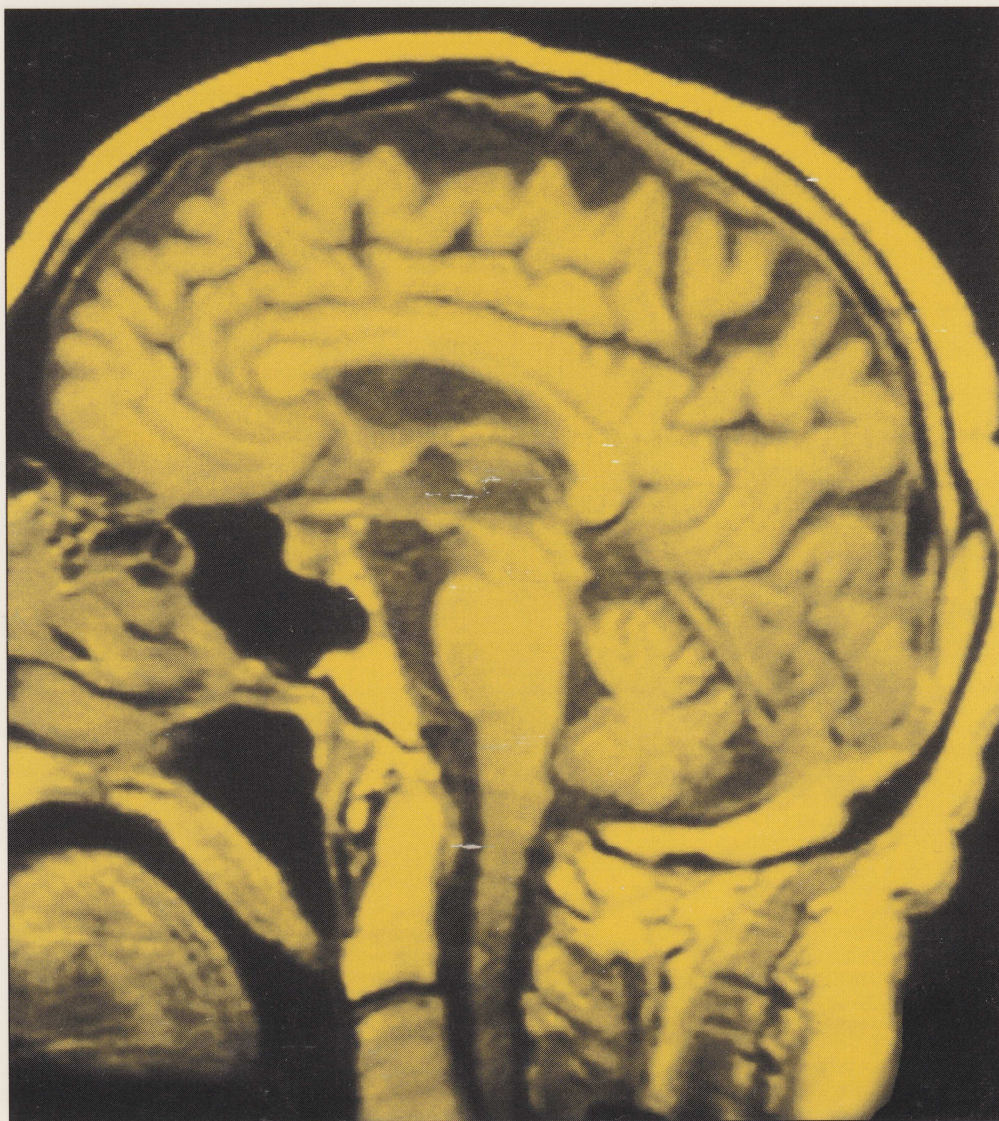


# Ethics & Medicine

*An International Journal of Bioethics*



Vol 18:1  
Spring 2002  
ISSN 0266-688X

# Ethics & Medicine

*An International Journal of Bioethics*

2

CONTRIBUTORS

3

GUEST EDITORIAL

*Nigel M de S Cameron, PHD and Lori Andrews, JD*

5

TO THE EDITOR

11

Clinical Ethics Case Consultation

*Robert D Orr, MD, CM*

15

The Advance Directive: An Expression of Autonomy, But Also of Care

*Prof Dr Klaus Schaefer, Prof Dr Ulrich Eibach, and Debi Roy*

21

'Euthanasia' in the Third Reich: Lessons for Today?

*JA Emerson Vermaat, MA*

33

Suicide, Physician-Assisted Suicide, and Euthanasia

in Men versus Women Around the World: The Degree of Physician Control

*Kalman J Kaplan, PhD, Martin Harrow, PhD, and Mark E Schneiderhan, PharmD*

49

Autonomy, Gender, and Preference for Paternalistic or Informative Physicians:

A Study of the Doctor-Patient Relation

*Kalman J Kaplan, PhD, Martin Harrow, PhD,*

*Mark E Schneiderhan, PharmD, and Russell Omens, PsyD*

61

Book Reviews

VOL 18:1, SPRING 2002

## CONTRIBUTORS

**Lori Andrews, JD**, director of the Institute for Science, Law, and Technology, at the Illinois Institute of Technology, USA

**Nigel M de S Cameron, PHD**, founding editor of *Ethics & Medicine*, chairs the London-based Centre for Bioethics and Public Policy and serves as dean of the Wilberforce Forum in Reston, VA., USA

**Dr Ulrich Eibach**, is a professor at Medizinische Einrichtungen der Universität Bonn, Evangelische Seelsorge, Sigmund-Freud-Str. 25, 53105 Bonn, GERMANY

**Martin Harrow, PhD**, is a professor in the Department of Psychiatry, University of Illinois College of Medicine, USA

**Kalman J Kaplan, PhD**, is a professor in the Department of Psychology, Wayne State University and in the Department of Psychiatry, University of Illinois College of Medicine, USA

**Russell Omens, PsyD**, is a professor at the University of Illinois at Chicago and Wayne State University, USA

**Robert D Orr, MD, CM**, is Director of Ethics at Fletcher Allen Health Care and the University of Vermont, USA

**Debi Roy**, is at St. Joseph-Krankenhaus, Med. Abt. II, Bäumerplan 24, GERMANY

**Dr Klaus Schaefer**, is Professor at St. Joseph-Krankenhaus, Med. Abt. II, Bäumerplan 24, GERMANY

**Mark E Schneiderhan, PharmD**, is Assistant Professor in the Department of Psychiatry, University of Illinois College of Medicine and in the Department of Pharmacy Practice, University of Illinois College of Pharmacy, USA

**Alta E Schutte, MSc Physiology**, is a researcher in cardiovascular physiology at the School for Physiology, Nutrition, and Consumer Science at the Potchefstroom University for Christian Higher Education in the REPUBLIC OF SOUTH AFRICA

**JA Emerson Vermaat, MA**, is a senior television reporter in Hilversum, THE NETHERLANDS, and specializes in international affairs and European history

## GUEST EDITORIAL: CLONING AND THE FUTURE OF US ALL

NIGEL M DE S CAMERON, PHD, AND LORI ANDREWS, JD

Italian fertility specialist Severino Antinori has announced that he will begin human cloning in early 2002. Two hundred couples desperately seeking to create children will become human guinea pigs in a massive experiment. The odds are not in their favor. In animals, cloning currently only results in a successful pregnancy 3 to 5 percent of the time. And, even in those rare instances, many of the resulting offspring suffer. One-third die shortly before or right after birth. Other cloned animals seem perfectly healthy at first and then suffer heart and blood vessel problems, underdeveloped lungs, diabetes, immune system deficiencies and severe growth abnormalities.

If an infectious disease were killing one-third of human infants, we would declare it a public health emergency. We certainly wouldn't set up a clinic to enable it to happen. Yet despite these grave risks, only five states have laws banning human cloning. There is no federal law on the subject yet. Despite widespread public opposition to human cloning, various researchers and biotech companies have so far prevented the passage of such a law.

This summer, however, a set of strange bedfellows emerged to shift the political dialogue about human cloning. A powerful new coalition has come forward in which traditional opponents—feminists and the Catholic Church, conservative Republicans and liberal, if not libertarian Democrats—have banded together to express concern about where the latest genetic and reproductive technologies are taking us. The result: the House of Representatives resoundingly passed a bill on July 31, banning human cloning and the creation of cloned human embryos for stem cell research. The next step is up to the Senate.

The hearing leading to that vote was one of the greatest occasions of political theater of our generation. Right next to pro-life advocate Richard Doerflinger of the National Conference of Catholic Bishops sat three witnesses whose testimony sent shock waves across the body politic. All three spoke in favor of a bill drafted by pro-life members of the House and Senate, and has been widely characterized as pro-life legislation. All three spoke against "therapeutic" cloning (the creation of cloned embryos to be the source of stem cells), which they argued should be outlawed. And yet all three were at pains to stress their pro-choice credentials.

Francis Fukuyama, eminent social philosopher and theorist and author of the unforgettable "End of History and the Last Man," began by saying that he was simply "agnostic" on the issue of abortion.

Stuart Newman of New York College of Medicine, on behalf of the respected Council for Responsible Genetics (the leading critical/environmental focus), set out CRG's position as pro-choice on abortion but entirely opposed to the therapeutic research use of embryo cloning.



Most striking of all was testimony from Judy Norsigian of the Boston Women's Health Book Collective (current editor of the benchmark feminist text *Our Bodies, Ourselves*). To describe her as pro-choice would be akin to describing the Pope as Roman Catholic. Yet she, too, spoke, in her case vehemently, against all cloning.

One special moment of theater came during questioning when, in a conversation with Richard Doerflinger, she agreed that "the embryo is not nothing." Abortion-rights advocates argued that maternal rights trumped fetal rights; in this case there were no maternal rights. Another came in exchanges between Norsigian and Rep. Diana DeGette (D-Colo.), perhaps the member most consistently and intelligently critical of the anti-cloning law at the hearing. DeGette acknowledged to Norsigian that "your book is one of the most important in my life." DeGette's face was a study in cognitive dissonance.

Of course, there is theater and theater; sideshows and the main attraction. There have been odd couples before. Some of the most interesting stories now running have brought unlikely coalitions together (religious freedom is one example).

But what is happening around genetics and reproductive technologies is something more. The most challenging questions faced by our civilization in the 21st Century will lie just here, in the unfolding biotechnology agenda. Nothing will matter more for the future of the planet and, especially, its human inhabitants. And a curious consonance is emerging of pro-life "conservatives" and generally pro-choice progressives with anchorage in the environmental, feminist and disability communities.

Cloning has brought many of them together, pitted against the powerful biotech industry (which continues to campaign against regulation, with all the credibility of King Canute), technological fatalists and libertarians of right and left.

It remains to be seen whether the testimony trio of Norsigian, Newman, and Fukuyama will set the debate between those who oppose abortion and those in favor of reproductive choice, which has hampered widespread societal discussion of important biotech issues, in the context of even wider concerns about human dignity and the human future.

But when history is written, we harbor no doubts that the cloning debate of 2001 will be noted as the start of something very big, in which those who oppose abortion and those who favor reproductive rights discovered common ground in their commitment to the human future and the distrust of uncontrolled biotechnology, and revealed the extraordinary potential of their working together.

---

**Nigel M de S Cameron, PhD**, founding editor of *Ethics & Medicine*, chairs the London-based Centre for Bioethics and Public Policy and serves as dean of the Wilberforce Forum in Reston, VA.

**Lori Andrews, JD**, director of the Institute for Science, Law, and Technology, at the Illinois Institute of Technology, is the author of *Future Perfect: Confronting Decisions about Genetics*.

## TO THE EDITOR

I read with interest Dr. Goodnough's article "Redux: Is the Oral Contraceptive Pill an Abortifacient?" *Ethics & Medicine* 17(2001):37-51 on the abortifacient effect of the oral contraceptive pill (OCP). One thing Dr. Goodnough and I share in common is that we both very much hope his theories are correct – and that my view of the evidence is eventually disproved. As one whose wife took oral contraceptives, and who for many years recommended oral contraceptives in premarital counseling—and who doesn't want for a moment to believe children may have been killed by my actions taken out of ignorance—I would certainly like to believe Dr. Goodnough's position. If one day he is proved right, I will rejoice. Unfortunately the evidence I've found, through painstaking research, does not support his conclusions. Furthermore, he made a number of factual errors of which the objective reader and a peer-reviewed journal such as *Ethics & Medicine* would want to be informed.

Some of the weaknesses of Dr. Goodnough's article have been pointed out by Dr. Walter Larimore, in his letter to the editor of *Ethics & Medicine*. These include, but are not limited to, the following: 1) In citing the 3% pregnancy rate for first-year pill-takers, Dr. Goodnough fails to take into account the fact that women who get pregnant while taking the pill and then get abortions are counted statistically as if they've never gotten pregnant at all, making the actual first-year pregnancy rate in pill takers much higher. 2) Dr. Goodnough's "turned on endometrium" theory is completely speculative, and he presents no scientific evidence supporting it. 3) By using a dated version of my book (1998, instead of the 2000 revision, which is three revisions later), and by drawing my quotes from a now long-dated email exchange with Dr. Larimore rather than Dr. Larimore's subsequent article in *Archives of Family Medicine*, Dr. Goodnough significantly misrepresented several of my and Larimore's conclusions.

My major concerns about Dr. Goodnough's article involve its considerable logical and ethical weaknesses, as well as one particularly serious misquotation of my book.

Dr. Goodnough asks, "Is the OCP an abortifacient? Or is it a contraceptive that has the potential for failure, a failure that may result in the death of the embryo?" (It's interesting that he narrows it down to these two choices, an apparent admission that the Pill may indeed result in the death of a child—which, ironically, is the central point that I present in my book.) He cites a medical dictionary's definition of an abortifacient being something deliberately used to cause an abortion. Then he argues that the Pill isn't an abortifacient. But this isn't the point. The issue isn't what the OCP should be called, it's what the OCP can do. My book's title is not "Should the Birth Control Pill Be called an Abortifacient?" but "Can the Birth Control Pill Cause Abortions?" The latter question, not the former, is what this is all about.

Dr. Goodnough gives considerable attention to semantics. He insists “a medication that is used to prevent conception is not an abortifacient even if it sometimes causes an abortion.” But the young men and women who talk to me about this issue are never concerned about labels and terminology. Their question is simple—can taking the Pill result in the unrecognized death of a pre-born child? Though at times he seems to deny it, at other times Dr. Goodnough appears to admit the answer is yes. Given what he regards as the positives of OCPs, he considers this a risk worth taking. Many couples, however, do not.

One of my main points is that couples have the right to know this information and the medical community has the legal and ethical obligation to inform them. This is why Dr. Larimore and I and others have simply encouraged physicians and health-care systems to provide full information to patients. If the patient is interested, show them the evidence, and let them come to their own conclusions. This is the crux of informed consent. But is it ethical for a physician to withhold evidence that many people—including other well-respected physicians—believe supports the contention of the Food and Drug Administration (FDA) and the OCP companies that the Pill sometimes prevents the implantation of a newly conceived child? Conscientious Christians who put their prolife convictions above their convenience are not unusual, and they are not stupid. They can handle the evidence and reach their own conclusions. They will be held accountable for their choices, just as we will be held accountable for whether or not we present them with the full body of evidence.

As I clearly state in the book, usually the birth control pill does *not* cause abortions. As far as I am aware, no one argues that it usually acts as an abortifacient. The question is whether it sometimes causes the death of a child. How often it does so, no one knows—some say it is infrequent, some say it may not be as unusual as we’d like to believe. But the moral question is, how much risk to an innocent child are we willing to take for the sake of convenience? We may come to different conclusions, to be sure, but unless the evidence is laid on the table, people can’t bring their own ethical values to bear on these matters involving themselves and their children.

Dr. Goodnough says, “It is particularly distressing that Alcorn refers to studies in order to make a point, even though one would be hard pressed to find actual support for the point within the context of the study.” If by “support for the point” he means that the authors cited don’t state the conclusion “oral contraceptives cause abortions,” obviously that is true. I’ve researched and written fifteen books and many articles. It is standard practice in presenting one’s research to selectively cite Plato, C. S. Lewis, *The New York Times*, or *The New England Journal of Medicine*, without implying that they necessarily agree with your particular conclusion. If we limited our citations only to those who have reached the same conclusion as we have, it would keep us from presenting evidence for any new or unpopular viewpoint. I present dozens of threads of evidence, documented in 138 endnotes. That some of them would not agree with my conclusions or share my ethical concerns is obviously true.

Dr. Goodnough does exactly what I did (indeed, so does every researcher) when he selectively cites certain statements from studies, not one of which states “oral contraceptives cannot cause abortions.” I disagree with his conclusions, but I do not find it distressing that he pulls data from sources which make no claim whatsoever to support his conclusions.

Dr. Goodnough admits that many sources, including *The Physician’s Desk Reference (PDR)*, refer to the effects on the endometrium as “reducing the likelihood of implantation.” He then calls such statements “speculation.” I always find this interesting. The disclosure of the medical information contained in PDR is mandated by no less an authority than the FDA. The information presented is more than a marketing ploy or a legal caveat. Anyone convinced that the manufacturers’ claims that the Pill sometimes prevents implantation are not truthful statements based on science, but false statements motivated by carelessness or public relations, has the responsibility to take this serious accusation to the oral contraceptive companies (all of whom make this claim) and the FDA. Dr. Goodnough and others should *not* expect either physicians or the general public to simply disregard this medical information from qualified research departments in favor of the more desirable (for proliferers) belief that the Pill really can’t do what the pharmaceutical researchers all claim it can.

Dr. Goodnough says, “in light of the fact that there is no definitive information on whether the embryo implants or not, [Randy Alcorn] could just as easily assume that the embryo always implants and survives despite seemingly hostile changes in the endometrium.” I would certainly like to make this assumption, as it would relieve me of any sense of moral obligation. Unfortunately, the assumption seems to be based on wishful thinking, not scientific observation or logic. It is clearly *not* equally valid to draw either conclusion after looking at what everyone, even Dr. Goodnough, agrees are “seemingly hostile changes in the endometrium” caused by OCPs. To admit that this appears to be true and then to say—without producing any evidence to support it—that one might just as well conclude the embryo “always implants and survives” is nonsensical, isn’t it? If the endometrium appears to be hostile, clearly the burden of proof falls upon those, such as Dr. Goodnough, who argue it is not (or, who argue that conception and a hostile endometrium are mutually exclusive). Dr. Goodnough needs to produce evidence to show that a *seemingly* hostile endometrium is not a *truly* hostile endometrium. But he fails to do so. In the absence of such evidence, aren’t we forced to assume that the endometrium is indeed what it seems to be—hostile to implantation? To present these conclusions as equally valid, in the absence of evidence supporting what is contradictory to empirical observation, is untenable.

Among those who have no vested interests, I have virtually never found anyone arguing that the Pill cannot or does not hinder implantation. The *only* people I’ve found who make that assumption are those who have vested interests in doing so—proliferers who use, prescribe, or recommend oral contraceptives, but do not (understandably) wish to believe they can jeopardize human life.



My most serious concern with Goodnough's article was a misrepresentation of my argument, followed by a striking misquotation from my book. The misrepresentation is claiming that I "attempt to equate the so-called morning-after pill with the OCP." In fact, I do not equate the two—I simply point out that the morning-after-pill is not some novel chemical invention, but four standard OCPs taken together (suggesting that the pills already have something in them which raises the frequency of an abortifacient effect as the dosage increases). But to back up his misrepresentation of my point, Dr. Goodnough quotes me as saying that the morning-after-pill "increases the chances of doing what it [the birth control pill] already does—cause an abortion."

That does indeed sound like I'm equating the two. Dr. Goodnough follows by expressing dismay that I could say such a thing. When I read the quotation, I too was dismayed. Why? Because I knew what other readers wouldn't—I did *not* say this. What I actually said, in all five editions of the book (Goodnough quotes from the second)—was this: the morning-after-pill "increases the chances of doing what it [the OCP] already *sometimes* does—cause an abortion."

Dr. Goodnough left out the all-important word "sometimes." This makes it appear I was claiming the OCP, like the morning-after-pill, acts primarily as an abortifacient. That would be an erroneous claim, of course. Indeed, readers of Dr. Goodnough's article now believe I was making that very claim. Any one who could have read what I actually said would know I was *not*. Unfortunately, this correction will never reach most of those who read the article, and will read it in the future. I am disappointed that such a misquotation was not corrected during the peer-review process of *Ethics & Medicine*. I can only hope Dr. Goodnough did not also leave out critical words when he cited other sources, but I have no assurance this is the case.

