of failure to provide medical coverage for the uninsured, and from the underground prejudice against gays and lesbians that surfaced and continues with AIDS.

Extrapolating from the last quarter century, I know that the big issues of the next twenty five years will be unpredictable. Past experience would dictate that the big issues will be justice in medical coverage, AIDS, genetic discrimination, and expansion of parental choice about traits of children through new techniques in assisted reproduction.

But if the history of Bioethics shows anything, it is that the biggest issues ambush the field. As Larry Altman, the physician-reporter of the *New York Times*, said in a retrospective in July, 2001 — twenty years after the first public report of AIDS — in 1981 every physician thought that all infectious agents had been discovered. Altman wrote that then no one in medicine seriously considered the hypothesis that an entirely new, lethal agent had emerged.

Just as new infectious agents will emerge in medicine, so will entirely unexpected ethical issues. It is the nature of

the beast. If you like to be challenged by unexpected issues (and to have reporters besieging you to take a stand almost instantly), bioethics is for you.

Of course, you can always play it safe and inveigh against each new change, citing the mantra of bioethicists, the slippery slope. You can imply that each new way of creating families endangers the traditional family. You can be cautious and side with the AMA on most moral issues, but who needs *philosopher*-ethicists for that?

It is more interesting to take some risks and to back changes you think are reasonable. In any case, and as I wrote in "Re-Creating Bioethics," medicine needs both "inside" and "outside" bioethicists — to understand its problems internally and to critique them externally.

Personally, I believe that philosophers who understand the facts about medicine and science will play an increasingly important role in public policy and in daily medical life, because no one else seems both willing and able to do so. If I am correct, then just as Philosophy spawned the separate, new field of Psychology a century ago, so one day we may look back and say the same about Bioethics.

## ***Reflections of an Idealistic Pragmatist: On Moving from a Philosophy Department to a Clinical Setting Twenty Years Ago***

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I have been asked to write my "spontaneous reflections" about the "early days" of bioethics from the standpoint of a philosopher who moved to a clinical setting during that time. Whether in fact I was there in those "early days" depends on what counts as early. When I left a regular philosophy department to join a medical school faculty, the year was 1982. I recall thinking that Albert Jonsen, a well-known figure in bioethics, had already spent 7 years in a clinical setting, and that until/unless I had acquired comparable experience, my contributions to the field would be less informed and less creditable than his.

Why did I leave a philosophy department for a medical school/hospital setting? Like many women (and some men), my reasons had a great deal to do with other-than-professional priorities. I had three young children and an hour's drive each way to work. Although my partner and I both liked our jobs, we could be attracted to positions requiring less travel time. When two universities offered us positions in which the commute would be considerably shorter, we chose the one we thought best for all of us. We welcomed the new professional challenges that we knew we would face.

Teaching elementary and junior high for ten years before I went to graduate school had convinced me that "doing" is a way of thinking as well as a way of behaving. The writings of John Dewey and Karl Marx had provided a philosophical foundation for this conviction: Dewey, through his insistence that philosophy be rooted in experience, and Marx through his critique of philosophy for having merely interpreted rather than changed the world. Moreover, like Plato's Socrates, I thought (and continue to think) that philosophy belongs in

the marketplace. A hospital setting was the marketplace that became available for me to “do” philosophy. (Some bioethicists, I soon learned, don’t take advantage of “marketplace” opportunities, preferring instead to “hang out” in offices in medical schools, ethics think-tanks, or philosophy departments where they talk to one another but have little or no contact with patients or actual cases).

Since my dissertation days, when I tracked the integration of philosophical idealism and pragmatism in American philosophy, I have considered myself “an idealistic pragmatist.” Accordingly, I particularly enjoyed teaching ethical theory and applied or practical ethics. Some issues in medical ethics were particularly appealing because they arose in my own life (e.g., an unplanned pregnancy, complications of pregnancy, premature birth, decisions about prenatal testing). The fact that my life partner is a researcher in the biological sciences abetted my interest in these issues. After agreeing to teach a graduate course in the nursing school, I decided to prepare by spending the summer at various clinical settings, so that I could learn a little of what relevant cases looked like from the perspective of those involved in them.

As I moved to a medical school/hospital setting, I felt it important to maintain my identity as a philosopher by going to philosophy meetings, reading and publishing in philosophy journals, etc. — because it was from that background that I might contribute something unique to the clinical setting. At the same time, I was committed to “being there” with clinicians and patients. So when the Dean proposed that my primary appointment be in a mainstream clinical department (the community health department, in his view, was not mainstream), I chose pediatrics, with a secondary appointment in reproductive biology. Although I later I had an appointment in medicine as well, I felt (and still think) that issues involving women and children specifically were underaddressed.

Having earned tenure in philosophy before moving and obtaining tenure in my new position freed me from worrying about job stability; it also facilitated my acceptance by clinician colleagues. My office was adjacent to the pediatric intensive care unit, where I rounded every morning at 7:30 a.m. On a regular basis, I attended departmental faculty meetings, grand rounds, interdisciplinary meetings, and case management conferences. While I learned a great deal about clinical problems and perspectives through these activities, I think I also educated others through my presence; I now refer to this type of “work” by clinical ethicists as a pedagogy of presence.

By the end of my first year in a clinical setting, I had given grand rounds, started two ethics committees, developed course work in the medical school, and was increasingly called upon to discuss specific cases (formal and informal “consults”). Because I had become a familiar face to my clinician colleagues, they no longer viewed me as an ivory tower philosopher who had little or no understanding of the complexity of real cases. What I had to say was not necessarily different from what philosophers in regular departments might have said, but I had gained credibility that made some people more receptive than they might have been. Throughout my tenure at this institution, I continued to round in the intensive care unit and participate in numerous other clinical activities. Still, gaining and maintaining credibility through such extensive participation was very time

consuming, leaving me little time for the academic reading and writing that I so enjoy. As the only philosopher “doing” medical ethics, I hoped for a philosopher colleague. Unfortunately, that was not to be.

Initially, the birth and death of Bloomington’s Baby Doe facilitated my work in the medical center. Baby Doe had Down syndrome and a surgically correctable but life-threatening obstruction in his esophagus. As a resident of Bloomington at the time, I knew most of the principals involved: the obstetrician (who was my obstetrician also), the pediatrician who challenged the surgeon’s decision not to operate on the infant, lawyers on both sides, the pathologist who examined the baby after he died, and the priest who baptized the infant. The publicity generated by the case had led to federal regulations requiring all government-supported nurseries and delivery suites to post signs describing failure to treat “handicapped” infants as illegal discrimination, and listing a “hot line” number to be called by anyone who observed such failure to treat. Experts appointed by the government would investigate reports of possible discrimination.

Not surprisingly, the neonatologists at my new institution wanted to avoid governmental intrusions if possible. Forming a hospital ethics committee was perceived as a means of addressing problematic ethical situations without governmental investigations prompted by hot line calls. I was identified as one who would facilitate the establishment of such a committee. Responding to this expectation, I found that an effective way of involving busy doctors in the ethics review process and in ethics education was to invite them to come and talk about their own experiences of cases involving ethical issues. In preparing for these presentations, some very high-powered clinicians read up on the topic and learned a great deal themselves. Over an 8-year period, no physician declined my invitation to “teach” members of the ethics committee or a class of medical students about a topic for which he or she had relevant expertise and experience. Only one person failed to show up after agreeing to come: a neurologist who was going to talk about definitions of death. In a phone call the night before the class, he apologized that he couldn’t make the class because he had to be in the state capital the next day for the governor’s announcement of his appointment to head the state’s Department of Health.

Once ensconced in the medical setting, I experienced a very different lifestyle and set of interactions than I was accustomed to in my previous position. Basically, I was expected to be at work every day, and there were no between-semester, Christmas, or summer breaks. It took a while to get used to the noise going on around my office, which was along a busy corridor, with patients, family members and clinicians, coming and going all the time. But the location itself was an education. One day, for example, I noticed a stretcher being pushed along the hall towards the operating room. There lay the pink faced figure of a robust-looking young man, about 17 or 18 years of age, his chest heaving with each breath that was apparently triggered by one of the many machines to which he was attached. A 5-year-old came out of the Play Room across from my office and looked up at the stretcher. “That’s my brother,” he said. “He’s dead, and they’re taking him to surgery.” That one so young could so clearly grasp what I had failed to recognize taught me what I could not have learned from articles or lectures. Through

encounters such as these as well as my own ongoing involvement in cases, I have developed an extensive repertoire of experiences that I recurrently draw upon in my teaching and writing.

Before moving to a clinical setting, I assumed there were significant differences between clinical decision making and ethical decision making. To my surprise, I soon discovered a number of similarities between the two domains. At rounds each day, the same generic question was asked about each patient: What should we do today to optimize this person's health? The assembled group of "rounders," residents and medical students led by the attending physician, sometimes with a consultant as well, would discuss alternative answers to the question, and conclude with a plan for the day as their collaboratively fashioned answer. Next day, if the patient seemed to have improved by following the plan, the group would usually think that their answer was the correct one; if the patient did not improve, they would think otherwise. Of course, either conclusion was fallible because patients can get better or worse regardless of whether their treatment is optimal.

In ethical decision making, we typically ask a similar question: What is the morally best thing to do in this case? If we collaborate in our discussion of the alternatives, and if, where pertinent, we seek others' expert input, we're likely to arrive at a better answer than if we don't collaborate. In ethical decision making, however, we may be less tempted to think that our answer or plan of action (or inaction) is the absolutely best or certainly true answer — because we don't have empirical criteria such as "the patient gets better or worse" by which to check.