I am not straining out gnats here. It is one thing to misunderstand an author and in the process misrepresent his position to others. It is another thing to actually revise what an author has said, in this case leaving out a critical operative word, resulting in misrepresenting the author and misleading the reader. I trust that was not Dr. Goodnough's *intention*, of course. But it certainly was the *result*.

This critical gap between intentions and results leads naturally to my final and most serious concern about Goodnough's theories, one that lies at the heart of my disagreement with him. He says, "When I prescribe the OCP, I do not want an embryo to die. The death of the embryo, should it occur, is the undesired result of intending to prevent fertilization" (p.45).

First, we should remember that some patients will consider the risk of carrying an unwanted child as less serious than the risk of killing an unwanted child. They will think in terms not simply of the preferences of adults to not have children, but the welfare of children themselves. We certainly all want physicians to have clear consciences—but let's not forget their patients also have consciences, and it is of paramount importance that the patient be able to act in good conscience, informed by their physician of the existing evidence, and the interpretations of not one, but both schools of thought.

But my main concern is with this matter of intentions. As a college ethics professor and author of several books on ethical issues I've interacted with people in hundreds of different vocations. Interestingly, I have found that the logic of "sincerity and good intentions makes something right" seems more prevalent among medical professionals than any other group.

I certainly agree most women taking the Pill don't intend to get abortions. In fact, I'm convinced 99% of them are unaware this is even possible. (This is precisely the problem, and why we need true informed consent by Pill-takers.)

The fact remains that while the *intentions* of those taking the Pill may be harmless, the *results* can be every bit as fatal. A nurse giving a child an injection may sincerely intend no harm to a child. But if she mistakenly injects him with a fatal poison, her good intentions will in no way lessen the tragedy. Whether the nurse has the heart of a murderer or a saint, the child is equally dead. The best intentions do nothing to reverse the most disastrous results.

Even if the Pill doesn't usually cause an abortion, whenever it *does* do so it is just as real an abortion as if that were its intended effect. So, I certainly believe that when he prescribes OCPs, Dr. Goodnough does not want an embryo to die. But I find that irrelevant to the question at hand. The chances of the embryo's (I prefer the term "pre-born child's") death is in no way lessened by the prescribing physician's or the mother's or anyone else's intentions.

By all means, let us be sincere and intend only to do good. But we must never argue for the legitimacy of a course of action based on our sincerity and good intentions. We must act instead in light of the actual evidence that indicates what consequences may come from the action itself. Whether or not an action is moral depends on a number of factors, not least of which is the possible impact on the welfare of a human being. This is particularly true when it involves an innocent human being who is unable to speak up for himself, and for whom we are commanded by God to act as advocates (Proverbs 31:8-9).

# Bioethics *at the* Bedside



**July 18-20, 2002**

**A Conference, Seminar, and  
Set of Institutes on Bioethics**

on the campus of Trinity International University, Deerfield IL USA

A major national/international event examining the host of ethical and caregiving challenges in clinical settings resulting from the interaction between health care givers and the patient, including quality of life considerations, patient demands and refusals, addressing spiritual issues, resource allocation, issues in long-term and palliative care, end-of-life treatment, and genetic and other interventions to postpone death.

**Presented by:**

The Center for Bioethics and Human Dignity • Christian Medical & Dental Associations • Christian Legal Society • Nurses Christian Fellowship  
Americans United for Life • Fellowship of Christian Physician Assistants  
Trinity International University

**Bioethics Institutes/Seminars July 15-20, 2002**

Intensive, Advanced, Ethics Committees & Consultants Institutes

July 17-20, 2002 Pre-Med/Undergraduate Institutes

July 22-24, 2002 *Making a Difference Through Bioethics Seminar*

888.246.3844 voice 847.317.8153 fax [www.cbhd.org](http://www.cbhd.org) on-line

## CLINICAL ETHICS CASE CONSULTATION

ROBERT D ORR, MD, CM

A family physician requested an ethics consultation on a hospitalized patient asking for advice about placement of a feeding tube in a patient 1 week after a stroke. The ethics consultant spoke with the physician, the patient's family, and her bedside nurses. He reviewed the chart and saw the patient, then wrote the following consultation report:

### **Narrative**

This 73 year-old white female developed multi-infarct dementia about 4 years ago, but remained quite functional (alert, responsive, ambulatory) with short-term memory loss, and was cared for by her children until she had an upper gastro-intestinal hemorrhage 3 months ago. After a few days in hospital, she went to a nursing home in the community where she settled in quite well, though she thought she was living in her daughter's home. Seven days ago she suffered a large ischemic cerebrovascular accident (CVA). Initially she was unresponsive, and it was felt that she would not survive. However, in the past few days she has improved. She now opens her eyes, smiles, recognizes family, and has given 1-word responses at least twice. She remains totally paralyzed on her right side. A swallowing evaluation shows very poor function; she would likely be unable to take in adequate nutrition and hydration with oral feedings, and would be at risk of aspiration.

On admission her family requested limitation of treatment (Do Not Resuscitate, Do Not Intubate, Do Not Transfer to Intensive Care Unit) based on previous statements and her written Durable Power of Attorney for Health Care (DPA/HC). She initially received standard intravenous fluids, but when she began to improve, total parenteral nutrition (TPN) was begun as a temporary measure until a decision could be made about a feeding tube. Her family are contemplating foregoing tube feeding based on her previous wishes, but they and the careteam share some discomfort with this plan since she is still improving, and her ultimate level of function is uncertain.

The patient is awake, fixes and follows, smiles, and grips fingers on request, but she is unable to give consistent answers or head shakes or finger squeezes to 'yes or no' questions. Her 2 daughters live locally, and they have been in close communication with their 3 brothers from out of state. They report that the patient was a homemaker and a substitute elementary school teacher. They describe her as an active, feisty, talkative woman before her dementia. Her husband died 24 years ago and she subsequently lived with a male friend for many years. He died about 4 years ago. She signed her DPA/HC nearly 5 years ago,



before she began to deteriorate. In it she named one daughter as her agent, and left instructions requesting no aggressive treatment, including no feeding tube, if she were to become (1) permanently unconscious, (2) terminally ill, or (3) when the burdens of continued treatment exceeded the benefits. In addition, she expressed verbally to her children that she did not want to be a burden, did not want to survive 'as a vegetable', did not want to be kept alive by artificial means, and did not want to live in a nursing home. Of note in her family history is that her father died at age 74 after his 3rd CVA, and her sister has been in a nursing home, disabled from a CVA, for the past 11 years. The patient was a member of the Church of the Nazarene as a young adult, but has not attended church for many years.

**Assessment:**

This woman is unable to make decisions but has left instructions about her treatment wishes. Her family are uncertain how to interpret her wishes in light of her uncertain prognosis.

**Discussion:**

The previously expressed wishes of a patient should almost always be honored by her caregivers. It is very important in honoring them, however, to have a clear understanding and interpretation of their applicability. It is ethically permissible to withhold treatment which might postpone death for a particular patient, if it is felt that the maximal function or quality of life that she can attain is below a threshold that she would find acceptable.

Most healthcare professionals consider artificially administered fluids and nutrition to be medical treatment, thus subject to the same degree of discretion as other standard treatments. A minority maintain that fluids and nutrition, even if they cannot be taken orally, are morally obligatory.

In this case, the patient specifically said she would not want a feeding tube in several circumstances. The important question is whether she is currently in one of those circumstances. It might be argued that she is 'terminally ill' because she is likely to die in the foreseeable future of cerebrovascular disease or its complications. However, with continued treatment, she might survive for some time and might find her quality of life acceptable. Some might also argue that the burdens of tube feedings are greater than the benefits of continued life in this severely disabled patient. This contention is difficult to defend since gastrostomy tubes are generally felt to represent low-burden therapy, although they do often require hand restraints. In addition, this patient has adjusted to nursing home care which she had previously thought would be unacceptable, so it may be that dementia has changed her values.

### **Recommendations:**

In light of the uncertainties of interpretation of her wishes and of her prognosis, the following treatment options would be ethically permissible:

- (1) If her professional caregivers believe there is insufficient chance of improvement to a level of function which her family believes she would find satisfactory, it would be permissible to stop TPN, not use tube feedings, and allow her to eat and drink if she wishes, recognizing this might not provide sufficient fluids and nutrition for long-term survival. Then comfort would be the primary goal of continued therapy. If she should aspirate, it would be acceptable to either use or not use antibiotics.
  
- (2) If her family believes she would choose to have adequate fluids and nutrition until her neurologic prognosis is more certain, it would be permissible to continue a short term trial of TPN (for a few days) or institute a trial of tube feedings (for a few weeks). If she failed to improve sufficiently, this treatment could then be stopped and comfort care continued.

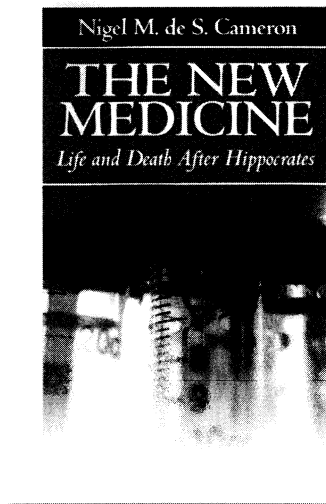
### **Follow-Up:**

The patient's TPN was continued for another 3 days during which she improved sufficiently to be able to swallow. She was discharged back to the nursing home with plans for comfort care and limitation of treatment, including no aggressive treatments and no re-admission to the hospital unless required for her comfort.

Six weeks later, the patient was maintaining adequate nutrition and hydration by mouth. She had experienced little further improvement in her neurologic condition. She was awake and smiled frequently, recognized her daughters, but was unable to speak. Her family and professional caregivers were satisfied with the process of decision-making and also with the outcome. **E&M**

# THE NEW MEDICINE

Bioethics Press presents the revised edition of founding editor Nigel Cameron's manifesto on the rise and fall of Hippocratic medicine. With a new introduction, *The New Medicine* is an important analysis of modern medicine's abandonment of the core principles that has been its essence for 2500 years.



**Price: \$21.95**

Visit [www.bioethicspress.com](http://www.bioethicspress.com)  
for ordering information.

The Bioethics Press  
PO Box 1032  
Highland Park, IL 60015 USA

## **Praise for the original edition:**

"It is hard to imagine a more timely and helpful book than *The New Medicine*."

**THOMAS KENNEDY**, PROFESSOR OF PHILOSOPHY, VALPARAISO UNIVERSITY

"*The New Medicine*... should be welcomed by those who have the courage to join a movement of reform aimed at restoring medicine to its healing mission."

**RICHARD JOHN NEUHAUS**, DIRECTOR, RELIGION AND PUBLIC LIFE

"In *The New Medicine*, Dr. Cameron has done much to earn the title of a second Hippocrates."

**DR. HAROLD O.J. BROWN**, REFORMED THEOLOGICAL SEMINARY

"In the post-WWII era physicians began to water down the basic tenets of the Hippocratic tradition, and then they abandoned them. That's what this important book is all about: the rise and fall of Hippocratic medicine."

**C. EVERETT KOOP**, FORMER US SURGEON GENERAL

"I welcome Dr. Cameron's scholarly contribution to a debate that is far from over."

**SIR JOHN PEEL**, KCVO, PAST PRESIDENT, BRITISH MEDICAL ASSOCIATION

## THE ADVANCE DIRECTIVE: AN EXPRESSION OF AUTONOMY, BUT ALSO OF CARE

PROF DR KLAUS SCHAEFER

PROF DR ULRICH EIBACH

DEBI ROY

Has, as has been frequently reported, the desire to determine the manner of one's own death really increased in Germany? Regardless of how long life lasts—whether “the years of our life are threescore and ten, or even by reason of strength fourscore,” as is written in Psalm 90, there is, in the opinion of many philosophers and ethicists, a desire for autonomy prior to death<sup>1</sup>. Some people are not only skeptical about modern medicine, but toward physicians who are incapable of sufficiently distancing themselves from this desire for autonomous death in borderline cases. Modern medicine and technology have, on the one hand, provided considerable new opportunities for treatment in many areas; on the other hand, they raise fears about extending life at all costs. By means of an advance directive it is possible decisively to influence the final stages of life<sup>2</sup>. There are, however, only a few studies available about what patients, i.e. the affected persons, think about advance directives<sup>3,4</sup>. This could be due to the fact that, despite an increasing interest in advance directives, the majority of the population is still unfamiliar with them. However, it is also necessary to ask if the premise that patients and/or healthy persons are interested in autonomously directing their final stages of life is even correct. It might very well be that the problem of dying is blocked out by the people, and that they hope that other people—relatives, friends, or physicians—will handle the final stages of their lives in the proper way. In St. Joseph Hospital in Berlin-Tempelhof, 120 patients, who had been admitted for various reasons, were systematically interviewed in connection with advance directives. The results of these interviews were in part very surprising and not only raised questions, but also indicated possible ways to help people not to avoid thinking about the final stages of their lives, but to make recommendations as to how the terminal stage of life can be arranged to meet their wishes.

### The Data

Only six of the 120 patients included in the study had already completed advance directives. Twenty-one additional patients were familiar with the concept of advance directives, but 93 patients (ca 77%) had never even heard of the possibility. The interpretation of these numbers appears to be simple, if you assume that despite all the publicity in the various media, insufficient attention has been given to the subject of advance directives. However, should it not also be considered that the problems which arise for every individual in connection with his



or her death are suppressed to such a degree that even the vaguest notion of talking about this will be rejected by stating that he or she is not familiar with advance directives?

Two of the study's questions dealt with *confidence*. Patients were asked if they assumed that their attending physician would make the correct decision for them in the case of a difficult situation, and additionally if they thought that close relatives or friends would also make the correct decision for them in such a case. In both cases the overwhelming majority of answers were "yes"; more than 75% of those questioned were certain that physicians and/or relatives and friends would make the right decision for their life. These responses were surprising in that only a few patients said that they had even spoken with relatives, friends, or the physician about how they were to be medically treated in cases where they were unable to decide the matter for themselves. Apparently the patients have a "blind faith" in these confidants that is so great that they can be relied on properly to solve problems that have never even been the subject of discussion between these people and the patients themselves. Seeing that this subject is so obviously avoided, it is necessary to ask if relatives, friends, or even family physicians can offer any information about the patient's *probable will*, when the patients have never spoken about it? Is there not a danger that it is only the patient's "*supposed will*" that is being expressed, which in turn is marked by the confidant's own concepts of life and not those of the affected person? It is also interesting that the vast majority of the patients questioned, although they are confronted with their illness in the hospital, are not of the opinion that they can make decisions about the end of their own life at that time. This response is attributable to the previously mentioned confidence, because most of the persons questioned suppose that decisions which affect the end of their life can be discussed by relatives, friends, or physicians whom they trust – *without the patients themselves*. Are these results not a clear contradiction of the widely propagated desire to be autonomous? Would it not be possible to argue that the patients consciously forfeit their autonomy in favor of the care expected of their relatives, friends, physicians, and healthcare specialists? Might it not furthermore be presumed that the expression of confidence also represents a self-determined behavior proving that patients want to surrender self-determination in this phase of life to trusted persons?

### **Ethical Reflection**

Medical advances have raised the question as to whether all the opportunities that modern medicine provides really serve the patient's well-being and desires. Simultaneously with the advances of modern medicine, western societies have been subject to a pluralization and individualization of their concepts of life and values, the core of which has become the pursuit of one's own happiness *in this life*. The consequence is that there are hardly any generally held concepts about the sense and success of life and the pursuit of "the good"<sup>5</sup>. Everyone decides for themselves how they would like to live and what they strive for. Simultaneously, the concept "human dignity" has become analogous to "autonomy" in the sense

of an empirical autonomy for decision-making and action. In medical ethics, court rulings have led the traditional ethos of care, as an expression of paternalistic guardianship, to be replaced by the autonomy of the patient. That has been increasingly emphasized and legally reinforced. The patient's will has become the greatest measure of medical treatment.

The results of this questionnaire, however, show that this ethical and legal approach to autonomy for decision-making and action is not only difficult to maintain with people who were never capable of such an autonomous self-determination and life (e.g., mentally impaired) or are no longer capable (e.g., dementia patients), but also for some such persons who, on the basis of their cerebral-organic, mental, and educational condition, are not in the position to make such decisions concerning their lives.

The more severe a crisis and helplessness set off by illness, the unpredictability of its progression, and the lower the social and educational status of the person, the less the person has the ability and opportunity to insist upon his or her rights as a patient. The rights of patients, which the ill or the person in need must first request, represent very little protection for those persons who—for whatever reason—are *not able* to demand their rights. In other words, this says that ethics based on the autonomy of the patient has to be entrenched in a primary ethos of care which provides binding general ethical principles for action and treatment for the providers of medical and health services; principles which serve the well-being of sick and terminally ill persons. On the one hand it is unethical to request that a person in a crisis be forced to make decisions which he or she is not able or willing to make, on the other hand such a lack of decision cannot be the justification for others treating such a person just as they themselves wish.

The persons surveyed show that the patient's confidence in the physician is great. By surrendering to physicians and relatives, for the most part, patients in crisis or borderline situations demonstrate that they consider proper or good decisions for them to be decisions which serve their well-being, and not primarily decisions that respect their will. The determination and nurture of their well-being is more important to them than respecting their will, about which they are unsure or which they do not wish to assert. In other words, their well-being is more important in the illness than is their autonomy. With respect to their well-being, they consider physicians to be competent, more competent than they are themselves. And the value placed on the relatives and their decision-making powers with respect to their well-being, shows that sick persons sense how important their relationships to loved ones and caretakers are, and how they—if they have such relationships—put great trust in these friends and relatives. More important than their autonomy and autonomous well-being is that they are involved in *interpersonal, loving, and trusting relationships*.

If this interpretation is transferred into an ethical theory, it implies an ethics of virtues, an ethic that formulates the medical and healthcare benefits and

contributes to making these virtues a part of the medical and healthcare training so that they mark and distinguish the actions, is decisive for the development of confidence. Admittedly, physicians who incorporate and express a virtuous attitude are not in and of themselves a guarantee that they will act in a manner that is beneficial to the patient's well-being. To accomplish this, even physicians and healthcare specialist who are "virtuous" and concerned about the well-being of their patients require ethical principles *for action*. Such principles are just as much a part of a confidence-building ethos of care as ethical virtues of the physicians and healthcare specialists. The two complement each other by necessity.

Regardless of the confidence expressed in the relatives and physicians, both patients and healthy persons should be encouraged to consider the possibility of making an advance directive. If there is no advance directive, an advisor will be appointed in those situations where a person is no longer competent to provide information concerning their desires<sup>6</sup>. This advisor will then decide in those cases in the field of healthcare that require approval of the guardian for risky treatment. Even if it can be assumed that these institutions are very capable of making appropriate decisions, an advance directive can provide more concrete evidence of desires for how the final phase of life should be arranged. An advance directive therefore represents an important source of information. Close relatives, friends, and physicians may—if there is no advance directive—offer information about the supposed desire of the patient in such situations, and this will certainly be given consideration, if it can be verified with some degree of certainty, but, as mentioned above, only a few patients have discussed this problem with their relatives. Therefore only a few relatives, at least according to the results of the study, are able to express the supposed desires of the patients; as mentioned, the vast majority will, in contrast, fall back on their own interpretation of the "supposed desires" of the person affected, and this is not necessarily a reflection of the patients own attitudes, but is frequently a summary of the confidant's own ideas. The consequence is that the writing of an advance directive with the appointment of a proxy in health affairs as a person empowered with the power of attorney, is the only solution for endowing trusted persons with the necessary, and legal, authority needed. Only in this manner is it possible to legally provide them with the care desired and apparently expected. In summarizing the results of the survey, it should be noted that advance directives should not only be seen as a possibility for maintaining autonomy prior to death. They should rather be seen as an empowerment of close relatives to make one's own desires credible. Even if, as per the results of the survey, it is not the autonomy, but the desired care of others that becomes the center of ethical considerations, the patient's ideas and expressed desires maintain a basic importance. The desire to legally establish such directives is therefore justified and helpful for everyone involved (patient, relatives, friends, caregivers, physicians, etc.).

In this manner it will also be possible to realize the patients expressed hopes that persons close to him or her take care of him or her. The legal appointed advisor or guardian would then only become involved in special borderline cases. **E&M**

## References

- <sup>1</sup> Beckmann JP. Patientenverfügungen: Autonomie und Selbstbestimmung vor dem Hintergrund eines im Wandel begriffenen Arzt-Patienten-Verhältnisses, Zeits. mediz. Ethik 1998;44:143-156.
- <sup>2</sup> Reiter-Theil S. Medizinethische und rechtliche Aspekte der Patienten-Verfügung: Kontroverse und Empfehlungen, Krankenhaus und Recht 1998;5:17-24.
- <sup>3</sup> Eibach U., Schaefer, K. Advanced directives: Results of a patient survey and commentary from the ethical perspective, Nephron 1998;78:373-377.
- <sup>4</sup> Kielstein R. Haben Sie eine Patientenverfügung? Deutsch-japanisch-amerikanische Studie Der Dialysepatient 1997;22:16-18.
- <sup>5</sup> Eibach U. Euthanasie und 'lebensunwertes' Leben. In: Sterbehilfe – Tötung aus Mitleid?, R. Brockhaus Wuppertal, 1998;261-65.
- <sup>6</sup> Anonymous. Grundsätze der Bundesärztekammer zur Ärztlichen Sterbebegleitung, Sept. 1998, Dt. Ärzteblatt 1998;95:A 2366-2367.

---

**Prof Dr Klaus Schaefer:** St. Joseph-Krankenhaus, Med. Abt. II, Bäumerplan 24, Germany.

**Prof Dr Ulrich Eibach:** Medizinische Einrichtungen der Universität Bonn, Evangelische Seelsorge, Sigmund-Freud-Str. 25, 53105 Bonn, Germany.

**Debi Roy:** St. Joseph-Krankenhaus, Med. Abt. II, Bäumerplan 24, Germany.



# CARE FOUNDATION

CALIFORNIA AUTOIMMUNE RESEARCH AND EDUCATION FOUNDATION

## **Medical Consortium to Investigate Diabetes Treatment without Using Embryonic Stem Cells in Research**

Santa Ana, California (September 16, 2001) – The newly-formed Orange County-based California Autoimmune Research and Education Foundation has begun a unique investigative project that will avoid using controversial embryonic stem cells in any of its research that will explore a novel treatment method for Type 1 diabetes.

The medical research consortium affiliated with CARE Foundation's **Diabetes Research Project** has suggested that it may be possible genetically to "reprogram" a diabetic patient's own adult stem cells to manufacture insulin, replacing damaged or destroyed insulin-producing Islet of Langerhans cells in the diabetic pancreas.

This reprogramming technology may allow creation of a custom-made treatment for Type 1 diabetes. "All of our research can be done," CARE Foundation president William Welty suggests, "without using embryonic stem cells in any of our study phases."

"Skyrocketing advancements in biotechnology have led to a recent firestorm of debate concerning use of embryonic stem cells in medical research," says Welty. "Proponents of using embryonic stem cells in research argue that using stem cells shows great promise as the basis for investigating new treatment methodologies for disease."

"Unfortunately for these proponents," Welty add, "their detractors cite numerous studies that warn researchers about the inherent instability of embryonic stem cells. These studies reveal that embryonic stem cells appear to be unsuitable as the experimental foundation upon which to craft medical research projects."

One of the most controversial aspects involved in medical research that uses embryonic stem cells is that harvesting stem cells from embryonic blastocysts kills the hours-old embryo from which the stem cells are harvested.

"CARE Foundation's Diabetes Research Project avoids the problem entirely by not using embryonic stem cells at all," Welty observes.

CARE Foundation's medical research consortium recently developed a proprietary and patentable method to identify, target, mark, and extract adult stem cells from consenting adult patients.

Intellectual property and patent rights regarding their technology have been assigned to CARE Foundation's parent company, the Compassionate Use Project, Inc.

*The CUP*, as it is popularly called, is a Nevada non-profit tax-exempt 501(c)(3) educational corporation. It operates a popular diabetes education web site at <http://compassionateuse.com>.

"The CUP has already taken steps to obtain both domestic and foreign utility patent rights to all processes affiliated with the marking and extraction technology," Welty says.

CARE Foundation's Diabetes Research Project, currently in its start-up phase for its six-year, \$28 million investigation, is slated to begin full-time operations in January 2002.

When perfected, the fully developed technology to "reprogram" the stem cells of diabetic patients as insulin-producing cells will be licensed directly to diabetic patients themselves, thus making the treatment available at a pennies-on-the-dollar cost compared to what costs might be were it to be made available through traditional for-profit corporations.

"The treatment that we hope to develop and perfect will belong to the afflicted patients themselves through our licensing process," Welty notes. "As a non-profit consortium, we don't have high-cost investment funds or venture capital developers to whom repayments must be made from eventual licensing income."

"As a result," Welty concludes, "the cost for treating—or perhaps even curing—Type 1 diabetes could be exponentially less than it might otherwise be."

The treatment methodology that CARE Foundation will investigate also shows promise for other disorders that are thought to be autoimmune-related, such as lupus and some forms of arthritis.

## 'EUTHANASIA' IN THE THIRD REICH: LESSONS FOR TODAY?

JA EMERSON VERMAAT, MA

'At this stage I do not feel that I am going to die, but I don't want to die away later with my body being reduced to a little more than a lump. Please, promise to help me before this moment comes.' Today, many physicians are familiar with incurably ill patients requesting them to end their lives because of unbearable suffering. In the case of the above quote the request for euthanasia is not made by a desperate twenty-first century patient. One finds it in the Nazi film *Ich Klage an* (I Accuse) which was produced in 1941. The message of the the two hour long film was that doctors who submit to an incurable patient's death wish act legally and morally.<sup>1</sup>

Hanna, the beautiful young wife of professor Thomas Heyt, is suffering from multiple sclerosis. Her husband, the newly appointed director of the Anatomical Institute of Munich University, knows that there is little hope for his wife. Hanna first asks her personal physician and family friend Bernhard Lang to end her life should the moment of unbearable suffering occur. Lang refuses and says: 'I am your best friend, but I am also a doctor, and as such I am a servant of life. Life must be preserved at any cost.'

Hanna then approaches her husband Thomas in a very emotional way: 'You must help me. I want to remain your Hanna till the very end, I don't want to become somebody else who is deaf, blind, and idiotic. I wouldn't endure that. Thomas, if you really love me, promise that you will deliver me from this beforehand.'

Hanna's medical condition rapidly deteriorates. Thomas and Bernhard realize she has only a few weeks to live. One day they are together at Hanna's bedside. Hanna kindly asks Bernhard to leave the room. She wants to be alone with Thomas. Bernhard goes to the piano in the living room where he starts to play. While the piano music can be heard in the bedroom Thomas fetches a bottle containing a sedative and pours a fatal dose into Hannna's glass. Before passing away Hanna says, 'I feel so happy, I wish I were dead.' Thomas replies, 'Death is coming, Hanna.' Hanna responds, 'I love you, Thomas.' 'I love you, too, Hanna,' says Thomas.

Bernhard is furious when Thomas informs him what has happened. Domestic servant Bertha then accuses Thomas of murdering his wife and takes him to court. At issue is: can a doctor be allowed to cause the death of a terminally ill patient after that person explicitly requested him to do so? One of the witnesses is Bernhard. He says that he initially also opposed Hanna's request,

but now he sees things from a different perspective. 'Thomas, you are not a murderer!' he says loud and clear in the courtroom. Thomas himself then accuses ('I accuse!') those doctors and judges who by adhering to strict rules fail to serve the people. 'Try me! Whatever the outcome, your judgment will be a signal to all those who are in the same position like me! Yes, I confess: I did kill my incurably ill wife, but it was at her request.'

From a propagandistic point of view the film was a success. The Gestapo, the secret state police, reported that the film received much attention in the whole Reich.<sup>2</sup> A Dutch woman living in Düsseldorf at the time told me in an interview: 'All my colleagues were impressed by the film. They suddenly understood the dilemma of a doctor who is confronted with an incurable disease.'<sup>3</sup>

### **Hitler's 'Euthanasia Decree'**

This remarkable propaganda film presents a case and a logic with which today's medical profession is quite familiar. It is not the crude Nazi ideology of killing 'worthless life.' Rather it makes a smart plea for a terminally ill patient's right to a 'humane' way of dying. Sixty years ago the Nazis occasionally used similar arguments as today's humane and sincere advocates of euthanasia. Karl Brandt, the head of Hitler's euthanasia program, claimed at his trial after the war: 'The underlying motive was the desire to help individuals who could not help themselves and were thus prolonging their lives of torment.'<sup>4</sup> However plausible or humane this may sound, the reality was far from humane. Indeed, the Nazis went far beyond killing the incurably sick, and few of the 'individuals' Brandt had in mind actually made a request that 'their lives of torment' should not be prolonged.

'Euthanasia' in the Third Reich was even a prelude to the Final Solution (*Endlösung*).<sup>5</sup> Euphemistic terminology and covering up was the rule. Hitler's Euthanasia Decree ('Erlass') of 1 September 1939 ordered his personal physician Dr. Karl Brandt and Reichsleiter Philip Bouhler, head of the Reich Chancellery, 'to enlarge the authority of certain physicians to be designated by name in such a manner that persons who, according to human judgment, are incurable can, upon a most careful diagnosis of their condition of sickness, be accorded a mercy death (*Gradentod*).'<sup>6</sup>

Similar criteria were later found in *Ich Klage an: Mercy killing (Gnadentod* is in Nazi language synonymous to *Erlösung*) for those whose suffering could not be prolonged. However, the decree did not refer to the need for a specific request by the patient, in most cases persons with mental disorders. Karl Brandt later said in Nuremberg that 'incurably sick persons' primarily meant 'insane persons.'<sup>7</sup>

Hitler's decree was written on personal letterhead ('Adolf Hitler. Berlin') and highly secret. It was never made law, even when pressure was brought to bear to do so. The official bureaucracy was largely bypassed. Even Franz Gürtner, the Reich Minister of Justice, initially knew nothing about Hitler's secret legalization of euthanasia, which by 1941 was practiced on a rather wide scale.

When Evangelical-Lutheran pastor Friedrich von Bodelschwingh, head of the large hospital and nursing-home 'Bethel,' confronted Gürtner with mass killings in nursing homes and mental institutions, the latter was upset.<sup>8</sup> While Nazi law provided for forced sterilization (Sterilization Act of July 1933) of those having congenital diseases, euthanasia itself had never been officially legalized.<sup>9</sup> Gürtner also received telegrams and letters from bishops who protested the killings. He then raised the matter with Philip Bouhler from the Führer's Reich Chancellery and Interior Minister Wilhelm Frick who both seemed to know more about the matter. When finally in 1940 a representative of Bavarian governor Franz Xaver von Epp showed up in Gürtner's office and asked him to do something about certain Gestapo actions in mental institutions and subsequent disappearance of mentally ill patients, Gürtner sounded resigned. 'My hands are tied,' he said. 'I can't do anything about it, go to Mr. Bouhler at the Führer's Chancellery Office, he can tell you from whom originated the order.'<sup>10</sup>

### Operation 'T-4'

The Nazi euthanasia program was code-named T-4. This referred to *Tiergartenstrasse 4*, the headquarters of the newly created bureaucratic apparatus. It was an insider's group bound to strict secrecy rules. The Führer's euthanasia decree was implemented through a number of instructions and administrative arrangements. Mercy killings took place in nursing homes and mental institutions. There were special questionnaires regarding a person's health. On the basis of these documents an ever growing number of individuals was selected for T-4 action. Heads of establishments who were not initiated into T-4 practice and procedures were often tricked into believing that a number of their patients had to be transferred to better equipped treating centers. Not everyone was tricked, however. Pastor von Bodelschwingh, for example, suspected widespread abuse of medical standards and successfully sabotaged attempts to transfer patients under his care.<sup>11</sup>

Abuse was beyond von Bodelschwingh's worst suspicions. Operation T-4 centers were places of brutal medical experiments and mass killings of unwanted people considered a burden to society. They were *Tötungsanstalten* (killing institutes). There were six of them: Grafeneck, Hartheim, Brandenburg, Sonnenstein, Bernburg, and Hadamar. In these special T-4 establishments nearly 9,000 people were gassed in the first half of 1940.<sup>12</sup> The total number of killings probably exceeded 100,000. The killings provided know-how for the subsequent gassing of the Jews in extermination camps. Indeed, under the name of *Sonderaktion 14 f 13*, T-4 even extended its activities to concentration camp inmates. More than 3,000 deformed children also fell victim to the T-4 frenzy.<sup>13</sup>

Doctors and medical staff involved in T-4 and other killing operations generally performed their duties with devotion and zeal. They sometimes even presented their actions as 'humane.'<sup>14</sup> According to Menges, 'It is incomprehensible that doctors lent themselves to such things. Even more incomprehensible is this: they did their job often with great enthusiasm, sometimes they were even excited

about its scientific value.’<sup>15</sup> On the other hand, their duties could turn into routine, especially in the concentration camps. *Sonderaktion 14 f 13*, according to Menges, ‘marked a new stage which would eventually lead to the destruction of all undesirables. Doctors were part as an extra: their role was to give the action ethical legitimacy.’<sup>16</sup>

These hideous crimes were still called ‘euthanasia,’ which was synonymous with the elimination of unworthy life. They had nothing in common with the humane kind of voluntary euthanasia which the Nazi filmmakers and the leadership wanted to portray as reality in a film like *Ich Klage an*. Yet, this portrayed reality, too, was part of the multifaceted Third Reich. Only a minority of doctors participated in mass killings. Many others did not know about them or acquiesced as soon as rumours could no longer be denied. However, euthanasia proper as portrayed in *Ich Klage an* was also practiced. The fact that some bureaucratic elements pushed for official legalization<sup>17</sup> (in vain, however) is an indication that ‘normal’ euthanasia was practiced on a rather wide scale. In cases of euthanasia death certificates invariably mentioned different causes of death than the real one. The film *Ich Klage an* shows that such euthanasia practices were a topic of debate among physicians. The Security Service (SS) reported that younger doctors were less inclined to oppose voluntary euthanasia than their older colleagues.

### **Protests**

In general the medical profession was conspicuously uncritical about the Nazi euthanasia programme.<sup>18</sup> Instead, abuse of human life by leading scientists and university professors was widespread. ‘Every university anatomical institute in Germany was the recipient of the cadavers of Nazi terror.’<sup>19</sup> Nazi ideological thinking on racial superiority and eugenics pervaded the whole profession. As Shevell notes, ‘a perversion of medicine occurred in the more traditional settings of the medical clinic, the chronic care institution, the university hospital and academia among the mainstream of physicians.’<sup>20</sup> However, a number of doctors did protest or sabotage the euthanasia programme, particularly in the Rhineland. Menges describes the case of a ‘Professor C’ who through his contacts in Berlin had been briefed about the gassing of mental patients. He informed all the Rhineland mental institutions which then took measures of obstruction. Consequently T-4 actions in the Rhineland utterly failed.<sup>21</sup>

Others protested and sabotaged, too, particularly people with a church background. We have already mentioned Pastor von Bodelschwingh’s intervention with Justice Minister Gurtner. Lothar Kreyssig, a judge from Brandenburg/Havel also informed Gurtner on what was going on. He did so in a letter dated 8 July 1940:

About two weeks ago an acquaintance told me about rumours of numerous mental patients having recently been transferred by the SS from their clinics and nursing homes to institutions in southern Germany where they were killed. . . . The issue of the meaning of these lives actually touches on the very issues of existence. It leads directly to the question of God. . . .

Destroying 'worthless life' is a serious matter of conscience. Life is a mystery of God. . . . It is man's incredible rebellion and arrogance to think he can terminate life because his limited judgment tells him that such life does not or does no longer have any meaning.<sup>22</sup>

Dr. Kreyssig was a member of the 'Confessing Church,' a vocal anti-Nazi movement within the mainstream German Evangelical Church (DEK). It was clear that his religious conviction prompted him to voice his concern. Evangelical-Lutheran Landbishop Theofil Wurm (Württemberg) was also very concerned. Grafeneck, one of the *Tötungsanstalten*, was in Württemberg and Wurm had noticed that a crematorium had recently been built there. Wurm saw and heard that great numbers of sick people were transferred to Grafeneck many of whom died soon after. The continuous dark smoke emanating from the crematorium's chimney could be seen clearly from far away. The bishop, who had previously performed pastoral duties in a health and nursing asylum, was well aware of what was going on Grafeneck. He knew that some Nazi doctors lied about the real causes of death on death certificates. On 19 July 1940, Wurm wrote a letter to Interior Minister Wilhelm Frick protesting the way death certificates were falsified and criticizing attempts to hush everything up (*Geheimnistuerei*). 'Destroying the life of feeble and helpless people, not because they pose a threat to us, but because we are weary of feeding and nursing them, is against the commandment of God.'<sup>23</sup>

Protests from the Catholic clergy had more effect. While Protestant leaders largely confined themselves to letters of protest or visits to officials and ministers, some Catholic clergymen raised the matter in public. Most vocal among them was Bishop Clemens August Graf von Galen (Münster). On August 3, 1941, Bishop von Galen preached fire and brimstone in the church of Saint Lamberti—and he made history.

It is a terrible theory which wants to justify murdering the innocent, which practically legalizes the violent killing of disabled people who are no longer able to work, the crippled, the incurably sick and the decrepit ones. . . . When one upholds and practices the principle that "unproductive" fellow human beings may be killed, woe then unto us all when we ourselves will be old and weak! When unproductive human beings may be killed, woe then unto the disabled who gave, sacrificed and lost their strength and healthy bones in the production process!<sup>24</sup>

It was not the first time that Bishop von Galen raised his voice, nor would it be the last time. According to Menges 'the protests of the Catholic clergy were a powerful factor which contributed to the suspension of the "euthanasia action" in August of 1941.'<sup>25</sup> What was suspended, however, was the official euthanasia action, unofficially 'euthanasia' practices continued. For example, in a special clinic near Düsseldorf 'euthanasia' was practiced as late as the Summer of 1943.<sup>26</sup>

Hitler was furious at Bishop von Galen. Letters of protest could be handled bureaucratically, public protests were quite something else. Himmler wanted to arrest the influential church leader straightaway, but Hitler, fearing further

confrontations with the church, preferred to wait till the war was over.<sup>27</sup> The Gestapo was ordered to monitor the bishop's movements and sermons. After the assassination attempt of 20 July 1944 on the Führer, Bishop von Galen was sent to the concentration camp of Sachsenhausen. He survived the camp, but he died in March 1946, shortly after the Pope had made him a Cardinal.

Thus, it is clear that the Nazi's failed to keep their euthanasia programme secret. Things were happening at too large a scale, too many people were involved, both as killers and as victims. As early as November 1940, William Shirer, the noted American correspondent in Berlin, knew interesting details about the 'mercy killings' in special asylums and about Philip Bouhler's leading role.<sup>28</sup>

### **The Nazi's Rationale for the 'Mercy Killings'**

Those involved in the *Euthanasie Aktion* sought rationalizations of all sorts. Although a number of Jews were also subjected to 'mercy killing' the basic intent of the 'action' was not ideological or racial. Hitler's political, social, and racial ideas were a hotchpotch. He detested people like chief ideologist Alfred Rosenberg for creating some sort of coherent *Weltanschauung*.<sup>29</sup> Most victims of the mercy killings belonged to the 'superior' Aryan race, Germans that is. Shirer believes that the killings 'were simply the result of the extreme Nazis deciding to carry out their eugenical and sociological ideas.'<sup>30</sup> On the other hand, Stephen Saetz argues that 'the Euthanasia Programme was instituted for pragmatic reasons which bore no relation to eugenics.'<sup>31</sup> In my view, the main impetus of the euthanasia programme was the view that for the sake of man's own preservation the weak and the strong cannot live and survive *together*. Hitler clearly pointed this out in *Mein Kampf*:

This preservation is bound up with the rigid law of necessity and the right to victory of the best and the stronger. Those who want to live, let them fight, and those who do not want to fight in this world of eternal struggle do not deserve to live.<sup>32</sup>

In time of war there is no place for the weak and the incurably sick, and euthanasia was the best way of getting rid of them. As Hitler formulated it in 1935: 'In the event of war he would take up the question of euthanasia and enforce it,' and 'solve the problems of the asylums in a radical way.'<sup>33</sup> Church leaders would be less inclined to oppose him in times of war than in times of peace, Hitler reasoned. And patients in need of long and continuous care were only a burden on society. The German economy did not have the resources for a long war, that is why the concept of *Blitzkrieg* (sudden and quick victories) was introduced in Nazi military thinking.<sup>34</sup> It was not accidental that Hitler's Euthanasia Order was officially given on the very first day World War II. But the order really dated from October 1939, and had been backdated to 1 September. Thus, the Nazi euthanasia drive was inseparably linked to the needs of 'the best and the stronger' in war, the weak and defenseless were a nuisance and had to be eliminated.