The collaborative model prevalently employed in clinical decision making is supported by philosophers such as Charles Peirce and John Dewey. In their writings Peirce and Dewey also endorse the experience or case-based model of reasoning, or casuistry, that Al Jonsen and Steve Toulmin defend as a means of settling ethical quandaries in health care. Complementing the pragmatic model and enriching my own understanding of both casuistic and principle-based approaches to issues in clinical ethics are recent writings about "standpoint theory." Standpoint theorists argue that optimal collaboration requires attribution of "privileged status" to the input of those whose experience is relevant and whose views might otherwise be ignored or neglected, i.e., those members of the community who are not dominant figures or decision makers. In health care practice and policy making, patients obviously deserve this privileged status.

When Al Jonsen rounded in the neonatal intensive care unit in San Francisco many years ago, clinical ethics was hardly a dominant field, and I doubt that it is dominant yet, except perhaps in a few instances. Nonetheless, some individuals have become dominant, even while lacking the experience that Jonsen acquired or the collaboration he achieved in his interactions with Steve Toulmin and others who served on the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. Lest the fruits of collaborative inquiry and clinical experience be compromised, it seems crucial that those who join or continue to labor in the field follow this example.

## ***My Life in Bioethics***

**Tom Tomlinson**

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When I was asked to write about how I got started in bioethics, and reflect on the changes I've seen over my career, I agreed with too little hesitation. Later, I had second thoughts. Autobiography can be a risky business. Most anxiety-provoking, I risk revealing more than I intend. Most likely, I risk being boring. My life in bioethics may turn out to be interesting to no one but me. Still, a promise is a promise, particularists be damned.

I didn't start out to be a "bioethicist." In 1971, when I entered the graduate program in philosophy at MSU, no one aspired to be such a thing. I had just returned from a 3-year stint in the U.S. Army, which had interrupted my completion of the BA. My wife was also completing her BA, and taking a course in the philosophy of mind from Martin Benjamin, then newly-appointed at MSU. She urged me to sit in on class. When I did, I was hooked. Here at last I had found an academic discipline (and a mentor) which allowed, indeed encouraged me, always to ask "But why?" My high school biology teacher had dubbed me "Doubting Thomas." When the claims asserted in our textbook struck me as implausible, I'd refuse to accept them merely on the authority of the authors. I'd demand to see the evidence. I was a doubter and skeptic, sometimes all too eager to deflate the conventional wisdom. Before encountering academic philosophy, I had read and re-read all of Nietzsche's work. At least at the time, this was required reading for all intellectually disaffected youth. Temperamentally, philosophy and I were hand and glove.

And so when I started my MA, I had no particular objective in mind short of vague hopes that I might eventually be able to make a living in philosophy. It wouldn't matter if I didn't, I naively told myself. It would be just fine if I ended up driving a cab. The very idea of "doing philosophy" for six years delighted and excited me. Not just ethics, but virtually everything — formal logic, epistemology, metaphysics, philosophy of science, philosophy of mind, Kant, the British empiricists, Thomas Aquinas — was welcome exercise for my puny but developing philosophical muscles.

Whatever its other virtues, one of the unfortunate side-effects of the institutionalizing of "bioethics" as a career goal can be a premature narrowing of intellectual curiosity and ambition. When students enter a philosophy program with their hearts set on becoming ethicists, they may lack the open spirit that drinks everything in. Required course work outside ethics becomes nothing but a hurdle to be surmounted. Some philosophy graduate students are like the medical student who is so certain he's going to be a neurosurgeon that he denies himself the possibility of seeing that he might be more skillful, and happier, as a psychiatrist.

As I've suggested, my own entry into bioethics was serendipitous. After completion of my MA in 1975, I was gone from MSU for three years while my wife worked on the theater department faculty at SUNY-Plattsburgh (and had Tim Robbins as one of her acting students). As everyone knows, the decade of the 70's saw the birth and fledgling development of the "practical turn" in philosophical ethics. The Hastings Center was founded in 1969. *Philosophy and*

*Public Affairs* began in 1971. 1973's *Roe v. Wade* decision triggered what was to become a massive philosophical literature on the ethics of abortion. While I was away, I was becoming acquainted with bits and pieces of this movement, which was also being felt at MSU. When I returned in 1978, MSU had a regularly scheduled and wildly popular course on "Moral Problems in Medicine" (started by Martin Benjamin). And it had a "Medical Humanities Program" in the medical school, under the direction of the school's founding dean, Andrew Hunt. The Program had no faculty lines, relying instead on the largely volunteer efforts of Martin and Bruce Miller, supported by key medical school faculty like William Weil, who would later chair the American Academy of Pediatrics' Ethics Committee during the "Baby Doe" controversies.

The Program had a ½-time GA position, which helped support me while I worked on my dissertation. The dissertation was in moral epistemology, concerned with the role of principles in ethical reasoning, not with practical ethics. In 1980, when the dissertation was completed, it would have been unacceptable, despite the growing literature in practical ethics, to write a dissertation devoted to a practical ethical question.

That has changed of course — at least in most departments. This, too, is not an unmixed blessing. Dissertations devoted to an issue in bioethics present some challenges, and raise questions regarding where bioethics should hang its hat. The major challenge is to make such dissertations sufficiently philosophical. For me, work is "philosophical" to the extent that it squarely faces challenges to its own working assumptions. It pushes the demand for reasons as deeply as they can go. Most published work in bioethics, as informing and persuasive as much of it is, is not philosophical in this sense (and here I'm including much of my own work). From a socially pragmatic point of view, this is just fine. Our pragmatic objective is to "solve the problem" of social disagreement over a contentious issue, and if we don't need to get philosophical to be persuasive, all the better. But if one doesn't always need to do good philosophy to do good bioethics, why should the study of bioethics be confined to philosophy departments? I have reservations about free-standing bioethics-centered Ph.D. programs, mainly because I worry about their graduates' job prospects. They reflect, however, the recognition that bioethics as a practical pursuit cannot live comfortably within the confines of a single academic discipline.

None of these remarks imply that bioethical controversies are any less challenging or invigorating. They still are for me, after twenty-odd years. But they highlight a danger for those of us who come to bioethics by way of their love for philosophy, rather than the other way around. Total immersion in bioethics teaching and literature can slowly dull the philosophical senses and tools we once delighted in using. One may awaken one day to realize that a loss has been suffered. One needs to be vigilant, and take corrective action, as I hope I am doing this fall with a seminar that uses persistent vegetative state not as a focal point, but as a springboard for explorations in the philosophy of mind and the nature of personhood.

When I first sat down to write, I didn't imagine I'd have this much to say. I haven't even gotten to my faculty appointment. But if I go on, the risk of boredom will escalate dramatically.

## ***A Philosopher in the Land of Bioethics***

**David C. Thomasma**

*Loyola University Chicago Medical Center*

This is a story of valor and dedication. It is a story of hunches and ingenuity too. It is a story of accomplishment and reward. But it is also a story of powerlessness. The story starts with a fact. All great philosophers were intimately involved in the major issues and debates of their day.

Although I have regularly denied it, I am one of those bioethicists or philosophers of medicine regarded as a pioneer in the field. To apply such an appellation to oneself is the height of folly, since we all develop our ideas in dialogue with past and present thinkers and colleagues. Few are truly pioneers. However, the image of pioneers carving out a legitimacy in a new land is apt. I did start out in the discipline of modern bioethics in the early 70's and have remained in the field more than 30 years. Longevity more than any other reason gives rise to these reflections. The late K. Danner Clouser, the first philosopher to obtain an appointment in a medical school, used to speak of his "codgerations." There are many fine philosophers of my generation who also turned to bioethics. Most of us could congratulate ourselves on our experiences and the development of the discipline. So I accept with humility the offer to share some perceptions of this vigorous and challenging field. I will organize my remarks around the themes of courage, ingenuity, accomplishments, and powerlessness.

### **Courage**

After agreeing to leave regular academic life and move into the strange new territory of bioethics, I was astonished to discover that other philosophers did not view it as a land of opportunity as well. In fact, a number of them who tested the waters withdrew rather rapidly. For some the challenges lay outside their real interests. Others were skittish about relating closely to physicians. The majority of those who held back were concerned about the regard of other members of their departments of philosophy.

In our time, the action in philosophy was not in ethics. Instead, it lay in philosophy ethics of science, linguistics, logic, epistemology, and critiques of existentialism and phenomenology. Ethics was considered far softer than those fields. Further, bioethics, or medical ethics, was seen as applied philosophy, the lowest possible kind of philosophy in the hierarchy of the department. Individuals were justifiably concerned that their careers in the field and in the department might suffer a serious blow by their involvement in medical ethics.

Those of us who did move into medical and other professional schools were courageous or foolhardy. Good, creative philosophy needed to chew on a new bone. The old debates were inward turning and involved philosophers arguing about philosophy. Ortega involved the analogy of a trip through a pleasant insane asylum! The idea of responding to new challenges excited people with different backgrounds and training. We discerned that the problems posed by modern medicine provoked genuine philosophical analysis. We also saw that our effort might one day evolve into a discipline in its own right. Although a few colleagues thought of medical ethics as an applied philosophy, more of us saw it as a philosophy of medicine, grounded in the practices and

conflicts of modern medicine. An early essay by Stephen Toulmin on how medicine saved the life of ethics put it exactly.

### **Ingenuity**

It seems now that there are three branches of bioethics: clinical, medical, and public policy. Individual philosophers contributed greatly to all three of these. A common thread through all three was articulated midway in the last century by Bertrand Russell, who noted that if a scientific civilization were to be a good civilization, it had to aim at good human ends, something which science itself could not provide. The problem is that there is no Archimedean point outside of a scientific civilization from which to draw those good human ends. Even the humanities, that traditionally provided the fodder for such reflection, have been completely subsumed into our scientific culture. This calls for a new kind of philosophizing in which individuals participate directly in the problems. I call this “participatory ethics.”

The ingenuity in bioethics comes from being a philosophy on the go. It was created as philosophers made efforts to resolve problems, and then refined when there was time to reflect on the legitimacy of its claims and assumptions. That process continues now with second about the role of autonomy, the American cultural propensity for consensus ethics, assumptions about the value of human life, and so on. These healthy developments signify the maturation of the field. However, they also telegraph the beginnings of philosophy turned in on itself that we originally sought to avoid. In this regard, a recent essay by Albert Jonsen, one of the authentic pioneers in the field, asks why medical ethics has become so boring.

In all three arenas of bioethics, clinical, medical, and public policy, innovations arose. Rather than trying to teach the whole history of ethics, or philosophy, we developed heuristic devices that helped students, physicians, and ethics committee members “work up” an ethical problem. We saw that individual’s own virtues and training came into play. We drew again on ancient sources of ethics, particularly, the Aristotelian view of *phronesis*, and virtue theory of the Middle Ages, to amplify principle-based ethics, even while turning to very modern ideas of narrative ethics and feminist ethics. The creativity itself stemmed from a genuine appreciation of the full complexity of the moral issues faced by doctors, patients, and society in our time. The struggle is to do exactly what Russell asks, to articulate the direction of our technology even as it is being developed through self-suggestion rather than external norm.

### **Achievement**

Most philosophers who entered the field, have had the satisfaction of directly contributing to the resolution of complex clinical, medical (in terms of research and delivery), and public policy dilemmas. Think of the many Federal and Congressional committees that formulated guidelines for research on human subjects, animals, and on embryos, of the thousands of ethics committees, of the patient rights movement, of the growth and development of clinical ethics consultations, and of the challenges posed by biotechnology.

When I first began there were only a handful of books and really only one journal, *The Hastings Center Report*. Since then, medical ethics journals and books have proliferated throughout the world. In my case, I am editor-in-chief of

*Theoretical Medicine & Bioethics* (for 15 years), founding co-editor of *Cambridge Quarterly of Healthcare Ethics* (10 years), founding co-editor of an *International book series called International Library of Ethics, Law, and the New Medicine* that has produced five volumes in one year of existence, and I have published over 300 articles and 25 books. Many of my colleagues can point to even more impressive accomplishments than these.

How exciting it has been to feel part of an important movement, to contribute to it and to the development of others’ ideas, to grapple with serious mind-bending problems, and to try to articulate the philosophy of medicine and society required for grappling with the explosive issues of the future. That is why I began this brief essay with the fact that every great philosopher has been intimately involved in the major issues of his or her day. It has been a privilege to have played even a small part.

### **Powerlessness**

In the end analysis, though, despite all of the achievements, I have a gnawing sense of powerlessness over the direction our culture and society are taking, embarrassment among international peers at the poor health care planning and provision in our advanced nation compared to almost 30 other countries who are ahead of us, and a conviction that the levers of real power lie far outside of the medical centers and even governmental bodies where we have plied our trade for so many years.

Participatory ethics teaches that more and more of us will have to enter the corporate boardrooms of major international corporations and contribute to the articulation of economic and social developments worldwide. Bioethics in the future certainly does not have to become boring!

## ***Late Expectations: Clinical Ethics and Beyond***

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### **Introduction**

I am currently a self-employed Healthcare Ethics Consultant, with two principal contractual organizational clients. Both are hospitals. One is in Chicago, the other in California. While in Chicago, I am Principal Investigator at one of five sites for a National Institutes of Health-funded three-year empirical study of the impact of ethics consultations on patients, families, and staff in Intensive Care Units. During those two weeks each month I also provide educational programs, case consultations (averaging 12 per month), and assistance with a variety of clinical-organizational ethics process improvement projects.

I found my way into the practice of Clinical Healthcare Ethics before it was a field. Like many others in the field during its first three decades, my pathway has been idiosyncratic. In what follows, I’ll provide a narrative of that pathway, and then will conclude by describing how my experience has changed three of my initial expectations.

## Narrative

In 1976 I left my tenured Assistant Professor position (Religious Studies) at Santa Clara University, Santa Clara, California, to accept a position as Director of a one-year pilot program, Human Support Services, at a community hospital. My wife and I were parents of three very young children at the time. This decision to leave the House of Intellect for the House of Bodily Fluids prompted one basic question from most of our family and friends: Why, Dan? There were two interrelated factors.

First, seven years before, while in graduate school, my fiance died in an automobile accident. I managed to insulate my grief process, and kept myself on course with my studies, then secured the teaching position I had hoped to find and began my academic career. As the years passed, my repressed grief process began to surface. As I returned, with psychological assistance, to work through my grief, I began to question the professional course on which I had embarked.

Second, I had been teaching an undergraduate course, "Death and Religion," for two years. The students were reading books on the subject: by Jacques Choron, Robert Lifton, Elisabeth Kubler-Ross, and John S. Dunne. Classroom discussions were animated. Animated, but somewhat abstract, I began to feel. So I began working as a volunteer in two local hospitals, pushing book carts and providing emotional support to families in the ICU. I began learning from patients and their families about their experiences of confronting death and dying.

The contrast between my class discussions, filled with others' philosophical reflections on mortality, and the impact of encountering my own and others' actual experiences of confronting mortality, led me to feel a growing interest in finding a work setting in which to apply what I had learned in a more immediate, therapeutic way. In Epictetus' words,

Vain is the word of a philosopher which does not heal any suffering of man. For just as there is no profit in medicine if it does not expel the diseases of the body, so there is no profit in philosophy, either, if it does not expel the suffering of the mind.

So when a friend sent me a newspaper article describing a local hospital's pilot program in "emotional support," I saw an opportunity to integrate my academic studies with my personal learning. I applied for the position of Director.

My role as Director of Human Support Services was to develop emotional stress management systems for hospitalized patients, their families, and professional staff through direct patient care service and staff education.

The proliferation and development of life-sustaining technologies in the ICU setting, and the decisions about their use, became a major source of emotional stress for patients, families, and staff. I had begun to feel the need for further training in assisting with these difficult decisions, beyond providing basic human and emotional support to those involved. My academic background—a B.A. in Philosophy, M.A. in Theology, and Ph.D. in Religion (with half of my coursework in Philosophy), had provided me with a wealth of conceptual tools, but with little help in applying them.

A Cardiac Care nurse, observing my work with patients, families, and staff, and aware of my academic background, invited me to collaborate with her in forming a "Bioethics

Discussion Forum" in the hospital. She was enrolled in a Bioethics course as part of her Masters' Program in Nursing at a nearby university. In her course she had studied the New Jersey case of Karen Ann Quinlan, and had become interested in the Quinlan Superior Court Judge's recommendation that hospitals in his state establish "ethics committees."

We posted notices throughout the hospital, inviting physicians, nurses, and other staff to the first "brown bag" ethics discussion forum, in December 1979. Fifteen persons attended the first meeting: physicians, nurses, dieticians, and respiratory therapists. I acted as coordinator for this discussion and for those that followed each month. Attendance grew as participants told colleagues of a unique forum in which professionals from many disciplines shared their ethical concerns and gained support and perspectives from one another.

After six months, several members expressed an interest in forming an ethics committee. The discussions were extremely enjoyable, they said. But there should be a way to make them useful to the wider organization. Consensus quickly emerged to become a committee. But what kind: medical staff or hospital? Because members felt strongly that the forum should be confidential, so that participants could speak freely and in trust, the decision was to apply for status as a medical staff committee. One physician objected strongly that such a move would be the death knell of the group, as it would become enmeshed in medical staff bureaucracy and politics. He resigned in protest.

The newly formed committee then turned its attention to its mission, composition, and functions. A pulmonologist became Chair. I became Executive Officer. A Bioethics Professor from a local seminary agreed to participate. All agreed that the committee should first provide education in ethics for its members, and begin to provide educational programs to the hospital community at large. We began to circulate and discuss articles from professional medical and nursing journals. We began, at the Chair's suggestion, to review actual cases retrospectively, seeking to apply ethical concepts. We decided to do retrospective case reviews for six months, and then offer a consultation service in the hospital. Hospital Administration asked the committee to develop an institutional policy to address a recurring problem: refusals of blood transfusions by Jehovah's Witnesses.

The committee first articulated its mission in early 1980: to provide a confidential forum for patients, families, and staff, to address ethical issues arising in the hospital, through education, policy development, and case review.

In June, 1980 the Committee Chair, the Cardiac Care nurse, and I attended the first conference on ethics committees, held in Los Angeles. We were interested to learn what other committees in other hospitals were doing. We learned at the conference that our committee was more organized and more functional than any other ethics committee at a community hospital in California.

The Ethics Committee quickly became one of the most active committees in the hospital. As XO, I chaired the Education and Consultation committees, organized the annual "Ethics Expert" days and committee all-day retreats, and acted as the point person for most of the case consultations. When University of California, San Francisco, offered an intensive Bioethics Training and Certification course in 1985, I participated.

I began to attend the annual meetings of the Society for Health and Human Values and the Society for Bioethics Consultation. The Ethics Committee began collaborating with the Quality Assurance Committee, to address recurring ethical concerns arising in our consultation work. I began making “proactive ethics rounds” on all units in the hospital, in order to prevent and respond in a timely fashion to ethical problems in patient care.

In 1988, following a recommendation by the Medical Staff Executive Committee and the Medical Ethics Committee, I began to prepare to assume my role as full-time Hospital Ethicist. Five years later, I accepted a position as Director of Healthcare Ethics Consulting Services at the Park Ridge Center for the Study of Health, Faith and Ethics in Chicago.