An additional problem was that there were not sufficient physicians to provide for adequate health care. Especially ordinary health insurance patients did not have easy access to their doctors and to hospitals. Only too often, waiting lists were long. With the outbreak of war many doctors joined the military and hospital beds were diverted for military use. 'The civilian population as a whole was deprived of medical services by comparison with the army,' writes Grunberger. He adds, 'But the reluctant shortage was partly made good by means of the Euthanasia Programme.'<sup>35</sup>

### The 'Slippery Slope' Debate

Nazi practices of euthanasia did not appear out of the blue. They were preceded by Social Darwinism and the debate on 'eugenics.' Racial and social hygiene and sterilization of inferior and worthless life were dominant themes in the Twenties.<sup>36</sup> This was referred to as *Schädlingsbekämpfung* ('pest control'). For example, in 1925, Robert Gaub, Professor of Psychiatry at Tübingen University, delivered a lecture on 'The Sterilization of the Mentally and Morally Sick and Inferior.' Also, in Hitler's address to the 1929, Party Rally at Nuremberg he calls for the removal of 700,000 to 800,000 of the weakest children, 'the end result will then even be an increase of strength.'

In July 1949 Leo Alexander, Chief US Medical Consultant at the Nuremberg Crimes Trials, published his essay 'Medical Science Under Dictatorship.'<sup>37</sup> It is still considered a classic piece of research. The Nazi rule in Germany was preceded by 'a propaganda barrage directed against the traditional compassionate nineteenth-century attitudes towards the chronically ill,' Alexander writes. 'Sterilization and euthanasia of persons with chronic illnesses was discussed at a meeting of Bavarian psychiatrists in 1931.'<sup>38</sup> Alexander's main concern was the shift in medical ethics and attitudes after January 1933 when Hitler was appointed Reichchancellor: 'Nazi propaganda was highly effective in perverting public opinion and public conscience in a remarkably short time. In the medical profession this expressed itself in a rapid decline in standards of professional ethics.'<sup>39</sup>

The crimes which the Nazis would commit later had their origins in prior subtle changes as stated in the following:

The beginnings at first were merely a subtle shift in emphasis in the basic attitude of the physicians. It started with the acceptance of the attitude, basic in the euthanasia movement, that there is such a thing as life not worthy to be lived. This attitude in its early stages concerned itself merely with the severely and chronically sick. Gradually the sphere of those to be included in this category was enlarged to encompass the socially unproductive, the ideologically unwanted, the racially unwanted and finally all non-Germans.<sup>40</sup>

At medical facilities the principle that physicians must fight for the life of their patients in accordance with the Hippocratic Oath came under attack. In Alexander's view this did not happen overnight, it happened gradually. This slippery slope concept has been criticized by Hanauske-Abel. He studied the contents of leading German medical journals from late 1932 to late 1933. 'The evidence



for a “snowballing involvement” of physicians in 1933, “that had started from small beginnings” is scant at best.<sup>41</sup> “The medical crimes against humanity presented at the doctor’s trial in 1946, were the result of changes in German medicine that did not evolve gradually over several years but happened largely within a distinctly brief period during early to mid-1933.”<sup>42</sup>

Hanauske-Abel primarily limits his investigation to one year. On that basis he claims that “the German medical community set its own course in 1933. In some respects this course even outpaced the new government.”<sup>43</sup> Things were not right from the very start and there was no ‘sudden subversion’ of medical ethics. But Alexander never uses the term sudden subversion. When he claims there was ‘a rapid decline in the standards of professional ethics’ he does not specify the word rapid. Was it one year, or three, or five? Even a change in five years can be called rapid—if we are discussing fundamental changes in medical standards, that is. Alexander points out that ‘by 1936 extermination of the physically or socially unfit was so openly accepted that its practice was mentioned incidentally in an article in an official German medical journal.’<sup>44</sup> But he only refers to one journal. And ‘openly accepted’ is not the same as generally accepted. Even as late as 1940/1941 euthanasia was still a matter of debate in the medical community as the film *Ich Klage an* clearly shows. The film was not only aimed at convincing the general public but also (dissident) sections of the medical community. Hanna’s own husband is a doctor who clashes with Bernhard, another doctor and also his best friend, over the question whether ending the life of terminally ill Hanna is acceptable or not. After long hesitation Bernhard changes his mind—in court finally. At that time there were still doctors who opposed euthanasia under all circumstances.<sup>45</sup> Formally, the law was on their side, but pressure to conform was enormous. The majority of doctors acquiesced or had changed their mind.

Alexander’s slippery slope theory cannot be contested on the basis of what happened in one year only (1933) when the whole medical community supposedly went berserk. Alexander’s observations about ‘small beginnings’ and ‘subtle shift’ refer to an ‘early change in medical attitudes’ and ‘a propaganda barrage even before the Nazis took open charge.’ The notion ‘that there is such a thing as life not worthy to be lived’ marked the starting point. This was before the Nazis came to power. Alexander fully recognizes that the year 1933 was crucial as he mentions the effectiveness of Nazi propaganda early on. The coming to power of the Nazis in 1933 accelerated things and culminated six years later in Hitler’s Euthanasia Decree which was deliberately couched in cautious language (in practice it gave a free reign to those who practiced mass killings).

After quoting Hanauske-Abel’s paper Edmund Pellegrino points to the importance of ‘the ethical values of the larger community.’ ‘In Germany this support system was weakened well before the Holocaust and the experiments at Auschwitz.’<sup>46</sup> This observation does not at all contradict Alexander’s finding that the proportions which the Nazi crimes ‘finally assumed’ had small beginnings.

## Relevance for Today

Leo Alexander's findings are still valid today. His essay was reprinted in 1996 and positively reviewed in an editorial in *Medical Sentinel*.<sup>47</sup> It would be wrong to assume that the decline of medical standards and ethics in the Third Reich is completely irrelevant to contemporary bioethical debates. Writing about the 'Nazi Doctors and Nuremberg,' Pellegrino points out:

So obvious these moral lessons seem now, and so gross the malfeasance, that it seems redundant to revisit them. Certainly we do not need to study such gross moral pathology that could never happen again. That is a dangerous conclusion. Moral lessons are quickly forgotten. Medical ethics is more fragile than we think. Moral reasoning based on defective premises tends to recur in new settings.<sup>48</sup>

A pharisaical attitude like 'I thank Thee, O God, that I am not like all those evil men' (cf. Luke 18:11) will not help to widen the gap between past and present.

Euthanasia was recently legalized in The Netherlands. The debate in parliament attracted world wide attention. Leading proponents of the new euthanasia law argued that it bore no similarity whatsoever to the Nazi past. Senator Jacob Kohnstamm rejected any comparison between Nazi practices and contemporary Dutch euthanasia rules: 'As if a murderous and destructive system like that in Nazi Germany would care at all about a legal regulation as proposed here!'<sup>49</sup>

There is, of course, a wide gap between Nazi thinking on medical ethics and the mood of the Dutch medical community of today. Moreover, Hitler himself opposed attempts to legalize euthanasia (his secret decree was never made law) while today's euthanasia advocates seek legalization and legislation. Even if there would have been an official euthanasia law in Nazi Germany, it would have only served to legitimize widespread killings. The Nazis never really cared about legal regulations and Kohnstamm may be correct that they would have only laughed at laws like the new Dutch euthanasia law. Or, maybe some Nazis would have not laughed. For example, after receiving many complaints about crude euthanasia practices Reich Justice Minister Franz Gürtner and some high ranking officials wanted an euthanasia law, but they were stopped by Hitler. The euthanasia law (there, in fact, were several drafts) they had on mind contained a number of guarantees against abuse (*Sicherungsgarantien*), like euthanasia only in the case of incurably ill patients whose suffering could no longer be prolonged, and at their own request. One draft of the laws even stipulated that a commission of doctors and judges be appointed as an overseeing body.<sup>50</sup> A similar suggestion was made by in the euthanasia film *Ich Klage an*. The director of the film, Wolfgang Liebeneier, stated after the war that his film was intended to prepare the ground for official legalization.<sup>51</sup>

The new Dutch law specifies criteria of careful medical practice ('*zorgvuldigheidseisen*') which must be fulfilled before euthanasia can be agreed to.<sup>52</sup> Requests for euthanasia must be voluntary; well-considered and persistent;

made by patients who are experiencing unbearable suffering without hope of improvement; at least two physicians must be involved in the decision; and all cases must be reported to regional committees composed of a lawyer, physician, and ethicist/philosopher and be report to the Public Prosecutor. The role of the Public Prosecutor is significantly reduced by these 'committees' whose decisions are mandatory.

Another problem is that Dutch culture is one of tolerance. Laws are made and subsequently eroded by practice. Vocal advocates of euthanasia will contribute to this erosion by making further demands. Shortly after the new euthanasia law was passed in the First Chamber of Dutch parliament, Health Minister Els Borst suddenly widened the debate in a highly controversial interview. If old people who are 'tired of life' (*levensmoe*) would take a suicide pill—the so-called 'Drion-pill'—she, the Health Minister, would not object.<sup>53</sup> She said that this issue must be a matter of public debate. Prime Minister Wim Kok immediately distanced himself from Borst's statements saying it was not cabinet policy, but the damage was done. One month later NVVE announced a public debate on the suicide pill, which it hopes will be legalized after its conclusion. A TV-documentary is being prepared to arouse public awareness to the issue.<sup>54</sup>

During the parliamentary debates Senator Egbert Schuurman, a leading opponent of the new euthanasia rules, had predicted precisely this: 'Advocates of euthanasia will add new criteria, for example "being tired of life."' <sup>55</sup> Nobody paid attention then. This is undeniably a slippery slope trend, starting from the small beginnings described by Leo Alexander. It is this very trend that Professor Schuurman, a leading culture philosopher in The Netherlands, is worried about. Of course, there is not the slightest resemblance between Senator Kohnstamm or Minister Borst—both prominent in the Dutch euthanasia movement (NVVE)—and crude Nazis or their ideology. But the ghosts of the past will some day haunt those who proclaim principles like 'there is such a thing as life not worthy to be lived.'

It should be kept in mind that the propaganda film *Ich Klage an* started a similar public debate in Nazi Germany in 1941 as people who lived at the time told me. Again, the film did not show the crude ways in which the Nazis often conducted their euthanasia programme. On the contrary, it told a very sentimental story about human feelings and love, and finally about the decision of a man who killed his own wife because he loved her so much. Hanna had explicitly requested euthanasia. These lessons from the past can only be ignored at our peril. 'What experience and history teach is this - that peoples and governments never have learned anything from history or acted on principles deduced from it.'<sup>56</sup> **E&M**

## References

- <sup>1</sup> For more details on *Ich Klage an*, see: Courtade, Francis, and Cadars, Pierre, *Geschichte des Films im Dritten Reich* (Munich; Wilhelm Heyne Verlag, 1975): 138-143. The author is in possession of a copy of *Ich Klage an* (director: Wolfgang Liebeneiner). The film was based on the novel *Sendung und Gewissen* by Helmuth Unger.
- <sup>2</sup> Heinz Boberach, *Meldungen aus dem Reich. Die geheime Lageberichte des Sicherheitsdienstes der SS 1939-1944*, vol. 9: 3175 (Herrsching: Pawlak Verlag, 1984): 'Der Film hat im ganzen Reichsgebiet stärkste Beachtung gefunden.'
- <sup>3</sup> Author's interview with Mrs. G. Benit, Hilversum: 17 May 2001.
- <sup>4</sup> Karl Brandt, statement in Nuremberg, in: Mitscherlich, Alexander/Mielke, Fred, *Medizin ohne Menschlichkeit. Dokumente des Nürnberger Ärzteprozesses* (Frankfurt am Main: Fischer Taschenbuch Verlag: 1985): 206.
- <sup>5</sup> Menges, J., *op cit.*: 70-72.
- <sup>6</sup> *Trials of War Criminals*, Vol. 2 (Washington, DC: US Government Printing Office, 1949): 196.
- <sup>7</sup> *Ibid.*, Vol. 1: 893.
- <sup>8</sup> Menges, J., *op. cit.*: 102.
- <sup>9</sup> Ilse Staff, *Justiz Im Dritten Reich* (Frankfurt am Main: Fischer Taschenbuch Verlag, 1978): 52-53 (Sterilization Act); Rudolf Echterhölder, *Die Deutsche Justiz und der Nationalsozialismus*, Vol. 2 (Stuttgart: Deutsche Verlags-Anstalt, 1970): 321.
- <sup>10</sup> Heinrich Schmid, *Apokalyptisches Wetterleuchten. Ein Beitrag der Evangelischen Kirche zur Kampf im Dritten Reich* (Munich: Verlag der Evangelisch-Lutherische Kirche in Bayern, 1947), 400.
- <sup>11</sup> J. Menges, *op. cit.*: 101-104.
- <sup>12</sup> Israel Gutman, (Ed.), 'Enzyklopädie des Holocaust' (Munich/Zurich: Piper, 1995): 424.
- <sup>13</sup> Hermann Weinkauff, and Albrecht Wagner, *Die Deutsche Justiz und der Nationalsozialismus*, Vol. 1 (Stuttgart: Deutsche Verlags-Anstalt, 1968): 198.
- <sup>14</sup> Henry Dicks V, *Licensed Mass Murder. A Socio-Psychological Study of some SS Killers* (London: Heinemann and Sussex University Press, 1972): 143-177, 231.
- <sup>15</sup> J. Menges, *op. cit.*: 49.
- <sup>16</sup> *Ibid.*: 52.
- <sup>17</sup> J. Menges, *op. cit.*: 6.
- <sup>18</sup> Israel Gutman, *op. cit.*: 424.
- <sup>19</sup> William E. Seideman, 'Medicine and Murder in the Third Reich,' *Dimensions. A Journal of Holocaust Studies*, 1999; 13, Number 1 ([http://www.adl.org/braun/dim\\_medicine\\_murder.html](http://www.adl.org/braun/dim_medicine_murder.html)).
- <sup>20</sup> Micahel I. Shevell, 'Neurosciences in the Third Reich: from Ivory Tower to Death Camps,' *Can J Neurol Sci.* 1999; 26: 132-38.
- <sup>21</sup> J. Menges, *op. cit.*: 92, 93
- <sup>22</sup> Full text of Lother Kreyssig's letter in: Staff, Ilse, *op. cit.*: 112-115.
- <sup>23</sup> Full text of Bishop Wurm's letter in: Denzler, George, and Fabricius, Volker, (Eds.), *Die Kirchen im Dritten Reich*, Vol. 2: Documents (Frankfurt am Main: Fischer Taschenbuch Verlag, 1984): 193-198.
- <sup>24</sup> Full text of Bishop von Galen's sermon in: Klee, Ernst, (Ed.), *Dokumente zur "Euthanasie,"* (Frankfurt am Main: Fischer Taschenbuch Verlag, 1985): 193-198.
- <sup>25</sup> J. Menges, *op. cit.*: 137.
- <sup>26</sup> Author's interview with Mrs. G. Benit, Hilversum: 17 May 2001.
- <sup>27</sup> Henry Picker, *Hitlers Tischgespräch e im Führerhauptquartier* (Stuttgart: Seewald Verlag, 1976): 416.
- <sup>28</sup> Williame L. Shirer, *Berlin Diary. The Journal of a Foreign Correspondent 1934-1941* (New York: Galahad Books, 1995): 569-575.

## Ethics & Medicine

- <sup>29</sup> Henry Picker, *op. cit.*: 213. Hitler was highly critical of Rosenberg's *Mythus des XX. Jahrhunderts* which he did not consider 'an official party book.'
- <sup>30</sup> *Ibid.*: 574, 575.
- <sup>31</sup> Stephen B. Saetz, 'Eugenics and the Third Reich,' *The Eugenics Bulletin*, Winter 1985 (<http://www.eugenics.net/papers/3rdreich.html>).
- <sup>32</sup> Adolf Hitler, *Mein Kampf* (London: Radius Book/Hutchinson, 1972): 262.
- <sup>33</sup> Jeremy Noakes, and Geoffrey Pridham, *Documents on Nazism, 1919-1945* (London: Jonathan Cape, 1974): 613, 614.
- <sup>34</sup> *Ibid.*: 631.
- <sup>35</sup> Richard Grunberger, *The 12-Year Reich. A Social History of Nazi Germany 1933-1945* (New York: Holt, Rinehart and Winston, 1971): 221, 230. Much of my information on health care in the Third Reich is based on Chapter 15 ('Health') of this study.
- <sup>36</sup> Ernst Klee, *Euthanasie im NS-Staat, op. cit.*: 29-33. Much of my information here is based on Klee.
- <sup>37</sup> Leo Alexander, 'Medical Science Under Dictatorship,' *N Engl J Med.* (1949); 241: 39-47.
- <sup>38</sup> *Ibid.*: 39.
- <sup>39</sup> *Ibid.*: 39.
- <sup>40</sup> *Ibid.*: 44.
- <sup>41</sup> Hartmut Hanauske-Abel, 'Not a Slippery Slope or Sudden Subversion: German Medicine and National Socialism in 1933,' *Br Med J.* 1996; 313: 1453-1463.
- <sup>42</sup> *Ibid.*: 1454.
- <sup>43</sup> *Ibid.*
- <sup>44</sup> Alexander, *op. cit.*
- <sup>45</sup> J. Menges, *op. cit.*: 88-100.
- <sup>46</sup> Edmund D. Pellegrino, 'The Nazi Doctors and Nuremberg; Some Moral Lessons Revisited,' *Ann Inter Med.* 1997; 127: 307-308.
- <sup>47</sup> Miguel A. Faria, 'Euthanasia, Medical Science, and the Road to Genocide,' *Medical Sentinel* 1998; 3:79-83; see also: Michael I. Shevell, *op. cit.*: 132-138.
- <sup>48</sup> Edmond D. Pellegrino, *op. cit.*: 307.
- <sup>49</sup> *Handelingen Eerste Kamer*, 9 April 2001 (26): 1221.
- <sup>50</sup> Lothar Gruchmann, 'Euthanasie und Justiz im Dritten Reich,' *Vierteljahreshefte für Zeitgeschichte*, 1972; 20: 247-250; Ernst Klee, *Dokumente zur Euthanasie op.cit.*: 86.
- <sup>51</sup> Emerson Vermaat, *De nazi's en de euthanasie* (Utrecht: De Banier Publishers, October 2001).
- <sup>52</sup> H. Jochemsen, 'Update: The Legalization of Euthanasia in The Netherlands,' *Ethics & Medicine* 2001;17 (No. 2) : 9, 10.
- <sup>53</sup> Interview Minister Els Borst, *NRC Handelsblad*, 14 April 2001.
- <sup>54</sup> *Trouw*, 17 May 2001 ('Nu zelfdoding ter discussie').
- <sup>55</sup> *Handelingen Eerste Kamer*, 9 April 2001 (26): 1223.
- <sup>56</sup> G.W.F Hegel, *The Philosophy of History* (New York: Dover Publications, 1956): 6.

---

**JA Emerson Vermaat, MA**, studied law at Leyden University. He is a senior television reporter in Hilversum, The Netherlands, and specializes in international affairs and European history. He is the author of a book about international crime networks *Het criminele web: De globalisering van de misdaad* (De Banier Publishers Utrecht, 2000), and is currently preparing a book about Euthanasia in the Third Reich.

# SUICIDE, PHYSICIAN-ASSISTED SUICIDE AND EUTHANASIA IN MEN VERSUS WOMEN AROUND THE WORLD: THE DEGREE OF PHYSICIAN CONTROL

KALMAN J KAPLAN, PHD

MARTIN HARROW, PHD

MARK E SCHNEIDERHAN, PHARMD

The issue of whether or not to legalize physician-assisted suicide (PAS) has been front and center as a public policy issue around the world. Unfortunately, much of the debate regarding this issue has been ideological and indicative of a clash of paradigms rather than truly empirically based. Many proponents and opponents of PAS are largely operating on assumptions as to why people participate in PAS with only a limited amount of empirical support for their attitudes. These assumptions can be stated as hypotheses. Proponents of PAS often assume that people participate in PAS for primarily rational and biomedical reasons stemming from physical illnesses (Humphrey, 1987; Werth, 1996). Opponents of PAS, in contrast, often assume that participants in PAS are motivated primarily by psychosocial factors not so different from those emerging in more typical suicidal behavior, and push for suicide prevention intervention (Smith, 1997; Hendin, 1998) Clearly one's outlook toward PAS depends a great deal on the lenses through which one views it.

The present essay has two purposes. First, we will summarize some of the data emerging from the PAS sample we have been studying in Michigan (Kaplan, 2000). These data are striking in a number of important ways and are important in themselves in an attempt to characterize motivations of people who seek PAS. These data have been presented in detail in several recent articles published both by our research team (Kaplan, Lachenmeier et. al., 2000; Kaplan, O'Dell et. al., 2000) and others (Canetto and Hollenshead, 2000). Here we summarize these data around gender in a particular way to meet the second purpose of our paper: to place these particular data set in a more general model of PAS world-wide, focusing on differences in gender-ratios across these samples. This model will introduce the conception of the degree of physician control as an ordering principle and will examine its relationship to the gender ratio of the PAS participants. In other words, degree of physician control will be treated as an independent variable, ranging across various data sets from unassisted suicide (no doctor involvement) on the one-hand to full euthanasia (full doctor control) on the other. The proportion of women versus men participating in hastened death will be treated as a dependent variable.

## **1. The Michigan PAS Sample**

Generally, researchers agree that the relationship between physical illness and psychiatric symptomatology is complicated (Fawcett, 1972; Murphy, 1977; Conwell et. al., 1990). The present research report presents data to determine the relative roles of psychosocial versus biomedical factors in the PAS cases in Michigan performed by Dr. Kevorkian and his team. Specifically, we focus on the question of gender differences in this regard.

### **A. Methods**

*Sample.* The Michigan data derives from our own IRB approved research on the PAS conducted by Dr. Kevorkian and his team. Our research team, in conjunction with the *Detroit Free Press*, has identified 93 of these cases, and there is evidence that even with Kevorkian presently in prison, other members of his team have continued to perform additional PAS both in Michigan and in other states (*Detroit Free Press*, May 13, 1999). From these 93 cases, we have administered a psychological autopsy to friends and relatives of the first 47 of these decedents who were assisted in their death in the period June 4, 1990 to February 2, 1997. This psychological autopsy technique has been widely used in the study of suicide and allows the reconstruction of the psychological profile of the decedent in a manner parallel to a physical autopsy (Barraclough et. al., 1974; Hagnell and Rorsman, 1979; Fowler et. al., 1986; Clark and Horton-Deutsch, 1992). This will be discussed in more detail below.

We have also collected more cursory data gleaned from the death certificates and from the judgments of the medical examiners of the remaining 46 cases (Dr. Dragovic in Oakland County, Drs. Kahnluen and Somerset in Wayne County, and Dr. Spitz in Macomb County, all in Michigan).

*Measures.* The psychological autopsy involved collection of interview data with regard to demographic, biomedical, and psychosocial information about the decedent from families and friends in addition to medical personnel familiar with the case. The non-medical informants were of great value in obtaining information as to psychosocial issues regarding a decedent. To ensure accuracy, we followed standard psychological autopsy methodology in requiring the agreement of two or three informants who knew the decedent well. (Clark and Horton-Deutsch, 1992; Kaplan and Maldaver, 1993). Specifically, we only scored a symptom or piece of information as positive if it was indicated as present by at least two informants (Clark and Horton-Deutsch, 1992).

Guidelines were provided for the interviewers. For example, terminality was defined at autopsy as a projection of six months or less to live as determined by the respective medical examiner. Category of disease, anatomical basis for disease, and method of death were also defined by the medical examiner at autopsy. Reported pain, depression, and history of suicide attempts were assessed from the reports of friends and relatives regarding complaints of the decedent while anatomical basis for pain was defined by the medical examiner at autopsy as the

physical specification of an anatomical basis for reported pain on the part of the decedent. This is admittedly a very difficult judgment to make by a medical examiner at autopsy, but we felt it was important to attempt to distinguish reported pain that had a specific anatomical referent from that which did not (*Detroit Free Press Staff*, 1997; Kaplan, Lachenmeier et. al., 2000; Kaplan, O'Dell et. al., 2000).

## B. Results

*The First 47 Cases: Psychological and Physical Autopsy Data.* Analysis of the data from the first 47 cases in the Michigan PAS sample indicates the following patterns: 46 of these PAS patients are Caucasian (32 women and 15 men). The majority of patients are middle class and middle aged, with an average age of 52.8 years. There is no significant age effect between men and women. The following results involving patient gender emerged.

- a. Sixty-eight percent (32) of these 47 PAS are women, and only 32% (15) are men. The gender ratio for this PAS sample resembles the gender ratio for attempted suicides in America (75% women in 1995). It does not resemble the gender ratio for completed suicides in America (18.9% women in 1995).
- b. The great majority of probands in the pilot sample fell into one of four disease categories: a) 31% cancer, b) 22% MS, c) 19% neurological diseases, dementia, and ALS, and d) 4% cardio-vascular and pulmonary disease. Less than 10% of the sample have comorbid or multiple medical diagnoses. No significant diagnostic differences emerged between men and women.
- c. Only 31.1% of the 47 patient sample were described as terminal by the medical examiners while 87% were described as having some disability. While 73.9% of the PAS patients reported pain, only 42.6% of them were revealed at autopsy to have a specific anatomical basis for their pain. However, 36% of the PAS patients were described as depressed, 23.8% had a history of suicide attempts, and 90% of them expressed a fear of dependency. No anatomical sign of disease emerged in 3 out of the 44 (6.8%) cases for which autopsies were available (*refer to Figure 1, page 45*).
- d. Approximately three-quarters of both men and women were described by informants as having reported pain. However, the autopsies revealed that men were almost twice as likely (60%) to have anatomical basis for their reported pain than women (34%) and three times as likely to be terminal (57.1% to 19.4%,  $p < .01$ ). The PAS women were also twice as likely to have a history of previous unsuccessful suicide attempts and more likely to be described as depressed. All of the three cases with no anatomical sign of disease at autopsy were women (*refer to Figure 2, page 46*).
- e. The Michigan PAS team employed two methods of helping the patients kill themselves. The moderately structured PAS method involved the inhalation of carbon monoxide connected by a tube to a mask over the patient's nose and mouth, which was released by the patient. The highly structured PAS method involved the injection of a lethal chemical through a "suicide



machine” carefully set up and administered by the PAS team. This procedure takes three steps: first, establishing an intravenous line and starting a saline drip by the PAS team; second, the patient releases barbiturates into the intravenous line; and third, this triggers the release of potassium chloride. The first method (inhalation) involves considerably less physician involvement, is less structured, and takes much longer to reach death (an average of over ten minutes) than the second (lethal injection) method (an average of under two minutes). Of the 27 carbon monoxide deaths among the first 47 cases, 56% were women and 44% were men. Of the 20 lethal injection deaths, 85% were women and only 15% were men.

*Striking gender differences emerge here: Of the 27 carbon monoxide deaths, 56% were women and only 44% were men. Of the 20 lethal injection deaths, 85% were women and only 15% were men (chi-square = 4.58,  $p < .05$ ).*

**All 93 Cases: Physical Autopsy Data Only.** The average age of all 93 decedents was 58.3 years. No significant differences emerged between men and women in this regard. The overwhelming majority (89 decedents, or 95.7%) were Caucasian, two were African-American, one was Hispanic, and one was Asian.

- a. The gender ratio described above (68% women to 32% men) holds for the entire sample of 93 publicly acknowledged physician-assisted deaths (63 women and 30 men).
- b. Only 29% of the 93 patient sample were described as terminal by the medical examiners while 67% were described as having some disability. A higher proportion of male decedents were terminal (36.7%) than were female decedents (25.4%).
- c. No anatomical sign of disease emerged in 6 out of the 90 cases for which autopsies were available. Five of these six cases were women.

### **C. Discussion**

The above results highlight several different factors. First of all, disability (87%) and fear of dependency (90%) seem more a factor than terminality (31.1%) for the Michigan sample of people dying by PAS. This is especially true among women. This raises the question of what can be done by society to better enable people with physical incapacitation and disabilities to live more full lives.

A second finding indicates that almost twice as many patients reported pain (73.6%) than revealed an anatomical basis for that pain at autopsy (42.6%). This suggests that a considerable number of these decedents may have experienced psychological-based rather than anatomically-based pain. This trend seems to be higher among women than men, with 75% of both genders reporting pain, but men described as having almost twice the rate of anatomical basis for pain (60%) as women (34.4%). This pattern is very troubling. On the one hand, it may simply reflect the traditional inability of male physicians to adequately recognize the physical basis for women’s pain and thus to over-psychologize it. However, it may also indicate that there may be different bases for the pain behind the

decision of men and women to seek death, and that differential techniques may be appropriate to control that pain.

The third finding is related. Psychosocial factors seem as important as biomedical factors in the Michigan PAS sample, especially among women. For example, a typical man choosing PAS may be suffering from terminal lung cancer and be in a great deal of physical pain. A typical woman choosing physician-assisted suicide may be somewhat disabled from chronic multiple sclerosis and as a result, see her marriage break up and her economic situation deteriorate. Her pain may be just as intense as that of the man described above but emerging from a partially psychosocial source.

## **2. Gender Ratios in Different Hastened-Death Settings**

The preponderance of women in the Michigan PAS sample is quite striking in light of the preponderance of men in all the completed suicide statistics in America (Canetto and Hollenshead, 2000; Kaplan, Lachenmeier et. al, 2000; Kaplan, O'Dell et. al., 2000). It is important to examine whether this anomalous gender ratio will hold in other hastened death settings as well. To this end, we examine the gender ratios in different hastened-death settings around the world. This necessitates a delineation of these different hastened-death situations: suicide, PAS, and euthanasia. Suicide (unaided) describes a people ending their own lives by themselves. PAS describes a person being helped to end his or her own life by a physician. Euthanasia in this context refers to a person's life being ended directly by a physician (Wooddell and Kaplan, 1998; 2000).

To begin with, we examine gender ratios of suicides we have traditionally studied. These typically do not involve assistance by another (whether it is a physician or anyone else). Secondly, we examine data on unstructured PAS (where the physician makes a lethal drug available to the patient but is not otherwise involved), in the Netherlands, in Oregon, and in a physician survey completed in America. Thirdly, we will return to Michigan to again examine the cases of moderately structured PAS and highly structured PAS. Finally, we analyze data on physician-administered euthanasia (where the physician actually administers or writes an order for a nurse to administer the drug to the patient in order to intentionally end the patient's life) in the Netherlands, Australia, and in the previously mentioned physician survey.

### **A. America: Suicides for Men and Women**

The statistics for suicide rates for men versus women in America are fairly stable. We have chosen the American Association of Suicidology 1995 Suicide Statistics as the best comparison year for many of the Michigan PAS cases (Canetto and Lester, 1995). *In America in 1995, over four times as many men (81.1%) successfully completed suicide than women (18.9%).*

### **B. The Netherlands: Unstructured PAS and Euthanasia for Men and Women**

The largest source of data for physician aid in end-of-life decisions for patients has emerged in the Netherlands. In 1990, the Dutch government appointed the

Rommelink Commission to conduct a nationwide study of this practice, and it was published in 1991 (van der Mas et. al., 1991). It estimated from physician interviews that 2,300 (1.8%) of 130,000 deaths were the result of euthanasia (i.e., the administration of drugs by the physician with the explicit intention of ending the patient's life, at the patient's explicit request). Another 0.3% were assisted suicide (i.e., the prescription or supplying of drugs with the explicit intention of enabling the patient to end his or her life). Two more recent studies (van der Maas et. al., 1996; van der Wal et. al., 1996) concluded that both euthanasia and PAS seemed to have increased since 1990, again highlighting the importance of providing more data on PAS.

Examination of the data on the reasons for choosing to die given by the patients is quite instructive, pointing to the potential importance of psychosocial factors in requests for physician aid in ending life. One of the major studies reports loss of dignity was a reason provided by 57% of cases, 46% cited intolerable pain, 46% stated they didn't want an "unworthy dying," 33% didn't want to be dependent on others, and 23% claimed to be tired of life (Kissane et al., 1998). Psychosocial factors thus seem to be very important in the decision to seek hastened death (Hendin et. al., 1997; Hendin, 1998).

*Strong gender differences emerge. A majority of patients receiving unstructured PAS were male (61%). In contrast, a majority of those patients receiving euthanasia were female (57%).*

### **C. Oregon: Unstructured PAS for Men and Women**

The third data set emerges from Oregon. Oregon's "Death with Dignity Act" went into effect on October 27, 1997. A three-year report (Sullivan et. al., 2001) indicated that 70 people participated in PAS from 1998-2000. Fifty-two of these people were suffering from cancer, five suffered from obstructive pulmonary disease, and six suffered from ALS. The sixteen PAS deaths in 1998 were compared to two control groups (Hedberg et. al., 1999; Sullivan et. al, 2000). No difference emerged between those participating in PAS and matched controls for age, race, sex, Oregon residence status or education level. However, PAS participants were less likely to be married at the time of their death, though this ratio is reversing with time. Sixty-seven percent of decedents in 2000 were married as opposed to 44% in 1999 and only 12% in 1998. In addition, the PAS participants were 7.3 times more likely than controls to have expressed concerns to their physician about loss of autonomy. Finally, 63% of these patients (as compared to 26% in 1999) cited a fear of being a burden on family, friends, or caregivers as a reason for their suicide. A worrisome possibility is that concern with being a burden on their families may be increasing and especially strong among older married women (Doerflinger, 2001).

*Of the 70 persons participating in unstructured PAS in this period, 36 were men and 34 were women. Interestingly, the percentage of women seems to be increasing with time (56% in 2000 as opposed to 41% in 1999).*

### **D. Michigan: Moderately and Highly Structured PAS for Men and Women**

As mentioned before, the Michigan PAS team employed two methods of helping the patients kill themselves. One method involved the inhalation of carbon

monoxide connected by a tube to a mask over the patient's nose and mouth and released by the patient. The second method involved the injection of a lethal chemical through a "suicide machine" carefully set up and administered by the PAS team. This procedure takes three steps: first, establishing an intravenous line and starting a saline drip by the PAS team, second, the patient releases barbiturates into the intravenous line, and third, this triggers the release of potassium chloride. The first method (inhalation) involves considerably less physician involvement and is less structured than the second method (lethal injection). Of the 27 carbon monoxide deaths among the first 47 cases, 56% were women and 44% were men. Of the 20 lethal injection deaths, 85% were women and only 15% were men.

*Striking gender differences emerge here: Of the 27 carbon monoxide deaths, 56% were women and only 44% were men. Of the 20 lethal injection deaths, 85% were women and only 15% were men (chi-square = 4.58,  $p < .05$ ).*

#### **E. Australia: Euthanasia for Men and Women**

Between July 1, 1996 and March 25, 1997, the option of euthanasia for the terminally ill was legal in the Northern Territory of Australia under the Rights of the Terminally Ill Act 1995 (ROTI Act). Seven people officially sought to use this legislation to die. The first two patients requested euthanasia, but died before the Act became law, four died under the Act, and one following its repeal. All the requests were directed to Dr. Philip Nitschke, who performed the legal deaths under the ROTI Act.

All of these patients were suffering from cancer, most at advanced stages, and four were terminal. However, pain did not seem to be a dominant issue for most of them. Among psychosocial factors; three of the seven patients were socially isolated, and four were depressed. Three expressed anticipatory fear, and four reported both a sense of futility and a loss of dignity (Kissane et. al., 1998).

*Of these seven cases of requested euthanasia (where the doctor actually administered the drug) four (57%) were women and three (43%) were men.*

#### **F. Physician Surveys in America: Unstructured PAS and Euthanasia for Men and Women**

The final source of data involves surveys collected from physicians in America regarding their experiences with PAS and euthanasia. There have been several national surveys of practices involving active physician-assisted deaths in the United States (Emanuel et. al., 1998, Meier et. al., 1998) and a half dozen more regional or one-disease surveys of physicians, caregivers, or patients (Cohen et. al., 1994, Doukas et. al., 1995; Bachman et. al., 1996; Lee et al., 1996; Slome et. al., 1997; Ganzini et. al., 1998). One national survey (Emanuel et. al., 1998) reports that 56 out of 355 (15.8%) interviewed oncologists reported participating in unstructured PAS or euthanasia. Fifty-three of these oncologists agreed to participate in in-depth interviews in which 38 reported they had participated in PAS or euthanasia. Among the patients who received PAS or euthanasia, 60.5% were women. Although the authors report that 20 of these 38 cases appeared to be PAS

and 17 appeared to be euthanasia, they do not report gender breakdowns within these two death categories. The second national survey (Meier et. al., 1998) concludes that a substantial proportion of physicians report having received a request from a patient for assistance with suicide (18.3%) or a lethal injection (11.1%).

*Here patient gender is reported separately for the two procedures. Again the data indicates that gender is an important factor. Physicians report that 43% of patients receiving lethal injections (euthanasia) are women as compared to only 3% women requesting a lethal prescription (unstructured PAS).*

### **3. Gender, Physician Control and Hastened Death: A Theoretical Model**

#### **A. Gender, Suicide, and Physician-Assisted Suicide**

Let us now attempt to make sense of the above data by placing it in a more general model of gender and suicide. Kaplan and Schwartz (1993) found that women in classical Greek tragedy were typically depicted as committing suicide in these same plays (cf., Durkheim, 1897/1951; Kaplan, 1998). Canetto and her colleagues (Canetto, 1995; Canetto and Hollenshead, 2000) have suggested that one reason women tend to complete suicide successfully less than do men is that suicide is perceived as a masculine act, less acceptable for females than for males. Deluty (1988-1989), for example, presents data indicating that death by suicide among women is perceived as both more foolish and more wrong than suicide performed by men. Likewise, Lewis and Sheppard (1992) report data indicating that women who died by suicide were seen as less well-adjusted than men who committed suicide, regardless of the reason for the suicide.

Canetto (1995) suggests that what makes suicide unacceptable to women is that it involves taking charge of one's fate, an action that goes against conventional definitions of femininity. Canetto and Hollenshead (2000) argue that PAS may be more acceptable to some women because the suicidal death may appear more passive, deferential, and "gentle." If Canetto is correct, then the proportion of women participating in PAS relative to men should increase with the degree of control and structure initiated by the physician. In other words, the more passive a hastened death situation (i.e., the more structured it is), the more likely a woman is to engage in it.

Another line of research points to this same prediction. This involves the importance of gender in the reception and utilization of social supports. Women tend to receive and utilize social supports more than men (Hirsch, 1979; Flaherty and Richman, 1989; Vaux and Harrison, 1983). It would be reasonable, then, that women considering a hastened death may be more sensitive to physician support and control than men.