## **Expectations and Experience**

### **1. Medical Staff and Administrative Support.**

Because I entered the role of hospital ethicist in a hospital setting in which I had established credibility with the medical staff and hospital administration, and as a result of their recommendation, I expected their continuing support. Medical staff support in fact did continue. Administrative support, though, became increasingly conditional, as managed care pressured administrators to justify expenditures in relationship to demonstrated revenue or cost savings.

I have learned that credibility with the medical staff must be earned anew in every new setting. Formally or informally, physicians view ethics consultants as “on probation” for about five years. Ethicists interact with physicians, their patients and families, in times of great delicacy and sensitivity, with legal and economic as well as emotional consequences at stake. Only consistently competent, challenging, and clinically astute interactions over time earn that credibility.

I have learned that administrative support, except in religiously based hospitals whose missions explicitly include organizational-clinical ethics, or in university-based centers in which faculty staff the service (often with grant assistance), is increasingly difficult to obtain and maintain. Outcome studies showing the effectiveness and cost-savings of ethics consultation and education are only now being undertaken. Administrative support in managed care environments from now on will, I believe, require such data as a condition of support.

### **2. Models of Case Consultation**

I expected in the beginning that case consultation would continue to be a committee function, and that the small-team model would prove most effective. I now believe that managed care, with its financial stresses on healthcare professionals and its financial pressures on hospital administrators, has made case consultation most appropriately the role and function of individual consultants. For whole committees or consultation teams consisting of committee members to provide the service, physicians in private practice and healthcare professionals with full-time jobs in the hospital or organization must be able to find “extra” or “volunteer” time. That is becoming increasingly difficult, even impossible. The model that now seems most workable to me for case consultation is that of an individual consultant, reporting regularly and in detail to the ethics committee.

### **3. Organizational Ethics**

In the beginning I expected that I would be able to concentrate solely on clinical ethics. There was more than enough work to do at the bedside. Let clinical ethics not be sullied by “professional ethics” complaints, administration interests in reduced length of stay, or rising federal and consumer concerns about business practices in health care organizations.

In the beginning I resisted what I regarded as the “sully” of clinical ethics through collaboration with “Quality Control,” whose agenda at the time I discerned to be institutional financial well being.

I have learned, with the rest of the world, that clinical ethics naturally leads to organizational ethics, most often through Quality Management. Every case is simultaneously an individual problem and an organizational opportunity for systemic professional practice and patient care improvement. Integrating clinical ethics with organizational mission, and with other ethics-related initiatives in the organization (e.g., Business Integrity, Managers’ Values-Centered Training, Institutional Review Board) is very important work in progress. Ethicists’ and ethics committees’ contributions to defining and strengthening organizational ethical culture, in the long run, is the best chance patients have for better care at the bedside.

### **Conclusion: Back to the Future**

In the light of my journey into healthcare ethics during the past three decades, I’d probably make different strategic career choices if I were looking forward to working as a bioethicist instead of reflecting on the path I’ve taken. I would still study the history of philosophy and ethics, and would probably still major in Philosophy in undergraduate studies. I would spend some time as a volunteer at local hospitals and nursing homes, helping out and getting to know the concerns of patients, families, and staff. I’d also take elective courses in medical terminology, statistics, management, counseling, and organizational development. I’d set my sights on a graduate program in Bioethics, and lurk on as many bioethics listservs as I could find.

Given my discoveries that unanticipated life events have a way of overturning career plans, however, if I set my sights on a career as an ethicist, I’d probably wind up as a travel agent.

## Experience and Reflections

**Mark Sheldon**

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As an undergraduate, I was attracted to courses in both literature and philosophy. The big questions attracted me to philosophy: Does God exist? With what purpose should we live? What should we value? Why do we suffer? Yet, I always found it difficult to make sense of these questions without attending to the concrete lives that human beings actually live.

The day I graduated from college, I was drafted into the U.S. Army and discharged two years later as a conscientious objector. Next, I decided to apply for graduate school in philosophy, rather than literature. I did not have any idea what I was going to do with a philosophy degree. I just very much enjoyed being in an atmosphere where one could think freely about fundamental issues. I could not believe my good fortune at having such an opportunity. Of course, given all that was happening during this period, from 1967 (when I graduated from college and was drafted) to 1975 (when I graduated with my PhD), my sense of good fortune was mixed with a feeling of obligation and a desire to be of some use or service. I even contemplated going to rabbinical school but realized that I did not have the faith to sustain such a choice.

My first teaching position was on a campus that included part of the medical school. At the reception for new faculty, the medical school dean approached me. He had heard that the philosophy department had hired a new person with an interest in ethics. This was 1975, and he had concerns about the values that medical students were learning. He felt they were losing sight of the fact that patients are human beings, not diseases. He offered me an appointment in the medical school as an adjunct assistant professor of medicine.

While this offer was somewhat confusing from a professional point of view (how would this work in relation to tenure, etc.), it was intriguing from a personal perspective. First, members of my family were service focused — physicians, lawyers, social workers. While they tried to be supportive, they clearly questioned the value of my work as an academic. The appointment in medicine gave me some credibility on this front. Second, I was, after all, a child of the 60s. The idea that I would be an instrument in restoring some fundamental humanity to the hierarchical institution of medicine appealed to me from a political point of view. Third, the philosophical issues that I would consider — for instance, personhood, the meaning of death, and justice, were rich.

I was anxious about teaching in the medical school. I did not have “MD” after my name. What credibility would I have? Why would the students pay attention? I realized immediately that a purely abstract approach would fail. Discussions had to be based on cases. After pointing this out to the dean, he arranged for me to spend time with the residents at the hospital. They, too, he said, needed some work in ethics.

Then, I really wondered what I was doing. It seemed to me that the credibility issue, in going from medical students to residents, had been compounded. During my first several weeks at the hospital, where everyone wore one kind of uniform or another, I felt like Donald Duck, a guy without

pants. I felt very vulnerable, exposed, uncertain of my authority. I was very unclear about my role or purpose.

Fortunately, there were residents and attending physicians who had been philosophy or humanities majors as undergraduates, who understood the value of philosophical reflection, who actually thirsted for whatever light philosophical thought could bring to their activities. We engaged in long discussions, talked at length about cases that they encountered. Several suggested that I round with them. I did not understand what this meant, but I soon learned that it involved contact with patients. In a very short period, I had gone from contact with medical students, to contact with residents and attending physicians, to contact with patients. I remember how odd I felt the first time I was in the presence of a partially undressed patient.

Still, I regarded myself as essentially an academic. I was engaged in teaching, not doing. Then, one day, during rounds in the oncology unit, the attending physician, in the presence of several medical students and residents, told an elderly man that his diagnosis involved a tumor on the lung. He used language that was abstract and non-specific. Out in the hallway, only as a teaching point, I raised the question of whether the man really understood what had been said. The attending, truly an excellent physician, who had no ego whatsoever, said, “Let’s go back and see.” I found myself saying, “No, no. I was just raising a question for discussion.” He said, “And it’s a good question.” We all went back into the room. The attending sat down on the patient’s bed and slowly, carefully, explained the meaning of the tests that the gentleman had undergone. It was clear from the way the patient’s body suddenly slumped that he had not heard the diagnosis the first time. I felt terrible, and responsible.

It took me a long while to get used to the fact that my questions had concrete repercussions. Certainly, as a teacher in introductory philosophy courses, I have had undergraduates who were disturbed by questions about God’s existence. But the experience of the philosopher/ethicist is different. Physicians, patients, nurses, and families make decisions that involve immediate consequences. Yes, patients have always suffered terribly, and human beings regularly become aware of their impending deaths. But bioethicists increasingly contribute to these events. We do not control the conversations, but often we make them possible. This is a significant contribution in a world dominated by technology and rank.

In the twenty-seven years that I have been doing this work, I have certainly learned what I am not. I am not a physician, psychiatrist, nurse, social worker or chaplain. Instead, I am a student of philosophy, mindful of the importance of clearly identifying the question, of recognizing which argument or evidence provides support for which claim, and of being fully aware of the limitations of my learning. I resist any effort to establish a new hierarchy with the ethicist as expert. I find myself, instead, in dialogue with people from other disciplines, asking the questions that are so obvious that only a philosopher would think to ask them, or that only a philosopher can sometimes get away with asking.

## BOOK REVIEWS

### ***Is There a Duty to Die? and Other Essays in Bioethics*, by John Hardwig with Nat Hentoff, Dan Callahan, Larry Churchill, Felicia Cohen, and Joanne Lynn,**

Routledge 2000, 212 pp. (Paper 0-415-92242-9)

### ***Is There a Duty to Die?*, edited by James M. Humber and Robert F. Almeder,**

Humana Press, 221 pp. (Cloth 0-89603-783-5)

**Reviewed by Felicia Ackerman**  
*Brown University*

“Have mercy upon me, and suffer me not to die for thy love.”

Sir Thomas Malory — *Le Morte D’Arthur*

If you are old or terminally ill and if you keep up with trends in bioethics, you are probably feeling increasingly unwelcome in the world nowadays. Many bioethicists think you should not get life-prolonging medical treatment, particularly if it is expensive and high-tech. John Hardwig goes further. He thinks you can have a duty to kill yourself. He says, “There can be a duty to die before one’s illness would cause death, even if treated only with palliative measures. In fact, there may be a fairly common responsibility to end one’s life in the absence of any terminal illness at all” (Hardwig, 121). When does he think “many of us will one day have [the] duty [to die]” (Hardwig, 82)? When we are a burden to our families.