#### **B. Physician Structure and Gender Ratios**

This analysis depends on ordering our different data sets with regard to the degree of physician control. The columns in Table 1 represent successively more

structured cases of physician control. The left-hand column in Table 1 presents the statistics for unaided suicides in America in 1995. The second column summarizes the three sources of data already discussed (The Netherlands, Oregon, and the American physician survey) with regard to unstructured PAS. The third and fourth columns present the moderately-structured PAS and highly-structured PAS cases in Michigan described previously. The final right-hand column presents data on euthanasia from the three sources previously described (The Netherlands, Australia, and the American physician survey) (*refer to Table 1, page 47*)

A summary of this data is presented in Figure 3, utilizing unweighted proportion means across samples. The proportion of female participants in unaided suicide and PAS increases as the physicians become more involved. It rises from a pronounced minority in unaided suicides (19%) to a pronounced majority in highly structured physician-assisted suicide (85%). With euthanasia, per se, the gender differences tend to decrease somewhat [unweighted proportion means of females to males across samples: Suicides 19%—81%; Unstructured PAS 30%—70%; Structured PAS 67%—33% (divided as below into Moderately Structured PAS 56%—44% and Highly Structured PAS 85%—15%); and Euthanasia 53%—47%]. (*refer to Figure 3, page 48*)

#### 4. Summary

This essay has presented data on several precipitating factors for men and women participating in suicide, PAS, and euthanasia. The summary of results regarding the Michigan PAS sample is as follows. Disability and fear of dependency seem more a factor than terminality for the Michigan sample of people dying by PAS. This is especially true among women. A second finding indicated that almost twice as many patients reported pain than revealed an anatomical basis for that pain at autopsy. This trend seems to be higher among women than men, with 75% of both genders reporting pain, but men described as having almost twice the rate of anatomical basis for pain as do women. The third finding is related. Psychosocial factors seem as important as biomedical factors in the Michigan PAS sample, especially among women.

The fourth finding reveals that the proportion of women participants in PAS increases with increasing structure of the death situation across hastened death settings around the world. It rises from a pronounced minority in suicides (19%) to 29% in the unstructured PAS, to 67% in the moderately structured PAS to a pronounced majority in the highly structured PAS (85%). With euthanasia, per se, the proportion of women tends to decrease somewhat (53%).

These data suggest that PAS must be considered within the cultural milieu into which it is inserted. The preponderance of disability as opposed to terminality in the Michigan cases, especially among women, suggests the fears of advocacy groups of people with disabilities may not be unfounded. The role of biomedical versus psychosocial antecedents of reported pain is disturbing and suggests that reported pain, as well as expressed desire for suicide, may have dif-

ferent meaning for men and for women. Women may generally seek help from physicians, including those engaging in PAS, more than men (Flaherty and Richman, 1989).

Finally, the degree of physician control of the death situation seems to interact with patient gender. The very same factors which lead women to utilize social support in health care settings more than men may also affect their preferences for more paternalistic physicians (Emanuel and Emanuel, 1992) and more highly structured death situations where they may be more passive (Canetto and Hollenshead, 2000). The danger is that such structure will create a sense of obligation on the part of a woman, especially one who subscribes to stereotypic sex roles (Flaherty and Richman, 1989; Vaux and Harrison, 1983; Kaplan, Schneiderhan, and Harrow, 2001) to complete a physician-assisted death towards which she may be initially ambivalent. The role of other patient factors such as disability, age, religiosity, ethnicity, and socioeconomic status must also be examined in the context of physician-assisted death. Research with regard to the effects of the physician-patient relation (Emanuel and Emanuel, 1992; Kaplan, Schneiderhan, and Harrow, 2001) is clearly needed to provide a foundation for intelligent and informed legislation in this very important area. ■&■

## References

- Barracough BM, Bunch J, Nelson B, Sainsbury P. A hundred cases of suicide: Clinical aspects. *Br J Psych*, 1974;125:355-373.
- Chin AE, Hedberg K, Higginson GK, Flemming DW. Legalized physician-assisted suicide in Oregon-The first year's experience. *N Engl J Med* 1999;340(1):577-583.
- Clark D, Horton-Deutsch S. Assessment in abstinence: The value of the psychological autopsy method for studying antecedents of suicide and predicting suicides. In R.W. Maris et al., (Ed.) *Assessment and Prediction of Suicide* (pp. 144-182). New York: The Guilford Press, 1992.
- Cohen JS, Fihn SP, Boyko EJ, Jonsen AR, Wood RW. Attitudes toward assisted suicide and euthanasia among physicians in Washington State. *N Engl J Med* 1994;331(2):89-94.
- Conwell Y, Caine ED, Olson K. Suicide and cancer in later life. *Hosp Com Psych* 1990;41:1334-1339.
- Detroit Free Press Staff. *The suicide machine*. Detroit: The Detroit Free Press, 1997.
- Detroit Free Press, The. Doctor probed in New Mexico Death, May 13, 1999.
- Doerflinger, Richard M. Comments on Oregon's third year of physician-assisted suicide. E-mail, Feb. 12, 2001.
- Emanuel EJ, Daniels ER, Fairclough DL, Clarridge BR. The practice of euthanasia and physician-assisted suicide in the United States: Adherence to proposed safeguards and effects on physicians. *JAMA* 1998;280(6):507-513.
- Emanuel EJ, Emanuel LL. Four models of the physician-patient relationship. *JAMA* 1992;267:2221-2226.
- Fawcett J. Suicidal depression and physical illness. *JAMA* 1972;219:1303-1306.
- Flaherty J, Richman J. Gender differences in the perception and utilization of social support: theoretical perspectives and an empirical test. *Soc Sci Med* 1989;28:1221-1228.

- Foley K, Hendin H. The Oregon Report: Don't ask, don't tell. *Hasting Center Report* 1998;29(3):37-42.
- Fowler RC, Rich CL, Young D. (1986). San Diego Suicide Study: II. Substance abuse in young cases. *Arch Gen Psych*, 1986;43:962-965.
- Ganzini L, Johnston WS, McFarland BH, Bentson H, Tolle SW, Lee MA. Attitudes of patients with amyotrophic lateral sclerosis and their care givers toward assisted suicide. *N Engl J Med* 1998;339(14):967-973.
- Hagnell O, Rorsman B. Suicide in the Lundby Study: A comparative investigation of clinical aspects. *Neuropsychobiology*, 1979;6:319-332.
- Hendin H, Foley K, White M. Physician-assisted suicide: Reflections on Oregon's first case. *Issues in Law and Med* 1998;14(3):243-270.
- Hendin HH, Rutenfrons C, Zylicz Z. Physician-assisted suicide and euthanasia in the Netherlands: Lessons from the Dutch. *JAMA* 1997;277(21):1720-1722.
- Hendin HH. *Seduced by death: Doctors, patients and assisted suicide*. New York: W. N. Norton, 1998.
- Humphrey D. The case for rational suicide. *Suicide and Life-Threatening Behavior* 1987;17:335-338.
- Kaplan KJ, Lachenmeier F, Harrow M, O'Dell JC, Uziel O, Schneiderhan M, Cheyfitz, K. Psychosocial versus biomedical risk factors in Kevorkian's first 47 "suicides." *Omega*, 2000;40(1):109-163.
- Kaplan KJ, Maldaver M. Parental marital style and completed adolescent suicide: A literature review and an empirical study. *Omega*, 1993;27:131-154.
- Kaplan KJ, O'Dell JC, Dragovic LJ, McKeon MC, Bentley E, Telmet, K. An update on the 93 Kevorkian-Reding publicly acknowledged physician-assisted deaths in Michigan: Is Kevorkian a savior, serial killer, or suicidal martyr? *Omega* 2000;40(1):209-228.
- Kissane DW, Street A, Nitschke P. Seven deaths in Darwin: Case studies of death under the Rights of the Terminally Ill Act, Northern Territory, Australia. *Lancet* 1998;352:1097-1102.
- Meier DE, Emmons C, Wallenstein S, Quill T, Morrison RS, Cassel CK. A national survey of physician-assisted suicide and euthanasia in the United States. *N Engl J Med* 1998;338:1193-1201.
- Murphy G K. Cancer and the corner. *JAMA* 1977;237:786-788.
- Schneiderhan ME, Kaplan KJ. Autonomy, gender and preference for paternalistic or informative physicians: A study of the doctor-patient relation (under review).
- Smith WJ. *Forced Exit: The slippery slope from assisted suicide to legalized murder*. New York, N.Y.: Times Books, 1997.
- Sullivan AD, Hegberg K, Fleming DW. Legalized PAS in Oregon- the second year. *N Engl J Med* 2000;342(8):598-604.
- Sullivan AD, Hegberg K, Hopkins D. Legalized physician-assisted suicide in Oregon 1998-2000. *N Engl J Med* 2001;344(8):605-607.
- van der Maas PJ, van der Wal G, Haverkate I, DeGraaf CLM, Kester JGC, Onwuteaka-Philipsen BG, Van der Heide A, Bosma J, Willems D. Euthanasia, physician-assisted suicide, and other medical practices involving the end of life in the Netherlands. *N Engl J Med* 1996;335(22):1699-1705.
- van der Maas PJ., Van Delden JJM, Pijnenborg L, Looman CWN. Euthanasia and other medical decisions concerning the end of life. *Lancet* 1991;338:69-74.
- van der Wal G, van der Maas PJ, Bosma JM, Onwuteaka-Philipsen BD, Willems L, Haverkate I, Kostense PJ. Evaluation of the notification procedure for physician-assisted death in the Netherlands. *N Engl J Med* 1996;335(22):1706-1711.
- Vaux A, Harrison D. Support network characteristics associated with support satisfaction and perceived support. *Am J Com Psych* 1983;13:245-268.
- Werth JL. *Rational suicide? Implications for mental health professionals*. Philadelphia, PA.: Taylor and Francis Publishers, 1996.



- <sup>1</sup> The authors would like to acknowledge the support of the American Foundation for Suicide Prevention, the Richard J. Barber Fund for Interdisciplinary Legal Research at Wayne State University and the Research Infrastructure Support Program (RISP) of the Department of Psychiatry of the University of Illinois College of Medicine. Thanks are due to Kevin Lubbers who has helped us in the preparation of this manuscript. An earlier draft of this paper was presented at the 153rd Annual Meeting of the American Psychiatric Association, Chicago, Illinois, June, 2000.
- <sup>2</sup> This is a point not lost on Kevorkian who in a taped interview seen by the senior authors praises his first assisted suicide, Janet Adkins, and her husband as follows: "I think the world one day will thank you and Ron because what you're doing is a historical move. I don't think it's ever been done officially since the days of classical Greece" (also see Betzold, 1993, p. 73; Kaplan and Dewitt, 1996, Canetto & Hollenshead, 2000).

---

**Kalman J Kaplan, PhD**, Professor in the Department of Psychology Department of Psychology, Wayne State University and in the Department of Psychiatry, University of Illinois College of Medicine.

**Martin Harrow, PhD**, Professor in the Department of Psychiatry, University of Illinois College of Medicine.

**Mark E Schneiderhan, PharmD**, Assistant Professor in the Department of Psychiatry, University of Illinois College of Medicine and in the Department of Pharmacy Practice, University of Illinois College of Pharmacy.

Figure 1. Biomedical vs. Psychosocial Risk Factors for Kevorkian's First 47 Suicides

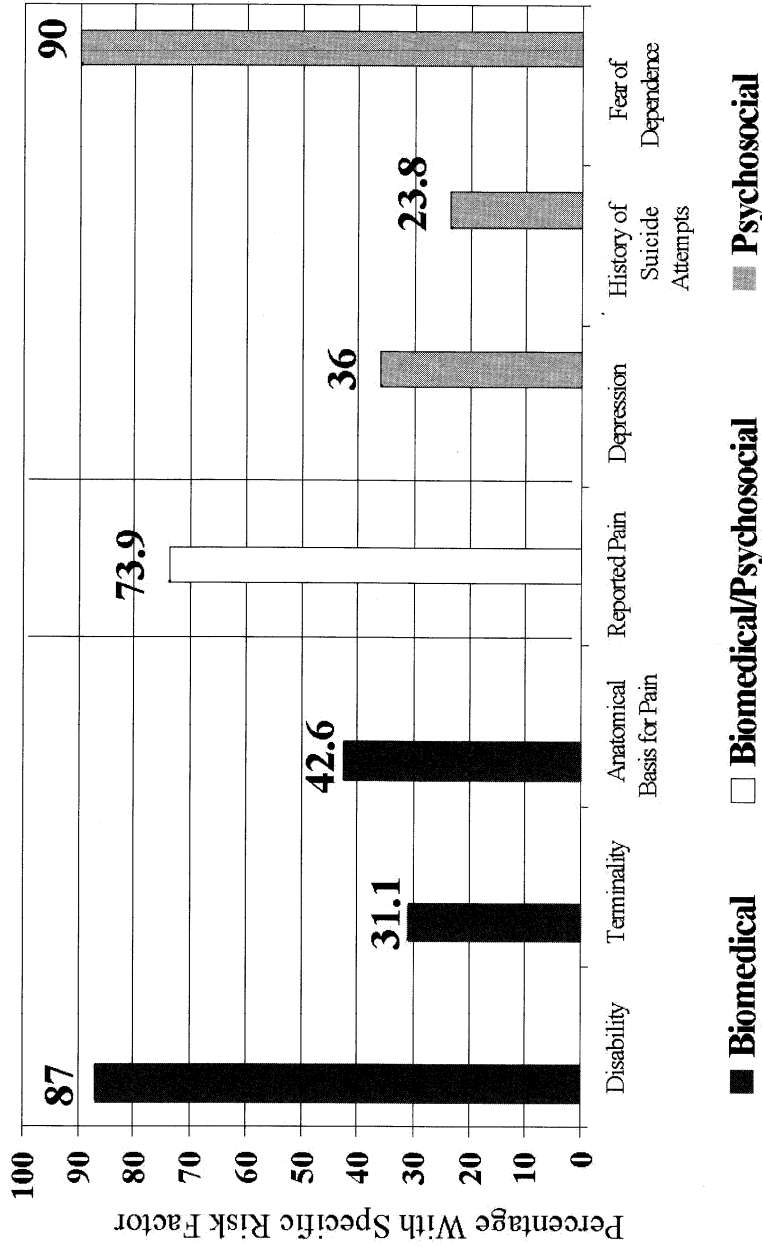
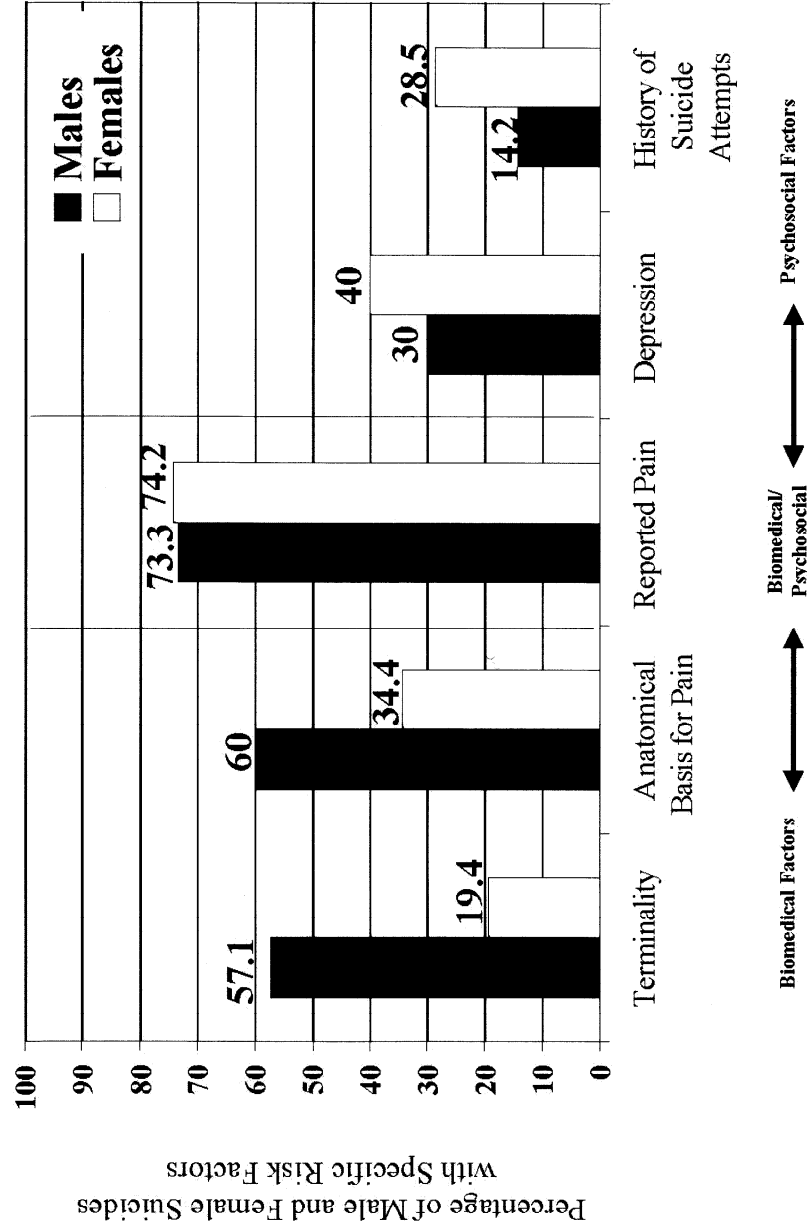


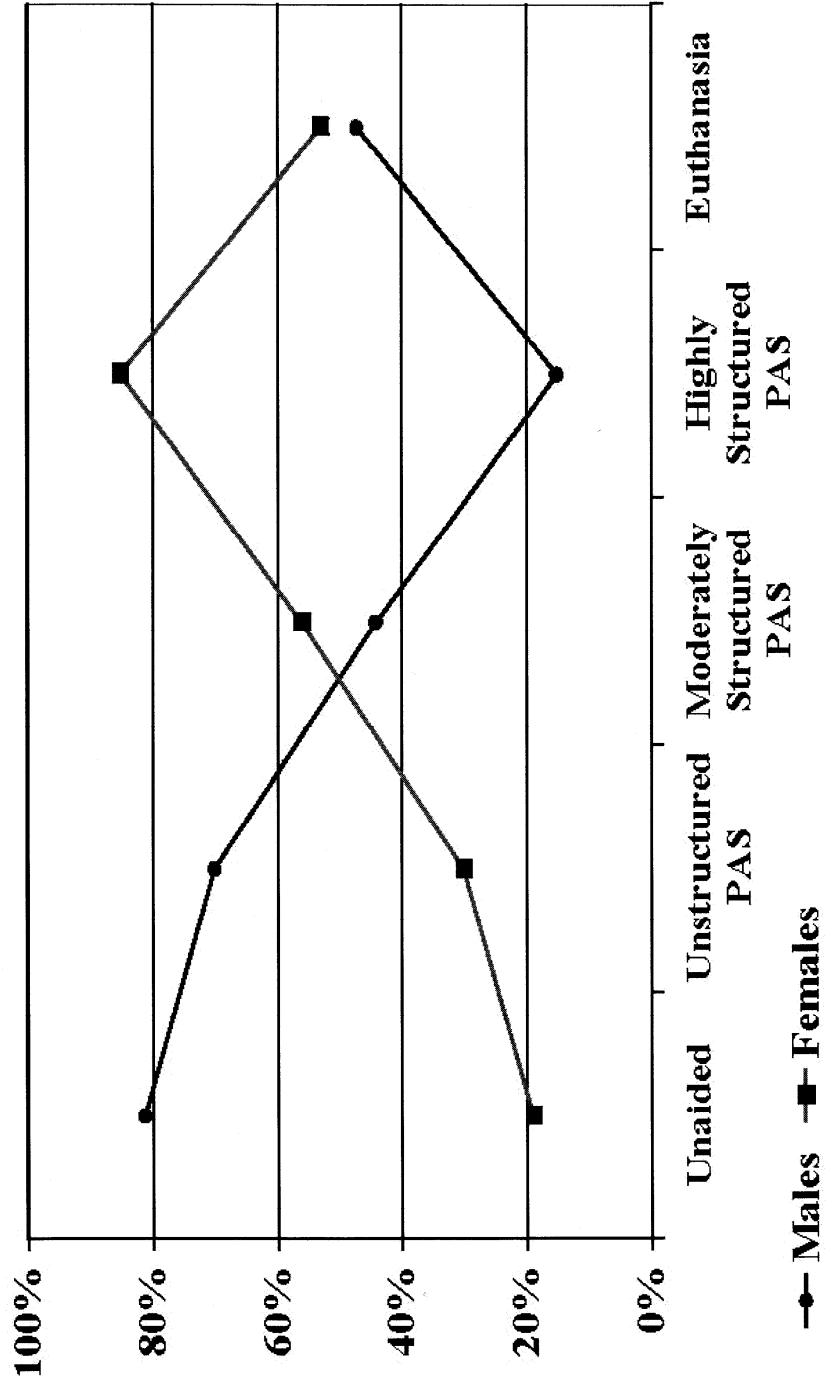
Figure 2. Gender Differences in Risk Factors for Kevorkian's First 47 Suicides



**Table 1. Decedent Gender and Physician Structure of Death Situation**

	Percentage of Deaths by Gender	Unaided Completed Suicides	Unstructured PAS: Prescription given to pt.	Moderately Structured PAS: CO inhalation activated by pt.	Highly Structured PAS: KCl injection activated by pt.	Euthanasia: Inject /Inhale Activated by MD.
<u>1995 American Suicide Statistics:</u> (AAS, 1995)	Males Females	81% (N≈30,000) 19%				
<u>1995 Netherlands Data</u> (van der Maas et al., 1996)	Males Females		61% (N=25) 39%			43% (N=257) 57%
<u>1996 American Physician Survey Data</u> (Meier et al., 1998)	Males Females		97% (N=38) 03%			57% (N=43) 43%
<u>1998-99 Oregon PAS Data:</u> (Chin et al., 1999, Sullivan et. al., 2000, 2001)	Males Females		51% (N=70) 49%			
<u>1990-1998 Michigan Data</u> (Kaplan et al., 2000)	Males Females			44% (N=27) 56%	15% (N=20) 85%	
<u>1996-1997 Australian Data</u> (Kissane, Street and Nitschke, 1998)	Males Females					43% (N=7) 57%

Figure 3. Decedent Gender and Physician Structure of Death Situation



# AUTONOMY, GENDER, AND PREFERENCE FOR PATERNALISTIC OR INFORMATIVE PHYSICIANS: A STUDY OF THE DOCTOR-PATIENT RELATION

KALMAN J KAPLAN, PHD

MARK SCHNEIDERHAN, PHARM D

MARTIN HARROW, PHD

RUSSELL OMENS, PSYD

In the past few decades, medical ethicists<sup>1,2,3</sup> have departed from the Hippocratic model in encouraging patients to take a more active role in their healthcare.<sup>4,5,6</sup> Emanuel and Emanuel<sup>4</sup> contrast informative versus paternalistic styles as endpoints in a continuum of doctor-patient relationships. In the paternalistic model the physician acts as the patient's guardian and articulates what is best for the patient.

In this model, the physician-patient interaction ensures that patients receive interventions that best promote their health and well-being. To this end, physicians use their skill to determine the patient's medical condition and his or her stage in the disease process and to identify the medical tests and treatments most likely to restore the patient's health or ameliorate pain. Then the physician presents the patient with selected information that will encourage the patient to consent to the intervention the physician considers best. At the extreme, the physician authoritatively informs the patient when the intervention will be initiated. (p. 2221)

The paternalistic model assumes that there are shared objective criteria for determining what is best for the patient. Hence, the clinician can discern with limited patient participation what is best for the patient.

In the informative model, the physician treats the patient as a consumer.

The objective of the physician-patient interaction is for the physician to provide the patient with all relevant information, for the patient to select the medical interventions he or she wants and for the physician to execute the selected interventions. To this end, the physician informs the patient of his or her disease state, the nature of possible diagnostic and therapeutic interventions, the nature and probability of risks and benefits associated with the interventions and any uncertainties of knowledge. It is the physician's obligation to provide all of the facts, and the patient's values then determine what treatments are to be given. (p. 2221)

In the informative model, the physician provides the patient the means to exercise control and to make an informed decision as to the course of treatment.

The present study explores the relationship of physician communication style to patient characteristics. Do some patients prefer one type of physician style and other patients another? Do some patients need the freedom implicit with an informative physician style while other patients need the protection implicit in the paternalistic physician style?

Some studies<sup>7,8,9</sup> report that younger and higher educated individuals are more likely to take an active role in medical decisions while men, married individuals, and patients with a more severe prognosis tend to prefer a more passive role and allow the physician to make medical decisions.<sup>10</sup> However, another study<sup>11</sup> reported that patient gender accounts for only a small proportion of the variance of decision-making style.

Several recent studies have specifically examined the decision-making style and preferences of patients diagnosed with cancer. One study<sup>12</sup> reports that an index group of 150 patients newly diagnosed with breast cancer were more likely to want to play a passive role in decision-making as compared to 200 women with benign breast disease. In both the index and control groups, older women and women of lower social class preferred a more passive role. A second larger study<sup>13</sup> examined 1,012 women with breast cancer. Women younger than 50, married, with English as a first language, having greater than a high school education, at earlier stages of the disease, and having undergone a lumpectomy were more likely to prefer active or collaborative roles in decision-making. The third study in this series studied examined men diagnosed with prostate cancer.<sup>14</sup> This study reports that among 60 men newly diagnosed with prostate cancer, rehearsal in self-efficacy tended to increase active participation in treatment decisions.

Unfortunately, none of these three studies take into account physician style<sup>4</sup> per se nor did they measure relevant patient personality characteristics such as locus of control or autonomy. Finally, each of these studies was nested within gender making it impossible to compare differences in gender in this regard. This is especially unfortunate because of the literature on gender differences in help-seeking behavior. A considerable amount of work, for example, indicates that women are more open than men to receive and utilize social supports<sup>15-19</sup> though one study<sup>20</sup> reports that gender differences are a function of sex role characteristics rather than sex per se.

The present study attempts to link this body of literature with the Emanuel and Emanuel model.<sup>4</sup> We hypothesize that non-autonomous individuals prefer paternalistic physician styles and autonomous patients, informative physician styles. However, this pattern may be affected by patient gender. The present study examines patient preference in clinician styles as a function of general patient autonomy level, knowledge of the specific disease, and patient gender.

## Method

### Sample:

One hundred thirty-one ambulatory care patients at Michael Reese Hospital and the University of Illinois at Chicago Medical Center were surveyed. The study was approved by the Institutional Review Boards of Michael Reese Hospital and the University of Illinois Medical Center. Of the 131 patients, 91 were women and 40 were men. The patients were of the following ethnic backgrounds: 18 Caucasian, 54 African American, 21 Asian American, 3 Hispanic, 32 other, and three unknown. The average age of the men was 37.6 years and the women was 45.6 years. Thirty-eight percent completed high school and 61% completed college. Thirty percent were professional, 20% were clerical, and 46% were unemployed.

### Survey overview:

The survey was comprised of three major parts. The survey took approximately 15 – 20 minutes to complete. The written survey was administered in the clinic waiting room by a research associate. The research associate was available to answer any questions pertaining to the study and to read the survey to the subject, if necessary, in a private location to ensure confidentiality. The first part was presented to all subjects and asked general demographic information about the subject. The second and third parts contained scenarios and questions specific to gender. In the second part, male subjects were asked to imagine that they were recently diagnosed with prostate cancer and were about to see a specialist to determine the treatment plan. Likewise, female subjects were asked to imagine that they had been recently diagnosed with breast cancer. Both male and female subjects were then presented with two potential physician response styles adjusted for the gender-specific disease: Dr. P (paternalistic style) and Dr. I (informative style). The third part measured the subjects' autonomy level on the Individuation-Attachment Questionnaire (IAQ). Finally, subjects were asked questions about their degree of knowledge of the specific imagined disease state (prostate cancer for men and breast cancer for women).

### Independent variables:

The major independent variables in this study consisted of the following: a) the degree of subject autonomy (high versus low), b) subject knowledge of the disease, c) subject gender, and d) the physician response style (paternalistic or informative).

*Subject autonomy level.* Subject autonomy level was conceptualized as an overall personality style and was measured on the (IAQ)<sup>21,22,23</sup> which has been used in the past in connection with NIMH psychological autopsy study on adolescent suicide<sup>24</sup> and consists of twenty five-point Likert scales asking subjects to agree or disagree with a series of statements dealing with attachment and individuation themes. It is designed to yield four separate attachment and individuation scores: Need for Individuation (NI) (the need to make one's own decisions: e.g., "I believe everyone must find his or her own way in life."), Fear of Individuation (FI) (the fear of making one's own decisions: e.g., "It is important



for me to do what other people think I should do.”), Need for Attachment (NA) (the need to form close relationships: e.g., “I need to share my feelings with others.”), and Fear of Attachment (FA) (the fear of forming close relationships: e.g., “A close relationship makes it hard to be yourself.”). It has been employed in a number of studies involving over 2,000 respondents at various ages across the life-span, both clinical and non-clinical, both male and female. Reliabilities on the four sub-scales ranged from .75 (FI) to .84 (NA) and inter-correlations between the four sub-scales are quite low (.22 to -.19). Validity coefficients of the four scales with independent clinical assessments of these same characteristics ranged from .58 (FI) to .71 (NI).

**Subject knowledge of disease.** Subject knowledge, of the specific disease state they were asked to imagine being diagnosed with, was measured on four three-point scales, varying from a little to a lot:

- a) Overall Familiarity (OF): To what extent have you heard about breast (prostate) cancer?
- b) Understanding of Effects (UE): Do you understand the effects of breast (prostate) cancer on a person’s life?
- c) Understanding of Treatment Options (UTxO): Do you understand the treatment options for breast (prostate) cancer?
- d) Understanding of Risks/Benefits (UR/B): Do you understand the benefits and risks of the different treatments?

**Subject gender.** Subject gender is self-explanatory. Men were presented with the following scenario:

Try to imagine being confronted with the following circumstance: You started noticing symptoms for prostate cancer: difficulty urinating and a nagging pain in the hips. These symptoms lead you to see an oncologist, who runs a series of tests. The two paragraphs below describe different hypothetical doctor responses to your situation. Please read them both and indicate which way you would prefer your doctor to act.

Women were presented with this alternate scenario:

Try to imagine being confronted with the following circumstance: You started noticing symptoms for breast cancer: skin irritation and a small lump around the breast area. These symptoms lead you to see an oncologist, who runs a series of tests. The two paragraphs below describe different hypothetical doctor responses to your situation. Please read them both and indicate which way you would prefer your doctor to act.

Physician response style (Paternalistic-Doctor P and Informative-Doctor I) is manipulated separately for male and female subjects. The styles for the male subjects are presented as follows:

**Doctor P:** The last time we met, I told you that we found a tumor and that the cancer cells are found only in the prostate gland. I know that you are probably afraid and anxious about what having the cancer means. The news

about the cancer must be shocking to you and speaking to you in our last visit, I know that you have had the support from your family and friends to cope with the disease. Given the stage of your cancer, the results of the various tests, and your medical history, you are a very good candidate for surgery. The sooner we schedule an appointment for the surgery the better. I am here to take care of you and to see you through this thing.

*Doctor I:* The last time we met, I talked to you about prostate cancer and briefly introduced treatments. We know from the tests that the cancer cells are localized in the prostate gland, and they have not yet spread to the other tissues surrounding the gland. For this stage of the disease, we can perform surgery, what we label in medical terms -a radical prostatectomy, to remove the prostate and some of the tissue around it. Unfortunately, the side effects of this operation are impotence and leakage of urine from the bladder. The other options outside of surgery are external beam irradiation or interstitial radioisotopes, which offer similar therapeutic effects to a prostatectomy. This therapy can lead to impotence and other side effects. If you are not too clear about the treatments, we have some pamphlets that will summarize what I have just told you.

The two styles for the female patients are as follows:

*Doctor P:* The tests that we performed during the last visit indicate that you have second stage breast cancer. The cancer is localized, and the tests show that the cancer has not yet spread to other parts of your body. A lumpectomy combined with radiation therapy offers the greatest chance for survival and the most favorable cosmetic result. Right now we need to schedule an appointment for the surgery as soon as possible. I have seen many patients with your type of breast cancer who have undergone these same procedures, and they have had good outcomes. I am here to take care of you and to see you through this thing.

*Doctor I:* The last time we met, I talked to you about breast cancer and briefly introduced treatments. Now that you have had some time to cope with this disease, we need to talk more about the treatment options. There are two main issues involved: local and systemic control. With local control, the options are to perform a lumpectomy or mastectomy with or without radiation. The lumpectomy removes only the cancer and some of the surrounding tissue, while the mastectomy can remove a segment or the whole breast. The studies have shown that mastectomy and lumpectomy combined with radiation result in identical overall survival, about an 80% survival of ten years. Lumpectomy without radiation results in a 30-40% chance of tumor recurrence in the breast. If you are not too clear about the treatments, we have some pamphlets that will summarize what I have just told you.

In addition, other demographic information such as age, job, ethnic background, marital and family status, and education was collected as well as more particular information regarding knowledge, of the disease they were asked to imagine they had, as well as anticipated family support.

**Dependent variables:** The subjects were asked: a) to decide which physician response style (Dr. P or Dr. I) they would want their own physician to act like and to describe why; and b) to rate Dr. P and Dr. I on a series of 9 seven-point semantic differential scales (i.e., nonhelpful-helpful, disrespectful-respectful, uninformative-informative, nonsupportive-supportive, aloof-compassionate, nondirective-directive, nondemocratic-democratic, nonprotective-protective, and nonreceptive-receptive).

**Results**

**Autonomy and Knowledge of Disease.**

The intercorrelations between measures of subject autonomy and subject knowledge of either prostate cancer (for men) and breast cancer (for women) are presented in Table 1. We present this data in three sections: a) the inter-correlations between measures of subject autonomy, b) the inter-correlations between measures of subject knowledge of disease, and c) the correlations between autonomy measures and measures of knowledge of disease.

**Table 1**  
*Intercorrelations between Measures of Autonomy and Knowledge of Disease across and within Patient Gender*

	<i>Patient Autonomy</i>				<i>Patient Knowledge of Disease</i>			
Males/ Females	NI	FI	NA	FA	OF	UE	UTxO	UR/B
NI	1.00	-.09/.43*	.71+/.32	-.69*/.43*	.17/-.17	.28/-.31+	.26/-.23*	.23/-.13
FI		1.00	.25/.06	.11/.32	-.38/.03	-.03/-.01	.19/.03	.23/.21
NA			1.00	-.64*/.03	.05/-.00	.06/-.46*	-.38/-.26	-.25/.03
FA				1.00	.08/.01	.22/-.30	.18/-.36	-.04/-.29
OF					1.00	.71+/.55+	.47+/.51+	.43+/.37+
UE						1.00	.59+/.65+	.60+/.50+
UTxO							1.00	.78+/.81+
UR/B								1.00

\*p<.05, †p<.01

NI=Need for Individuation, FI=Fear of Individuation, NA=Need for Attachment, FA=Fear of Attachment, OF=Overall Familiarity with Disease, UE=Understanding of Effects of Disease, UTxO=Understanding of Treatment Options, UR/B=Understanding of Risks/Benefits of Treatment

**Intercorrelations of Autonomy Measures.** The four scales used to assess subjects' overall autonomy shows markedly different patterns for men and for women. NI, our basic index of autonomy, is negatively related to FA for male subjects ( $r = -.69, p < .05$ ) but positively related to this same variable for female subjects ( $r = .43, p < .05$ ). NI is unrelated to FI for men ( $r = -.09, n.s.$ ) but is positively related to FI for women ( $r = .43, p < .05$ ). Finally, NI is very highly correlated with NA for men ( $r = .71, p < .01$ ) but not significantly so for women ( $r = .32, n.s.$ ).

This pattern suggests that autonomy may function differently for men and women in our sample. For male patients, autonomy is unrelated to either FA or FI and indeed is positively related to NA. For female patients, however, it does seem to be intertwined with both FA and FI and unrelated to NA.

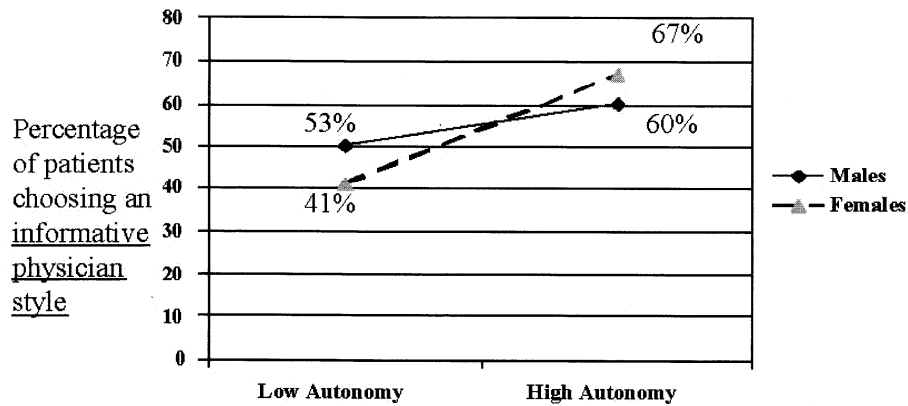
*Intercorrelations of Knowledge of Disease Measures.* The four scales used to assess subjects' knowledge of disease were highly intercorrelated for both men and women. The sizes of these correlation ranged from .37 to .81 ( $p$ 's < .01).

*Correlations Between Measures of Autonomy and Knowledge of Disease.* Very few of the correlations between the four autonomy scores and the four knowledge scores are significant. However, the data reveals tendencies for positive relations between the autonomy (NI) and knowledge scores for men ( $r$ 's = .17, .28, .26, .23) and tendencies for negative relations between autonomy and knowledge for women ( $r$ 's = -.17, -.31†, -.23\*, -.13, † =  $p$  < .01, \* =  $p$  < .05). Much of the same results can be seen in chi-square analyses of the relationship between dichotomized indices of autonomy and knowledge of disease. No relationship emerged between these two variables for males (chi-square = .65, n.s.). For females, in contrast however, a strong negative relationship emerged. Seventy-three percent of low autonomy women reported high knowledge of the disease as compared to 45% of high autonomy women (chi-square = 4.5,  $p$  < .03). This is somewhat understandable given the "fear of attachment" aspect of the female autonomy index. Acquiring knowledge from others about a disease may be predicated on an openness toward interaction with them (i.e., overcoming one's fear of attachment). For the sake of simplicity, all further analyses in this paper will employ the NI index of autonomy and OF, the most omnibus measure of knowledge of disease: "To what extent have you heard about breast (prostate) cancer?"

### **Autonomy, Knowledge of Disease and Physician Preference**

*Subject Level of Autonomy and Preferred Physician Style.* Males and females showed no difference in preference for physician style, with 51% of the male patients and 55% of the female patients preferring the informative style (chi-square = .11, n.s.). Further, males and females did not significantly differ from each other in autonomy levels ( $t$  = 1.80, n.s.). However, the interaction between gender and autonomy level was quite unexpected. Overall, 66% of highly autonomous (upper third) patients preferred an informative clinician style as compared to 45% of non-autonomous (lower third) patients (chi-square = 3.57,  $p$  = < .06). Although males and females did not differ in autonomy levels, autonomy was linked to doctor style preference only in the female patients. Among female patients, 68% of autonomous patients preferred an informative clinician style as compared to only 41% of non-autonomous female patients (chi-square = 4.25,  $p$  < .04). No difference emerged for male patients, with 60% of autonomous patients and 53% of non-autonomous patients (chi-square = .11, n.s.) preferring an informative clinician style.

**Figure 1**  
**Autonomy Level and Preferred Physician Style for Male and Female Patients**



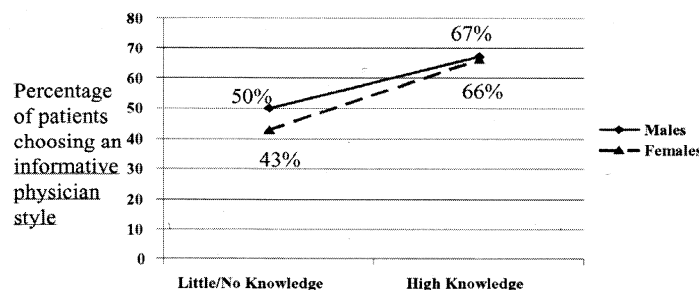
Females: Chi-Square = 4.25  $p < .04$ ; Males: Chi-Square = .11, n.s.

**Subject Knowledge of Disease and Preferred Physician Style:**

The results for overall knowledge of the disease are both dissimilar and similar to those involving autonomy. Female subjects report having a greater familiarity with breast cancer (1.59) than do men with regard to prostate cancer (1.29,  $t = 3.20$ ,  $p < .01$ ). This pattern is different than that regarding autonomy where no significant differences were reported between men and women. Nevertheless, the relationships between knowledge of disease and preferred physician style are quite similar to those involving autonomy.