The claim that there is a duty to die in order to avoid burdening one’s family is the central thesis of the title essay in Hardwig’s book, *Is There a Duty to Die? and Other Essays in Bioethics* (which I will call ‘H’ when identifying quoted passages). Hardwig’s other essays develop his view that bioethics should be “family-centered” rather than “patient-centered,” applying this view to a range of related issues, including assisted suicide, proxy decisions, patient advocacy, and elder abuse. The book ends with commentaries (on the title essay) by Hardwig’s five co-authors, Hardwig’s reply, “Family Responses” from his wife and children, and a list of “Responsibilities of Those Facing the End of Life.” Additional commentary appears in the Humber and Almeder volume (which I will call ‘H&A’), most of whose essays deal (in varying degrees) with Hardwig’s title essay. Several expand the argument by taking the issue beyond the family and discussing whether one could have a duty to die in order to avoid using a disproportionate share of national or global resources. This review essay will focus on Hardwig’s “family-centered” views and their critics and will concern itself almost entirely with his “duty to die” thesis.

### **What is Hardwig’s “Duty to Die” Thesis?**

Hardwig vacillates between strong and weak versions of this thesis. A strong version is suggested by his praise of the list of “Responsibilities of Those Facing the End of Life” that was formulated by a group of retirees (most of whom were in their seventies) in a discussion he led at a “seniors’ organization” (H, 196). The list’s eighteen strictures include (2) “Die in a way that will leave your family in the best position” and (5) “Don’t live so long that your loved ones will wish you were dead” (H, 198). A literal reading of these two strictures places so little value on the lives of the elderly that it is hard to take seriously. Stricture (2), taken literally, implies that any improvement, however small, in the family’s position, calls for any sacrifice, however great, from “those facing the end of life.” But as Rosemarie Tong asks, “Do care-receivers really owe a duty to die to caregivers who weight their own interests far more heavily than the interests of those for whom they supposedly care?” (H&A, 140). Elsewhere I have introduced what I call “the paradox of the selfless invalid”: if your family members would welcome the sacrifice of your life for their sake, how can they be worth it? And if they wouldn’t, why sacrifice it? This problem, which I will return to later, becomes especially pressing when we consider luxuries for the family vs. life for the patient. What if your forgoing a heart transplant will put your family in the “best position” of being able to buy a long-desired yacht?

Stricture (5), as I have argued elsewhere, treats life as a dinner party where the loved ones are hosts and the elderly are guests who should not be so rude as to overstay their welcome. The lack of qualification entails that the elderly should honor *every* reason their loved ones may have for wishing them dead. What if your loved ones wish you were dead so they could inherit your money and buy a Jaguar? And is it only the elderly who should die before their loved ones wish them dead? What about a healthy but tiresome 30-year-old whose family is starting to get fed up with his incorrigible foolishness and clumsiness? Marilyn Bennett points out that “A 70-year-old person may be just getting free of a lifetime of burdens and sacrifices for others when he learns that his remaining time will be limited and costly” (H&A, 51). I would add that the “others” are apt to be members of his family, and I think it is now high time for them to start making reciprocal sacrifices for him. The relevance of family reciprocation is also acknowledged by Felicia Cohn and Joanne Lynn (H, 153, note 6), Hardwig’s son Bill (H, 191), and Paul T. Menzel (H&A, 112 note 6). Hardwig himself touches on this issue, as I will discuss later.

A possible reply by Hardwig here is that the list should not be taken literally, and that, in any case, it was formulated not by him, but (as I have mentioned) by a group of retirees in a discussion he led. But although Hardwig admits the list is “not uncontroversial” (H, 197) and says he offers it “as an excellent starting point for moral discussion of our responsibilities at the end of life” (H, 197), he also praises it as “a remarkable list” (H, 197) and offers no criticism of any of its strictures. And if the list should not be taken literally, how should it be taken? When a philosopher leads a discussion aimed at formulating principles of practical ethics, isn’t part of his role to help make the principles clear enough to be a useful guide to action? Moreover, some of Hardwig’s remarks elsewhere in the book support a strong version of the “duty to die” thesis. For example, one way he seeks to

motivate his claim that people can have a duty to die is by saying, “[W]hen I ask my classes for examples of times when death would come too late, one of the first conditions students always mention is: ‘when I become a burden to my family’” (H, 82). He thinks this reflects “moral wisdom” (H, 82). But if this moral wisdom is supposed to support a duty to die, as he implies it does, it means that *any* burden, no matter how small, confers such a duty. Similarly, Hardwig’s statement, “I cannot imagine it would be morally permissible for me to...compromise the quality of [my grandchildren’s] lives simply because I wish to live a little longer” (H, 127) raises the question of what deprivation could *not* be said to compromise the quality of one’s grandchildren’s lives. Going without private schooling? Going without summer camp? Going without tennis lessons?

Elsewhere, however, Hardwig makes such claims as “Our families and loved ones...must be prepared to make significant sacrifices to respond to an illness in the family” (H, 124). In fact, much of his book supports a weaker version of the “duty to die” thesis: since there are limits to “how far family and friends can be asked to support and sustain the patient” (H, 32), the patient has a duty to die when “continuing to live takes too much of a toll on the lives of those connected to [him]” (H, 86).

The existence of limits seems obvious. Just as it is outrageous to suppose one has a duty to die in order to free up funds for one’s family to buy a yacht, it is preposterous to expect a family to sell literally everything it owns, in order to give a dying person a minute of extra life. The existence of such limits sets a restriction on the “paradox of the selfless invalid” mentioned above. But just what are these limits? I will argue that Hardwig asks far too much of the old and ill and asks far too little of their families. But first some clarification of the notion of a “duty to die” is in order.

What is a duty to die a duty to do? As Jan Narveson points out, “Duties...apply directly only to actions. The expression ‘a duty to die’ is *prima facie* a neologism. Therefore, to make the issue clear, we must say that what is meant is a duty that we would have to discharge by doing what results in our deaths” (H&A, 27). He lists committing suicide and “refraining from taking actions that would prevent death” (H&A, 27-28) as things that would fulfill such a duty. Hardwig, in fact, uses the phrase ‘duty to die’ to cover both a duty to forgo life-prolonging medical treatment and a duty to commit suicide. This leads him to exaggerate the originality and daringness of his “duty to die” thesis. His claim—that the conventional wisdom is that “[i]t goes without saying that there is no duty to die” (H, 119)—is close to the truth if ‘duty to die’ applies only to a duty to commit suicide. But if ‘duty to die’ also applies to a duty to forgo life-prolonging medical treatment, this claim is obviously false. The view that there can be a duty to forgo such treatment is popular nowadays to the point of cliché. It occurs with varying degrees of explicitness in numerous newspaper and magazine pieces, as well as in highly praised, widely read, and widely influential books by Daniel Callahan and by Sherwin B. Nuland, the latter a New York Times bestseller and National Book Award winner. The *denial* of this latter view is what goes against conventional wisdom. (When did you last hear anyone, bioethicist or otherwise, say that sick old people should feel free to try to extend their lives as long as possible and by the most aggressive medical treatment possible, regardless of financial and other costs?) Hardwig is conventional, not original, when he says that “we

must now face the fact: deaths that come too late are only the other side of our miraculous life-prolonging modern medicine” (H, 97). What is amazing is his claim (in an article first published in 1996!) that “[w]e have so far avoided looking at this dark side of our medical triumphs” (H, 97).

Unsurprisingly, Callahan, who is hostile to aggressive life-prolonging medical treatment for the old and ill but to whom suicide is anathema, expresses indignation over Hardwig’s view that you can have a duty to kill yourself in order to benefit your family. Callahan says that “the family should be that place where a cost-benefit calculus must be left outside the door, where we bear each other’s burdens come what may” (H, 143). But this lofty sentiment should be assessed in light of things he says elsewhere, for example: “It is not improper for people to worry about being a burden on their families...A family member should reject [a technologically extended death] for the sake of the family’s welfare after he or she is gone.” This latter quotation is also useful in evaluating Callahan’s claim that “[f]amilies in which their members were ready to kill themselves for some greater familial good, and to allow each other to acquiesce in death for that reason, would in principle be treating each other as dispensable and disposable once they got too much in the way” (H, 143). Why isn’t this equally true of families whose members are willing to forgo life-prolonging medical treatment “for some greater familial good” and to allow each other to acquiesce in death for that reason? Hardwig’s remark that “Callahan’s rhetoric [in his commentary in Hardwig’s book] sometimes carries him perilously close to implying that sick and dying people have no responsibilities to others” (H, 168) makes no acknowledgement of what Callahan says elsewhere. Hardwig even asks, “Would [Callahan] admit that one can have a responsibility to decline life-prolonging treatment?” (H, 172). But Callahan has affirmatively answered this question in a book Hardwig cites (H, 184, note 7)!

Moreover, Callahan’s remark that Hardwig’s family cost/benefit views are “all the worse for being dressed up in the sentimental language of decency and self-sacrifice” (H, 144) should be seen in light of the sentimental language in which Callahan himself dresses up his call for the old and ill to forgo life-prolonging medical treatment, for example, “It is hard to see how a death that impoverishes a family, or destroys the later years of an elderly spouse, or wrecks the family life of a dutiful child caring for an elderly parent, can be called entirely peaceful in its broader ramifications.” As Hardwig points out, there are illnesses that can take “a horrible toll on [one’s] loved ones” (H, 174) even when no life-prolonging medical treatment is involved. Callahan’s real objection is evidently to suicide, rather than to a family “cost-benefit calculus” or to cloaking such calculations in sentimental language. And although Hardwig says, “I generally use the word ‘duty’ because it strikes me as a hard word for what can be a hard reality...I think we should not attempt to soften what we are doing” (H, 98, note 1), his writing, like Callahan’s, is in fact full of sentimental verbiage, for example, “[R]ecovering meaning in death requires an affirmation of connections. If I end my life to spare the futures of my loved ones, I testify in my death that I am connected to them” and “[L]ife without connection is meaningless” (both H, 134). This supports my suspicion that the amount of sharing-and-caring language a bioethicist uses is inversely proportional to his willingness to have sick old people stay alive.

I have only a practical reason for objecting more to Hardwig's views about the duty to commit suicide than to Callahan's views about the duty to reject life-prolonging medical treatment: the former duty casts a wider net. But I lack space here to defend the moral equivalence of these claims to duty. This review essay will not distinguish further between these two purported duties, but will follow Hardwig's practice of using 'duty to die' for both. As Menzel points out, "the alleged moral relevance of the line between active lethal means and refusal of life-sustaining measures...is a separate issue, the argument over which need not enter the debate over a duty to die" (H&A, 99). Although he uses 'duty to die' for both sorts of cases, Menzel also says that "a 'duty to let death come relatively cheaply'" is "only crudely stated as a 'duty to die'" (H&A, 98). I am passing over this terminological issue.

The issue of what a duty to die is a duty to do is not the only issue needing clarification here. Another involves Hardwig's notion of duty. Hardwig says he "intend[s] no implication that...someone has a right corresponding to [one's duty to die]" (H, 135, note 1). He backs this up with references to philosophical literature on rights and duties (H, 183, note 1) but also says, in response to commentators in his book, "I do not think we should get sidetracked into a discussion of the word ['duty']. If 'duty' is a problem, we can just as well begin, at least, by considering a responsible death" (H, 165). This review essay will retain the phrase 'duty to die', as it is Hardwig's predominant usage, frequently occurring even after the remark I have just quoted. He says,

For me, the duty to die is, first of all, quite possibly my own duty, not someone else's. It is my own responsibilities that I most need to think about. But I invite you to think about yourself and your loved ones, too. For I believe a duty to die must, in the end, always be personal—self-recognized, self-imposed, and self-enforced. (H, 181)

This gentle tone contrasts harshly with things Hardwig says elsewhere in his book, for example, "In many cases, it is irresponsible and wrong for competent patients to make...exclusively self-regarding treatment decisions... Sometimes, no doubt, *we should seek to find ways to prevent patients from abusing their autonomy at too great a cost to their families*" (H, 55-56, italics added) and "[T]he interests of family members...are relevant *whether or not* the patient is inclined to consider them" (H, 38, italics in original). He does grant that "*perhaps* we should allow *some* patients to make *some* self-regarding decisions, especially if they insist on doing so *and the negative impact of their decisions on others is not too great*" (H, 40, italics added), but this grudging and limited admission is a far cry from his above-quoted remarks about a duty that is "personal—self-recognized, self-imposed, and self-enforced" (H, 181).

### When is There a (Purported) Duty to Die?

Taking all this into account, I now turn to Hardwig's discussion of the circumstances he believes can give rise to a duty to die. He says,

The lives of our loved ones can be seriously compromised by caring for us. The burdens of providing care or even just supervision 24 hours a day, 7 days a week are often overwhelming. When this kind of caregiving goes on for years, it leaves

the caregiver exhausted, with no time for herself or life of her own. Ultimately, even her health is often destroyed. But it can also be emotionally devastating simply to live with a spouse who is increasingly distant, uncommunicative, unresponsive, foreign, and unreachable. Other family members' needs often go unmet as the caring capacity of the family is exceeded. Social life and friendships evaporate, as there is no opportunity to go out to see friends and the home is no longer a place suitable for having friends in.

We must also acknowledge that the lives of our loved ones can be devastated just by having to pay for health care for us. One part of [a] recent...study documented the financial aspects of caring for a dying member of a family. Only those who had illnesses severe enough to give them less than a 50 percent chance to live 6 more months were included in this study. When these patients survived their initial hospitalization and were discharged about one-third required considerable caregiving from their families; in 20 percent of cases a family member had to quit work or make some other major lifestyle change; almost one-third of these families lost all of their savings; and just under 30 percent lost a major source of income.

If talking about money sounds venal or trivial, remember that much more than money is normally at stake here. When someone has to quit work, she may well lose her career. Savings decimated late in life cannot be recouped in the few remaining years of employability, so the loss compromises the quality of the rest of the caregiver's life. For a young person, the chance to go to college may be lost to the attempt to pay debts due to an illness in the family, and this decisively shapes an entire life. (H, 122-23)

These remarks cry out for critical examination. For one thing, Hardwig's conception of what can constitute an unacceptable family burden seems astonishingly weak. Should being "distant, uncommunicative, unresponsive, foreign, and unreachable" really be a capital offense anywhere, let alone in a "loving" family? Does a loving family really welcome a beloved member's suicide in order to keep a young person from having to work and/or borrow his way through college? Does the view that you have a duty to spend your hard-earned money to put your able-bodied child through college, rather than to prolong your own life, reflect a bias in favor of the young and healthy, a bias that will someday be as offensive to liberals as 1950s attitudes toward women are today?

The issue of women's roles is interesting here. Hardwig says, "To a large extent, care of the elderly is a women's issue. Most people who live to be 75 or older are women. But care for the elderly is almost always provided by women as well" (H, 99, note 7). This is true, but its implications are unclear. Tong argues that the "duty to die" mentality may be particularly destructive of women, since "because of the way men and women are typically socialized in our culture...women are more likely than men to respond positively to the duty to die" (H&A, 139), and

it is reasonable to hypothesize that the duty to die might rapidly be “feminized.” Women might perceive themselves as imposing unreasonable burdens on others simply because they typically live longer than men, suffer from more chronic conditions than men, and require more long-term care than men...Additionally, women’s caregivers—themselves predominantly women...—might expect the female recipients of their care to do the “womanly” thing, i.e., the “dying-so-that-others-might-live-happily-ever-after” thing...When [a woman caregiver] herself becomes needful of health care, memories of her [own attitudes as a caregiver, as well as other factors] will probably increase her desire not to be a burden to others. (H&A, 147-48)

But the “duty to die” mentality, although oppressive to the care-receiver, may well be liberating to the caregiver. She will be free of the caregiving burden after the purported duty is carried out—and possibly before, if she comes to spurn female care-recipients who fail to meet her expectation that they will “do the ‘womanly’ thing, i.e., the ‘dying-so-that-others-might-live-happily-ever-after’ thing.” She may even come to adopt the “duty to die” mentality strongly enough to spurn recalcitrant male care-recipients as well. Because the caregiving and care-receiving roles both are most apt to be occupied by women, there is no easy answer to whether the “duty to die” mentality helps or harms women overall. What is clear is that this mentality benefits (relatively) young and strong women at the expense of older and sicker ones. Hardwig says, “We fear death too much” (H, 133). But to the extent that his views are widespread, I think that what we fear too much is having our lives and plans disrupted by the healthcare needs of our “loved ones.” This fear may cause us to magnify such disruptions out of proportion, to the point where living with and caring for a distant and uncommunicative spouse or working and/or borrowing one’s way through college seems so terrible that the sick person’s death seems preferable and perhaps even obligatory.

There are other indications of bias in the long Hardwig passage I have quoted. The burden of providing “care or even just supervision 24 hours a day, 7 days a week,” far from being unbearable or unique to caregivers to the old and/or ill, is routine for many stay-at-home single mothers of babies and toddlers (and for stay-at-home married mothers whose husbands do no childcare). It is likewise common for “a family member [to have] to quit work or make some other major lifestyle change” or for a family to lose “a major source of income” when a baby is born. (Of course, people are aware of such needs when they choose to have children, but people who choose to marry are likewise aware of the strong possibility that their spouse will someday be ill and need care.) And Hardwig’s claim that “[s]ocial life and friendships evaporate, as there is no opportunity to go out to see friends and the home is no longer a place suitable for having friends in” raises some questions. Hasn’t Hardwig ever heard of the telephone or e-mail? Why is he so ready to see the hardships of taking care of a sick person as reasons why that sick person has a duty to die, rather than as practical problems open to practical remedies? And precisely why is a home with a seriously ill person “no longer a place suitable for having friends in”? Suppose that person is unpredictable and

incontinent. Is a home with a rambunctious toddler who is not yet toilet trained no longer a suitable place for having friends in?

### Elder Care and Elder Abuse

In his essay “Elder Abuse, Ethics, and Context” Hardwig amplifies his views of appropriate family behavior toward old people who need care. He says, “There will be only an *extremely* short list, if any at all, of activities which are always abusive. The fact that an elderly person is physically pushed into her room and locked there, physically restrained, threatened with physical harm, shouted at and frightened, or even hit does not necessarily mean that she is abused” (H, 77, boldface in original). Why not? Here are two of Hardwig’s reasons. For one thing, the caregiver (for example, a sleep-deprived elderly husband of a nocturnally wandering Alzheimer’s patient) may be so beleaguered, desperate, and lacking in alternatives that he is justified in physically restraining the patient in order to get a much-needed night’s sleep. Moreover, “[w]hat is owed to mentally competent elderly persons depends partly on how they act” and “[w]hat is owed to an elderly person, competent or incompetent, depends partly on how they [*sic*] treated others when they [*sic*] were younger, especially on how they [*sic*] treated those who now care for them [*sic*]” (H, 73).

If the circumstances are desperate enough, the first reason may in fact justify the caregiver’s use of physical restraint. But how many old people must be “shouted at and frightened, or even hit” so their exhausted caregiving spouses can get a needed night’s sleep? As for the second reason, how many ill and helpless old people really deserve such treatment? If your father “physically and sexually abused” you (H, 73), is do-it-yourself physical retribution any more justified than it would be in a case of date-rape? Having a father who abused you justifies your bringing criminal charges, as well as having no further dealings, let alone caregiving ones, with him ever again. But in a civilized society, it does not justify your taking it upon yourself to mete out physical revenge.