Overall, 66% of people who reported high familiarity with their imagined disease preferred an informative physician style as compared to 47% of people who reported moderate or low familiarity ( $\text{chi-square} = 4.26$ ,  $p < .05$ ).

**Figure 2**  
**Knowledge of Disease and Preferred Physician Style for Males and Females**



Females: Chi-Square = 3.70,  $p = .05$ ; Males: Chi-Square = .74, n.s.

The interaction between gender and knowledge of disease was similar to the pattern described above regarding autonomy. Among female patients, 66% of patients with high familiarity with their imagined disease preferred an informative style as compared to only 44% of patients with low familiarity (chi-square = 3.70,  $p = .05$ ). The difference among the male patients in this regard was not significant (chi-square = .74, n.s.). In other words, preference for an informative physician style increased with familiarity with their imagined disease for female but not for male subjects. (refer to figure 2)

*Level of Autonomy, Knowledge of Disease, and Preferred Physician Style for Men and Women.* This section presents chi-square data on the three-way relationship between autonomy, knowledge, and physician preference for men and women. Among low autonomy women, knowledge of disease is significantly positively related to preference for an informative physician (chi-square = 3.96,  $p < .05$ ). Fifty-nine percent of low autonomous women with higher knowledge of breast cancer preferred informative physicians as compared to only 14% of low autonomy women with some or little knowledge. The same trend (greater knowledge of breast cancer associated with informative physician styles) emerged for high autonomy women, but the relationship was not significant (chi-square = 2.31, n.s.). The same pattern can be looked at in the opposite way as well. For women with low knowledge of breast cancer, high autonomy is linked to preference for informative physician style (chi-square = 3.49,  $p = .06$ ). The same trend (greater autonomy associated with preference for informative physician styles) can be seen among women with high knowledge of breast cancer as well, but once again the relationship was not significant (chi-square = .24, n.s.). Among men, no such relationships emerged.

What this data seems to indicate is that, for women, autonomy is most important in predicting physician preference when knowledge of the disease is low or moderate. Likewise, knowledge of the disease is most important for predicting physician preference when autonomy is low.

### **Beliefs about Physicians and Physician Preference**

This section examines the relationship between beliefs about physicians and physician preference. In these analyses, a positive relationship indicates that the preferred physician (either paternalistic or informative) was more positively evaluated on the nine adjectival scales than the non-preferred physician. The multiple correlation between discrepancies in all nine predictor scales (i.e., nonhelpful-helpful, disrespectful-respectful, uninformative-informative, nonsupportive-supportive, aloofness-compassionate, nondirective-directive, nondemocratic-democratic, nonprotective-protective, and nonreceptive-receptive) was .88 for male subjects and .82 for female subjects ( $p < .01$  in both cases).

Male patients' physician preferences were most influenced by discrepancies in perception of clinician helpfulness ( $r = .84$ ,  $p < .01$ ) and respectfulness ( $r = .81$ ,  $p < .01$ ) and least influenced by discrepancies in perceived clinician directiveness ( $r = .15$ , n.s.). Female preferences of clinician style were influenced by slightly

different factors. They were most influenced by discrepancies in clinician helpfulness ( $r = .76, p < .01$ ) and supportiveness ( $r = .73, p < .01$ ) and least influenced by discrepancies in perception of clinician compassion ( $r = .16, n.s.$ ). Both patient autonomy and patient knowledge of his or her imagined disease affected the relative importance of discrepancy in perceived clinician informativeness for physician preference. Informativeness was the second most important attribute after helpfulness for low autonomy men ( $r = .73, p < .01$ ) but the least important attribute for low autonomy women ( $r = .38, n.s.$ ). For both men and women of high autonomy, in contrast, discrepancy in perceived informativeness remained a moderately important attribute ( $r = .61$  for men,  $r = .48$  for women). With regard to knowledge of the specific disease, the effects were somewhat different. Informativeness discrepancy was of high importance in predicting physician preference for low knowledge men ( $r = .76, p < .01$ ) but of lowest importance for ( $r = .40, n.s.$ ) for low knowledge men. Informativeness was of moderate importance for women, whether they had high ( $r = .58, p < .01$ ) or low knowledge ( $r = .56, p < .01$ ). To some degree, then, both level of autonomy and the level of knowledge affect what attributes are important.

Examination of the open-ended reasons provided by patients underlying their preferences explores this pattern further. The most frequent reasons given by those who chose the paternalistic physician was that the physician: a) showed more concern, b) simplified the situation, and c) had superior knowledge regarding treatment. The most frequent reasons provided for the choice of an informative physician was that the physician: a) gave more choices and b) provided more options.

### **Discussion**

These results are quite rich. As is indicated in Figures 1 and 2, autonomy level and degree of knowledge of the specific disease seem to affect physician style preference for female patients but not for male patients. At the same time, autonomy and degree of knowledge of the specific disease are slightly positively related for men and significantly negatively related for women. (*refer to Table 1 page 54*)

This pattern suggests that autonomy may function differently for men and women in our sample. For male patients, autonomy is unrelated to fear of attachment. Acquiring knowledge from others about a disease may be predicated on an openness toward interaction with them (i.e., overcoming one's fear of attachment). Autonomous men may be more open to listen to others about their disease than nonautonomous men. Nonautonomous women, in contrast, may be open to hear about their disease than autonomous women.

More generally, this research suggests that the doctor's role cannot be understood in a vacuum, for a particular style taken by him or her may or may not be appropriate depending on the patient's personality and awareness. The effectiveness of the particular doctor's style, whether paternalistic or informative, must always be judged against the patient's autonomy level and/or knowledge.

Future research in this important area should examine the resiliency of the reported effects across different disease states, psychiatric as well as medical. Finally, gender may play a critical role here, both with regard to the patient and physician. Such sensitivity seems to be consistent with the highest ends of medical practice. **E&M**

## References

- <sup>1</sup> Veatch RM. *A Theory of Medical Ethics*. New York: Basic Books Inc. Publishers. 1981.
- <sup>2</sup> Macklin R. *Moral Choices*. New York: Pantheon Books Inc. 1987.
- <sup>3</sup> President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. 1982.
- <sup>4</sup> Emanuel EJ, Emanuel LL. Four models of the physician-patient relationship. *JAMA*. 1992;267:2221-2226.
- <sup>5</sup> Richards T. Partnership with patients. *BMJ*. 1998;316:85-86.
- <sup>6</sup> Katz J. *The Silent World of Doctor and Patient*. New York: Free Press. 1984.
- <sup>7</sup> Cassileth BR, Zupkis RV, Sutton-Smith K, March, V. Information and participation preferences among cancer patients. *Ann Intern Med*. 1980;92(6):832-836.
- <sup>8</sup> Ende J, Kazis L, Ash A, Moskowitz MA. Measuring patients' desire for autonomy: decision making and information seeking preferences among medical patients. *J. Gen Intern Med*. 1989;4:24-30.
- <sup>9</sup> Kapp MB. Health Care Decision Making by the Elderly: I get by with a little help from my family. *Gerontol*. 1991;31:619-623.
- <sup>10</sup> Blanchard CG, Labreque MS, Ruckdeschel JC, Blanchard EB. Information and decision making preferences of hospitalized adult cancer patients. *Soc Sci Med*. 1988;27:1139-1145.
- <sup>11</sup> Degner LF, Sloan JF. Decision Making During Serious Illness: What role do patients really want to play? *J Clin Epidemiol*. 1992;45:944-950.
- <sup>12</sup> Beaver K, Luker KA, Owens R, Leinster SJ, Degner LF, Sloan JA. Treatment decision making in women newly diagnosed with breast cancer. *Cancer Nurs*. 1996 Feb;19(1):8-19.
- <sup>13</sup> Degner LF, Kristjanson LJ, Bowman D, Sloan JA, Carriere KC, O'Neil J, et al. (1997) Information needs and decisional preferences in women with breast cancer (The Patient-Physician Relationship). *JAMA*. 1997;277(18):1485-1492.
- <sup>14</sup> Davison BJ, Degner LF. Empowerment of men newly diagnosed with prostate cancer. *Cancer Nurs*, 1997;20(3):187-196.
- <sup>15</sup> Miller, P. and Ingram, J. G. (1976) New Measures of Daily Coping: Development and Preliminary Results. *Soc. Psychiat*. 11, 51-58.
- <sup>16</sup> Hirsch BJ. Psychological dimensions of social networks: a multimethod analysis. *Am. J. Soc*. 1979;78:812-835.
- <sup>17</sup> Staker JP, Wilson DG. The inventory of socially supported behaviors: dimensionality, prediction and gender differences. *Am. J. Commun. Psychol*. 1984;12:53-69.
- <sup>18</sup> Stone AA, Neal JM. New measures of daily coping: development and preliminary results. *J. Per. Soc. Psychol*. 1984;46:892-906.
- <sup>19</sup> Flaherty J, Richman R. (1989) Gender differences in the perception and utilization of social support: theoretical perspectives and an empirical test. *Soc. Sci. Med*. 1989;28(12):1221-1228.



## *Ethics & Medicine*

- <sup>20</sup> Vaux A. Harrison D. Support network characteristics associated with support satisfaction and perceived support. *Am. J. Commun. Psychol.* 1983;13:245-268.
- <sup>21</sup> Kaplan KJ. TILT: Teaching individuals to live together. *Transactional Analysis Journal.* 1988;18:221-230.
- <sup>22</sup> Kaplan KJ. TILT for couples: Teaching couples to grow together. *Transactional Analysis Journal.* 1990;20:229-244.
- <sup>23</sup> Kaplan KJ. *TILT: Teaching Individuals to Live Together.* London: Taylor and Francis. 1998.
- <sup>24</sup> Kaplan KJ, Maldaver M. Parental marital pathology and completed adolescent suicide. *Omega.* 1993;27:131-154.

The authors would like to acknowledge the support of the Richard J. Barber Fund for Interdisciplinary Legal Research at Wayne State University and the Research Infrastructure Support Program (RISP) on Women and Gender of the Department of Psychiatry of the University of Illinois College of Medicine. We also wish to thank Mithun Nallari, Joyce Li, and Prithi Karmali, all summer fellows in the Summer Fellowship Program at Michael Reese, for their help in developing and studying the doctor-patient relation.

---

**Kalman J Kaplan, PhD**, Professor in the Department of Psychology Department of Psychology, Wayne State University and in the Department of Psychiatry, University of Illinois College of Medicine.

**Martin Harrow, PhD**, Professor in the Department of Psychiatry, University of Illinois College of Medicine.

**Mark E Schneiderhan, PharmD**, Assistant Professor in the Department of Psychiatry, University of Illinois College of Medicine and in the Department of Pharmacy Practice, University of Illinois College of Pharmacy.

**Russell Omens, PsyD**, Professor at the University of Illinois at Chicago and Wayne State University.

## BOOK REVIEWS

### **Culture of Death: The Assault on Medical Ethics in American**

Wesley J. Smith

San Francisco, CA: Encounter Books, 2000

ISBN 1-893554-06-6, 285 pp., hardback, \$23.95

Slippery slope. This phrase and notion occurs quite often in Wesley Smith's book *The Culture of Death: The Assault on Medical Ethics in America*. Smith describes the deterioration in how human beings, especially the very sick and the poor, are viewed within much of the medical culture, and how these attitudes are then bleeding down into the general population and being absorbed as normative.

Early on, he quotes Dr. Leo Alexander, from a 1949 article in the *New England Journal of Medicine*. Dr. Alexander had investigated the medical aspects of the Nazi Holocaust, and described how a society could descend to the level of the Holocaust. The starting point was the idea that 'there is such a thing as life not worthy to be lived.'

Mr. Smith, an attorney based in Oakland, California for the International Anti-Euthanasia Task Force, has written a heavily annotated and well-documented book of smouldering outrage over the direction of medicine and 'bioethics' especially in the past thirty years. He quotes Richard John Niehaus from a 1988 essay in *Commentary*, 'The Return of Eugenics,' in which Niehaus describes a shift in thinking very similar to what Alexander had said: 'Thousands of ethicists and bioethicists, as they are called, professionally guide the unthinkable on its passage through the debatable on its way to becoming the unjustifiable, until it is finally established as the unexceptional.'

Smith deals with the very real fear that many people have of ending their life tied to a machine, living in pain and humiliation, and feeling that they are a burden to their loved ones, both emotionally and financially. While not denying either the substance or the basis for this fear, he then shows how the 'culture of death' has painted a false picture of the prospects, denying the valuable work that hospices can accomplish, and belittling the substantial benefits of palliative medications. This leaves these individuals (and society at large) believing that the only reasonable course of action is to die, whether voluntarily or with the help of family members or physicians.

Considering Smith's role with the Anti-Euthanasia Task Force, he understandably has much to say about euthanasia; what is perhaps more revealing than the mere recounting of Jack Kevorkian's brazenness or similar stories is his depiction of how it appears inevitable that, once the culture of death gets its foot in the door, there's a gradual shoving and nudging until the door-opening is wider and wider. As a case in point, the Oregon Death-with-Dignity law was supposed to have rigorous safeguards so that no one else would administer the deadly cocktail except for the patient, yet within only a few years after passage of the law, this guideline was circumvented because a man claimed his brother was incapable of self-administering the poison, so he administered it to him. And as far as either the actions of Jack Kevorkian or those that are becoming commonplace in the Netherlands, he simply has too many examples from which to choose.

Next examined is Futile Care Theory and the resulting 'duty to die' imposed upon some of the very ill. This appalling situation—still in its nascent stages—is resulting in certain kinds of people being viewed as or used as 'organ farms,' that is to say, people whose only contribution should be seen as donors of organs (again, the majority are the very sick or the very poor, precisely those who lack the political, financial, or societal clout to protect themselves). Here again, though initially there were strict safeguards erected to protect people, the sheer scope of the need for organs and the cost of keeping the donors alive on the one hand is being used in a deadly calculus, the purpose of which is to justify harvesting the useful organs while the donor is still alive, so that the organs do not undergo the deterioration of 'warm ischemia.'

Smith also examined the use of animals in medical research. The matter is certainly both significant and relevant, and he does point to the considerable irony of the culture eagerly defending animal rights while at the same time claiming some people's lives are not worth living and viewing them as suitable subjects of medical research. While relevant, this topic seemed at least somewhat peripheral.

For one new to bioethics, this book is both completely novel and generally appalling. I am neither a Luddite nor a hermit, yet I consistently found myself still at the point of considering certain things to be 'unthinkable' (in Niehaus's characterization), whereas they had already progressed, completely unnoticed, to the unexceptional. The question of how far down the slippery slope Western culture has gone depends on where one locates the bottom. In reading this book, the thought often arises, 'Surely it can't get much worse than this?' Smith's final chapter proposes four steps to turn back the tide: a) Reject assisted suicide/euthanasia, b) Close the door to Futile Care Theory, c) Hold the line in dehydration cases, and d) Grapple with the moral dimensions of abortion.

Wesley Smith's book can and should serve as an eye-opener, particularly because the changes in thinking take place away from public scrutiny, leaving them both insidious and relatively invisible. It is grim to have to say, 'Physicians should not be involved in killing people,' yet Smith has done an admirable and thorough job of it.

**Kevin B. Peet, B.A.**

*Senior Fellow Center for Bioethics & Culture Oakland, California, USA*

### **Enhancing Human Traits: Ethical and Social Implications**

Erik Parens, Editor

Washington, D.C.: Georgetown University Press, 1998.

ISBN 0-87840-703-0, 258 pp., hardback \$49.95

This book is the result of a project conducted by The Hastings Center in New York and funded by the US National Endowment for the Humanities. From 1995 to 1997, the contributors to *Enhancing Human Traits: Ethical and Social Implications* met at four major research meetings to present papers, debate perspectives, and respond to one another's criticisms.

The editor, Erik Parens, a philosopher at The Hastings Center, first summarizes the history of this project, and points to the core issues debated by the project. Society has taken an ambiguous stance on enhancement. On the one hand, parents are lauded for attempts to enhance their children's lives through education, good nutrition, and many other activities. Yet when parents consider, or enlist, the help of medicine to further these same goals, ethical questions arise. He concludes that these concerns revolve around two very different issues.

First, medical enhancement requires examination of the goals of medicine. The book's contributors presented different perspectives on the so-called treatment/enhancement distinction, often using the example of human growth hormone. If the goals of medicine should be restricted to treatment of diseases, only children with a hormone deficiency should be given human growth hormone. Giving the hormone to children with normal hormone production, no matter what their height, would be a form of enhancement and thus go beyond the appropriate goals of medicine. Critics of the treatment/enhancement distinction claim this approach is inherently unjust as then some children would receive the hormone (for treating a hormone deficiency) while other children of exactly the same height would be refused the medicine (because they were not hormone deficient).

Eric T. Juengst defines enhancement for the purposes of the book. 'The term *enhancement* is usually used in bioethics to characterize interventions designed to improve human form or functioning beyond what is necessary to sustain or restore good health' (p. 29). He surveys the many approaches to distinguishing enhancement from treatment and reveals weaknesses in all. He concludes that when a medical intervention does not obviously treat a disease, further ques-

tions should be asked about its appropriateness. However, he concludes that a simple distinction between enhancement and treatment, which has broad application, will not be easy to develop or defend.

Dan W. Brock elaborates on the second major problem raised throughout the book. Regardless of the goals of medicine, a society that promotes enhancement therapies accepts and promotes certain values that may be detrimental to that society. The contributors who address this issue claim that the problem is not enhancement per se; it is the means towards enhancement that matter. Brock points to how enhancement may give competitive advantages to some, who will only be those who can afford the therapies. If beauty helps people get better jobs, and the rich can afford cosmetic surgery, the rich and beautiful will become even more rich. Medicine would then be co-opted to promote injustices in society.

At the same time, enhancement therapies can pressure people into using them who would otherwise not want to use them. Athletes using dangerous performance-enhancing drugs exemplifies this pressure. Several contributors raised concerns that enhancement therapies promote mechanistic views of people, discriminate against those who do not fit a society's view of 'normal,' and erode people's ability to empathize with others, especially the underprivileged. These issues were addressed via chapters on cosmetic surgery, Prozac, Ritalin, and other drugs. Also addressed were the ways advertisements and movies shape society's values and can promote enhancement.

While the contributors raised many concerns with enhancement therapies, and were very discerning of the values promoted by these therapies, there was a sense of some larger issue missing from the discussion. The contributors had no common foundation for their discussion. To anchor medicine within its goals, a description of the goals of life is needed. To raise concerns about the values promoted by enhancement therapies requires some meta-narrative by which those values can be evaluated. Yet only rarely in the book was mention made of a person's view of the good life.

Carl Elliott approached this issue when claiming that the Western popularity of drugs like Prozac arises in part because of the philosophical bankruptcy of post-modernism. People now question 'whether *any* form of life can have the kind of justification that you feel you need. It is a sense that all our ethical and epistemological practices are up for grabs' (p. 180). Therefore, our lives are ours to shape as we determine, and by whatever means we choose. Ironically, the book's contributors contribute to this perspective. They astutely point to problems when medicine adopts enhancement as a legitimate goal, but have little to offer instead.

A Christian worldview, which sees medicine as primarily restorative, seeking to overturn the effects of the Fall, and not outdo God's original creation, provides such a framework. This volume points to the urgent need for Christians to develop and promote such perspectives. The other element glaringly absent from this book was application of its ideas to genetic technology, something which is addressed by this reviewer in a forthcoming article on genetic enhancement in the *National Catholic Bioethics Quarterly*.

**Dónal P O'Mathúna, PhD**

*Professor of Bioethics & Chemistry Mount Carmel College of Nursing Columbus, Ohio, USA*

## CALLING ALL PHYSICIANS AND MEDICAL STUDENTS!

The Center for Bioethics and Culture (CBC) announces a Hippocratic Dinner the weekend of the big debate between Nigel Cameron and Peter Singer, on *What It Means to be Human*. CBC Executive Chairman, Nigel M. de S. Cameron Ph.D. will give the keynote address and preside over the Hippocratic Ceremony. Plan early on attending this very special weekend!

**Date:** Saturday, June 8, 2002

**Time:** 6:00pm

**Place:** The Bellevue Club Oakland, CA

For details contact Jennifer Lahl at, [Jennifer@thebc.org](mailto:Jennifer@thebc.org) or visit our website [www.thebc.org](http://www.thebc.org)