Another question arises here. In the introduction to his book, Hardwig says, “Although [“Elder Abuse, Ethics, and Context”] focuses on care of the elderly, there are important similarities in the analysis of the care—and the abuse—of younger family members” (H, 7). Now consider a beleaguered single mother who physically pushes, locks up, physically restrains, threatens with physical harm, shouts at and frightens, and even hits a rambunctious child or rebellious teenager so she can have a much-needed night’s sleep. And what about a man (working two jobs to support a family of six) who daily comes home aching and exhausted, only to be met with screaming children and a nagging, shrewish wife who constantly taunts him for being a failure? If he gets angry and belts them one, or if he pushes them into a room and locks them there so he can have a desperately needed night’s sleep, would Hardwig find this excusable (as he finds some cases of elder abuse) or even justifiable? If not, why not?

Hardwig’s views about old people and their grown children also figure in the following case.

An 87-year-old woman was dying of congestive heart failure. Her [prognosis was] that she had less than a 50 percent chance to live for another six months. She was lucid, assertive, and terrified of death. She very much wanted to live and kept opting for

rehospitalization and the most aggressive life-prolonging treatment possible. That treatment successfully prolonged her life (though with increasing debility) for nearly 2 years. Her 55-year-old daughter was her only remaining family, her caregiver, and the main source of her financial support. The daughter duly cared for her mother. But before her mother died, her illness had cost the daughter all of her savings, her home, her job, and her career. (H, 126)

Hardwig seems to think this old woman had a duty to die rather than opt for “the most aggressive life-prolonging treatment possible.” He does not mention his above-quoted principle that “what is owed to an elderly person...depends partly on how they [sic]...treated those who now care for them [sic]” (H, 73). By contrast, Menzel recognizes that “[i]f, for example, the mother had endured truly great sacrifice to prevent or significantly ameliorate some disaster to the daughter, or if certain genuine and voluntary promises had been made earlier in their lives, then perhaps the daughter’s burdens do not finally create a duty to die” (H&A, 112, note 6). Hardwig does not say anything about the mother and daughter’s prior relationship, let alone answer such questions as the following. Did the mother pay, and make sacrifices to pay, for the education that enabled the daughter to have the career Hardwig is so distressed about her losing? Did the mother, like many parents nowadays, give her daughter the money that enabled the daughter to buy the home Hardwig is so distressed about her losing?

Even by Hardwig’s own principles, how can such matters be irrelevant? He does acknowledge the relevance of “many details of the family history—not only...the values to which they have been committed, but also...how various members have treated each other, who has made sacrifices for whom,” etc. (H, 184, note 5) in his discussion of a 62-year-old man whose potentially lifesaving bone marrow transplant would leave his wife destitute. Is Hardwig’s failure to mention such considerations in the parallel case of the 87-year-old woman with congestive heart failure merely an oversight, or does it illustrate his greater devaluation of the lives of the very old (a devaluation epitomized by his generalization, “A duty to die becomes greater as you grow older” [H, 129])?

### Broader Social Issues

Hardwig recognizes that the Alzheimer’s case invites the objection, “Any demented woman who is locked in her room or tied in her bed *is* being abused! Only she is being abused by *society*, not by her caregiver. Perhaps her husband is being abused by society, as well. After all...if appropriate social services were in place, the old couple would not be in such a desperate situation” (H, 74, boldface in original). He also says, “There are a number of social policies we could pursue that would [have the result that] [t]he duty to die would then be virtually eliminated” (H, 132) (although he argues that such a duty would probably later re-emerge [H, 179-81]). But he maintains reasonably that one’s duty to his family is his duty in the world as it actually is, rather than what would be his duty in a utopian society. Hardwig also makes some sketchy remarks about desirable social policies, including (in his discussion of the case of the 62-year-old man’s bone marrow transplant) the claim that “it may not even be true that the government should pay for more health care. Other needs—

[including] better rehabilitation efforts for juvenile first offenders—may well be more important” (H, 176). He does not explain why, simply because they are young, criminals should get higher priority than people whose only crime was to get old and sick. Nor does he explain how to reconcile this claim with his claim (three pages later) that he believes in “a system of collective responsibility” such that if the reforms he favors in our health care system came about, “[a] responsibility to end your life would be rare” (H, 179)...at least until escalating healthcare costs caused the responsibility to re-emerge.

Broader social issues figure more prominently in the Humber and Almeder volume, where, as I have mentioned, several essays discuss the question of whether the old and/or ill could have a duty to die in order to avoid using a disproportionate share of national or global resources. Drawing upon Hardwig’s case of the octogenarian whose insistence on aggressive life-prolonging care for her congestive heart failure made her a burden to her daughter, Margaret P. Battin points out that the \$200,000 she hypothesizes that such care costs “would go a very long way” in a Ugandan village, where it would “purify the water supply, provide vaccines for all the village children, hire a health care worker to treat wounds, [etc., raising the very low] life expectancy of these villagers by, say, 5 years on average” (H&A, 12). Space limitations prevent me from discussing this sort of issue further here, except to praise some of the writers for having the decency to suggest inequity-reducing sacrifices from those far less vulnerable than the old and ill. Although sympathetic to a duty to die, Battin also mentions ways of aiding impoverished nations without invoking such a duty. As for our possible obligation to “be more frugal in our use of health care so that less prosperous persons...might have their fair share” (H&A, 194), Judith Lee Kissell points out that “[w]e might more easily fulfill this...obligation by simply forgoing such procedures as face-lifts, liposuction, and fertility treatments...rather than by committing suicide” (H&A, 194-95). And I will conclude by suggesting that, before scapegoating the old and ill for using an unfair share of social resources, bioethicists consider the ethics of accepting substantial honoraria and attending all-expense-paid conferences to discuss inequities in the distribution of healthcare. How many bioethicists donate their honoraria to Doctors Without Borders?

### Notes

1. Although the title on the book cover is ‘Is There a Duty to Die? and Other Essays in Medical Ethics,’ the title ‘Is There a Duty to Die? and Other Essays in Bioethics’ appears on the title page. The subtitle in the Library of Congress listing also uses ‘bioethics,’ but hyphenates it.
2. Elaine of Astolat (who may be more familiar to many philosophers as Tennyson’s Lady of Shalott) utters this beautiful line in *Le Morte D’Arthur* when she implores Lancelot to marry her or be her lover, for otherwise she will die of sorrow. In the context of the present review essay, the line has a different and very appropriate sense.
3. These “Family Responses” display, in extreme form, the problems that can arise when contributors to a book are chosen on the basis of connections. Not all the family members Hardwig includes write at an intellectual level suitable for a philosophy book, and his son Jay’s writing is often embarrassingly corny. For example,  
Now, my father is not in general a grim man, and to this day he enjoys a Ralph Stanley record and a plate of barbecue as well as any man, but for years he has been

less than elusive about premeditated suicide. (Here I'll gladly confirm my father's contention that he is not "idiosyncratic, morbid, mentally ill, or morally perverse." Sometimes he doesn't match his clothes too well, but give the guy a break.) (H, 186)

This is about as appropriate as it would be for me to include in this review essay a testimonial from my family to the effect that I am not a grim woman and to this day I enjoy a plate of brownies and a soft blue purring cat. (Sometimes I dress a little oddly, but give the gal a break.) (I thank Donna Harvey for help formulating my testimonial.)

4. Apparently, though, the group acknowledged the possibility of drawing the line at suicide, as Hardwig comments on this stricture that "[a] discussion followed about whether there is a responsibility to commit suicide. Some [members of the discussion group] think there is" (H, 198).

5. See my "Goldilocks and Mrs. Ilych: A Critical Look at the 'Philosophy of Hospice,'" *Cambridge Quarterly of Healthcare Ethics* (1997) 6:318; "Assisted Suicide, Terminal Illness, Severe Disability, and the Double Standard," in M. Battin, R. Rhodes, and A. Silvers (eds.), *Physician-Assisted Suicide: Expanding the Debate* (Routledge, 1998), pp. 156-57; and "'For Now Have I My Death': The 'Duty to Die' vs. the Duty to Help the Ill Stay Alive," *Midwest Studies in Philosophy XXIV* (2000): 179. For treatment of this issue in a short story that is more fleshed-out than the usual philosophical schematic example, see my "The Forecasting Game," in W. Abrahams (ed.) *Prize Stories 1990: The O. Henry Awards* (Doubleday, 1990), pp. 318-19.

6. "For Now Have I My Death": 183, note 5.

7. He later qualifies this by granting that conventional wisdom would acknowledge a duty to die under "very unusual circumstance[s]—... 'lifeboat case[s]—[and in] poor, technologically simple, and especially nomadic cultures" (H, 120), but not in mainstream present-day American circumstances. Of course, this qualified claim is just as vulnerable to the objection I will make.

8. For example, see his *The Troubled Dream of Life* (Simon and Schuster, 1993).

9. Sherwin B. Nuland, *How We Die* (Knopf, 1994). I reviewed this book in *The American Scholar* 64:1 (1995): 131-35, review reprinted in *American Philosophical Association Newsletter on Philosophy and Medicine*, 94:2 (1995): 98-100.

10. *The Troubled Dream of Life*, pp. 218-19.

11. See the material cited in my note 10.

12. *The Troubled Dream of Life*, p. 218.

13. Callahan and Hardwig (and Hardwig's son Jay—see note 3, above) do not have a monopoly on bad writing, of course. The abstract of Robert E. Ehman's paper includes a sentence that looks like a right-wing parody of politically correct language: "I try to show that it is rational for an agent to consent to a duty to die when he or she finds it in his or her prospective interest to adopt and comply with such a duty and when he or she likewise finds it in his or her prospective interest to accept the principles determining the situation in which he or she assesses the duty" (H&A, 61). And Narveson says, "Under a system like [Canada's], your life is literally in the hands of the government" (H&A, 38)—a sentence that literally leaped off the page and grabbed me by the throat.

14. Or, more accurately, this burden is as closely approximated in both sorts of cases. Hardwig's description is, of course, hyperbole. No one actually provides care or even just supervision "24 hours a day, 7 days a week." (When would the caregiver sleep? Even people whose caregiving tasks often interrupt their sleep do not actually provide care or supervision 24/7.) This is not a stylistic point, but an illustration of Hardwig's tendency to exaggerate the horrors of taking care of the ill.

## **Berney Goodman, *When the Body Speaks Its Mind: A Psychiatrist Probes the Mysteries of Hypochondria and Munchausen's Syndrome*, 1994, G.P. Putnam's Sons, New York.**

**Reviewed by Jorge R. Petit**  
*Mount Sinai School of Medicine*

*When the Body Speaks Its Mind*, by Dr. Berney Goodman, is a psychiatrist's journey into uncovering the complexities of hypochondria and Munchausen syndrome. Although these disorders are not common in clinical practice, Dr. Goodman, by virtue of his personal experience and his training in both internal medicine and psychiatry, has been able to shed some light on these psychiatric disorders. He illustrates, by describing several of his patients with diverse somatization disorders, how complex and impaired their lives are. He adds a needed human element to the description of this difficult group of disorders and the people who suffer from them.

Dr. Goodman starts his account by sharing a personal story that inspired his interest in somatization and somatoform disorders. He defines somatization as a process in which a patient experiences subjective physical discomfort or pain for which there is no objective medical explanation, pointing out that patients who somatize often do not receive psychiatric treatment because their symptoms are mistakenly thought to have a medical etiology. He spends a chapter recounting some anecdotes, a historical perspective of this phenomenon, and a summary of how the psychiatric community ultimately became involved. Finally, Dr. Goodman takes the reader through the "telltale symptoms" which characterize these disorders.

Hypochondria, the irrational fear of having an illness despite evidence to the contrary, is explored. Several historical and personal patient stories are interspersed in this chapter the author launches fully into the most interesting part of the book: case studies. Dr. Goodman writes about six of his patients, whom he saw for different lengths of time over the years. His easy-to-read prose describing his patients' lives and afflictions is riveting, from the elderly man with a lifetime of hypochondriasis stretching back to earliest childhood to the Italian princess and her somatization and panic symptoms. His progressive insight into their conditions and the discovery of the underlying somatization components is fascinating. He takes us through the slow process of unraveling patients' mysteries, therefore allowing us a peek at a therapist's mind at work. Dr. Goodman reveals the difficulties he encounters in these cases—the mistakes as well as the successes. The case studies are the backbone of this book and its most informative aspect. They allow us to empathize with these people's suffering, but, most importantly, they emphasize the need for psychiatrists to be more aware of somatization and its varied manifestations.

Dr. Goodman then moves into more uncharted, but infinitely more intriguing territory: Munchausen syndrome and the more peculiar Munchausen by proxy. Munchausen syndrome is rare, but severe and difficult to comprehend fully. It is the intentional and conscious production of an illness with the unconscious goal of getting attention and medical care. Dr. Goodman provides several case vignettes of this

uncommon disorder that few psychiatrists have had the chance to see, much less treat.

Somatization—as a primary or secondary illness manifestation—is a very common occurrence, especially in the psychiatry emergency room. The degree to which people will manifest their myriad psychological stresses through their body is remarkable. The need to inquire deeper into these symptoms and the possibility of more complex somatoform disorder are highlighted by this book and its conclusions. Dr. Goodman makes a compelling argument that we must keep our eyes open, but, even more importantly, we must listen when the body speaks its mind.

**Martin Shepard, *Dying: A Guide for Helping and Coping*, The Permanent Press, 2000.**

**Reviewed by Daniel Fischberg**  
*Mount Sinai School of Medicine*

In the first pages of, *Dying: A guide for helping and coping*, Martin Shepard tells us that the purpose of his book is to provide “practical information regarding the everyday details involved in preparing for death...”. In doing so, Dr. Shepard provides a valuable addition to the already considerable literature on modern death and dying. However, Dr. Shepard goes much further in his analysis and criticism of the contemporary death experience. His scope spans from the incredibly practical (advice on preparing a will, setting up a trust, collecting death benefits, and arranging a funeral) to the sublime (a chapter discussing perspectives on life after death).

In *Dying*, Dr. Shepard clearly and convincingly argues his point that by far the worst thing about dying in our society today is the potential for isolation. Open and honest communication, he asserts, not only lessen this isolation but are essential to allow us to die in comfort and dignity.

Throughout his book, Dr. Shepard makes extensive use of interviews with people who are approaching death and, in a chapter on bereavement, with those who have cared for or lost a family member. Using these interviews, the author provides advice to family members, clinicians, and caregivers on how to treat, talk with, and be with the dying. Dr. Shepard also relies heavily on his personal experience with the death of his own father. These portions lend an intimacy to the book which seems wholly appropriate to its theme.

Although written by a physician, the book is completely free of medical jargon and readily engages the reader with the intimacy of its narrative.

Dr. Shepard makes good on his promise to demystify death and illness with a section dedicated to a simple accounting of the manner of death from over a dozen common illnesses. This section, while plainly written, lacks for nothing in medical accuracy.

Dying delivers on the author’s promise to portray the potential for the “all-rightness of the dying process” and what can, and so often does, go so horribly wrong with it today. It is highly recommended reading for anyone suffering from a serious, potentially life-limiting illness as well as those who love and care for the dying.

## ANNOUNCEMENTS

### Workshop

The University of Virginia Center for Biomedical Ethics in cooperation with Continuing Medical Education announce a workshop: “Fundamentals of Research Ethics” to be held November 5th - 6th, 2001 in Charlottesville, Virginia.

This two-day program will include instruction in the primary topics which investigators and IRB members need to meet NIH training expectations in Research Ethics. Limited to 50 participants, the program will begin with a session in the history of research ethics, with review of several of the great cases that set the stage for federal regulation in the biomedical arena. Nationally prominent faculty from the University of Virginia and elsewhere will explore the principles that define permissible conduct of research, and survey the regulatory structure under which ethical research must be conducted. Each session will be designed around an interactive format to encourage participant involvement. Program fees are \$350. For information: Carrie Gumm, University of Virginia, Center for Biomedical Ethics, (804) 924-5695; [cg2b@virginia.edu](mailto:cg2b@virginia.edu).

### Conference

“Training in the Responsible Conduct of Research” November 16th and 17th, University of Alabama at Birmingham. Co-sponsored by the Office of Research Integrity, East Carolina University, Vanderbilt and Meharry Medical College. Topics include fraud, authorship, data access and management, conflict of interest, misrepresentation, and human subjects, with a focus on teaching about these issues. Conference fee \$150, CME available. For more information go to [www.uab.edu/ethicscenter](http://www.uab.edu/ethicscenter) or contact Harold Kincaid at [kincaid@uab.edu](mailto:kincaid@uab.edu).

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### Masters in Bioethics Program

Albany Medical College and Union College are pleased to announce that they are now accepting applications for a Masters in Bioethics Program. The twelve-course degree is taught primarily through distance learning and is designed for administrators, health professionals, lawyers, philosophers, and students in advanced and professional degree programs who seek credentialing for professional involvement in clinical ethics, biomedical policymaking and professional biomedical ethics education. The program’s curriculum is modeled on the American Society for Bioethics and Humanities’ *Core Competencies for Clinical Consultants* guidelines. In addition to nine courses taught on-line by distance learning, the program involves three on-site courses: an initial two-week summer pro-seminar, a two-week clinical practicum and a capstone seminar. Practia are offered at Albany Medical College, at the Mount Sinai School of Medicine and at the University of Rochester School of Medicine. The

opening two-week proseminar will be taught by: Robert Baker (Union College), Jane Greenlaw (University of Rochester), Susan Lederer (Yale School of Medicine), Laurence McCullough (Baylor College of Medicine), Wayne Shelton (Albany Medical College) and Robert Veatch (Kennedy Institute of Ethics, Georgetown University). All classes have limited enrollments. The introductory pro-seminar commences in August 2002. For information see [www.bioethics.union.edu](http://www.bioethics.union.edu) or contact Ann Nolte, Administrator Masters in Bioethics Program, Center for Bioethics, Union College, Schenectady NY 12308, 518-388-8045, [bioethics@union.edu](mailto:bioethics@union.edu).

### **NEH Summer Seminar**

We are happy to announce the NEH Summer Seminar “Justice, Equality, and the Challenge of Disability,” (June 24-July 26) co-directed by Eva Feder Kittay and Anita Silvers. The seminar will be held at Sarah Lawrence College, a small and beautiful residential college located a half hour north of New York City.

The seminar will last for five weeks and will address philosophical questions important to understanding, assessing the adequacy of, and reforming or rejecting, traditional approaches to justice, especially health care justice. These questions relate to (1) conceptions of normality and disability, (2) equality and disability rights, (3) virtue theory and the ethics of care, (4) well-being and the quality of life, and (5) the intersectionality of roles and relationships constitutive of identity.

Seminar participants will receive a stipend of \$3,250 for the seminar, whether or not they reside on campus.

College and university teachers and qualified independent scholars are eligible to apply. Successful applicants will be at various career stages, with background experience at different kinds of academic or non-academic institutions, and with different perspectives both on disability and moral philosophy. We encourage applications from scholars of philosophy, literature and the arts, religious studies, communications theory, history, political theory and jurisprudence, and the humanistic social sciences (including philosophy of economics), women’s studies and from faculty members who work with students interested in medicine or other health care careers.

For more information, and for an application form, please email Anita Silvers at [asilvers@sfsu.edu](mailto:asilvers@sfsu.edu), NEH Seminar Information Officer, Dept. of Philosophy, San Francisco State University, San Francisco CA, 94132. Applications are due March 1, 2002. Successful applicants will be notified at the beginning of April, 2002.