Less Bull, Better Bioethics

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BOOK REVIEW:

BIOETHICS BEYOND THE HEADLINES:
WHO LIVES? WHO DIES? WHO DECIDES?

Authored by: Dr. Albert R. Jonsen*

Bioethics Beyond the Headlines. Who Lives? Who Dies? Who Decides? is a book about the growing interest in bioethics and the study of the ethical questions involved in medical science and practice. It is written for the general reader who sees daily media stories about complex topics such as stem cell research, euthanasia, organ transplantation, genetic diagnosis and therapy and other “medical miracles” that offer great benefits but equally perplexing problems. The author, one of the pioneers in the field of bioethics, attempts to explain in plain language what the ethical problems are and how bioethicists attempt to deal with them.

LESS BULL, BETTER BIOETHICS

Reviewed by: Dr. Jerry Menikoff**

Over the several weeks this was being written, headlines raced across the globe, heralding unsavory doings in the laboratory of the leading Korean stem cell researcher. The story was initially broken by the Washington Post on November 12 with the headline: “U.S. Scientist Leaves Joint Stem Cell Project; Alleged Ethical Breaches By South Korean Cited.”¹ The article went on to note how stem cell pioneer Hwang Woo Suk had obtained some of the human eggs used in his work from junior researchers in his laboratory. It noted that if this was true, his actions would be “in violation of widely held ethics principles that preclude people in positions of authority from accepting egg donations from underlings.”²

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² Id.
The *Washington Post* article also noted that Dr. Hwang might have paid the women for providing the eggs, an action that also was described as highly problematic. A researcher at Harvard's Stem Cell Institute was quoted as saying that such payments were in violation of guidelines adopted by the National Academy of Sciences: "There is a right way and a wrong way, and we must be sure to perform this vitally important medical research the right way." Within two weeks of the revelations, Dr. Hwang admitted that two junior researchers had indeed supplied eggs and that about 20 of the women who supplied eggs had been paid. He subsequently stepped down as director of the Korean stem cell center. Leading U.S. bioethicist Arthur Caplan co-authored an op-ed claiming that these events demonstrated the need for the U.S. to be playing a prominent role in stem cell research, since otherwise "ethics can get forgotten" as other nations race to be leaders in this field.

Hold on a minute. Was everything quite as black-and-white as some of these headlines suggested? Yes, Dr. Hwang had indeed breached commitments to not use his subordinates as sources for eggs and to not pay for the eggs. But to what extent were these two practices violations of "widely held ethical principles"? It is interesting to note that in the United States, which has an extensive and long-standing set of regulations designed to protect human subjects, there is no general prohibition against enrolling a subordinate in a research study. The official *Institutional Review Board Guidebook* notes that the "issues with respect to employees as research subjects are essentially identical to those involving students as research subjects: coercion and undue influence, and confidentiality." While it notes that special attention needs to be given to make sure that such subjects are not enrolling as a result of coercion or undue influence, it does not recommend an

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3 *Id.*

4 James Brooke, *Korean Leaves Cloning Center in Ethics Furor*, N.Y. TIMES, Nov. 25, 2005 at A1. The discussion in the text is limited to the ethical issues relating to the recruitment and payment of egg donors. Dr. Hwang was subsequently accused of having fabricated substantial portions of a major paper. See, e.g., Nicholas Wade, *Korean Scientist Said to Admit Fabrication in a Cloning Study*, N.Y. TIMES, Dec. 16, 2005, at A1. Those accusations, if true, would indeed constitute major violations of "widely held ethical principles."


outright ban on the use of this category of subjects.\textsuperscript{7} As for Dr. Hwang's subordinates, there have been few, if any, details regarding the conditions under which he obtained eggs from them. Thus, at best we can say that we don't really have enough information to know whether their participation was truly voluntary. Indeed, the \textit{New York Times}, writing about Dr. Hwang's resignation less than two weeks after the \textit{Washington Post} exposé, concluded that at the time the egg donations took place, they "were not considered a legal or ethical violation."\textsuperscript{8}

And what about the second issue raised with regard to Dr. Hwang's conduct: the fact that he paid these women to supply eggs? As the Harvard stem cell researcher noted, this was the "wrong way" according to the National Academy of Sciences ("NAS") guidelines. The NAS guidelines, however, represent solely the views of that body, which merely acts as an advisor to the federal government. The federal government has not even adopted the guidelines. Thus, they have no binding legal authority. Indeed, these guidelines were developed under unusual circumstances, since the federal government had not even asked for any advice from the NAS, as would be the usual case before the NAS gives its advice. The NAS produced the guidelines in furtherance of an explicit goal, to promote stem cell research, faulting the federal government for its inaction in this area.\textsuperscript{9}

Moreover, anyone who reads the actual guidelines, at least with regards to paying subjects, will discover that this aspect of them actually does not have that much to do with ethics. The guidelines themselves note that "paying research subjects is 'a common and long-standing practice in the United States.'"\textsuperscript{10} The reason for that practice

\textsuperscript{7} See id at 6-52 - 6-55.
\textsuperscript{8} Brooke, supra note 4, at A1.
\textsuperscript{9} See Nicholas Wade, \textit{Scientists Draft Rules for Ethics on Stem Cells}, N.Y. TIMES, Apr. 27, 2005, A1. It is interesting to note that the NAS guidelines say very little about many of the most controversial aspects of stem cell research, such as whether it is ethical to create new embryos as a source of stem cells. The guidelines deal with such issues by proposing the creation of special ethics committees to review each research study involving stem cells. However, the standards that the committees would use to approve or disapprove such studies are not made clear.
\textsuperscript{10} \textsc{National Research Council and Institute of Medicine of the National Academies, Guidelines for Human Embryonic Stem Cell Research 85} (2005) [hereinafter NRCIM]. The Guidelines also would likely not have permitted Dr. Hwang's collection of eggs from his subordinates. \textit{Id}. at 85 quoting N. Dickert et al., \textit{Paying research subjects: an Analysis of Current Policies}. 136 \textsc{Annals Internal Med.} 368 (2002); and J.A. Anderson & C. Weijer, \textit{The Research Subject as Wage Earner}, 23 \textsc{Theoretical Med. and Bioethics} 359 (2002).
appears to be that "moral principles of fairness and gratitude support providing payment to those who bear the burdens of research on behalf of society." The guidelines, nonetheless, went on to recommend that, although there is not a consensus on the ethics relating to payment, egg (or sperm) donors should not receive any payments in excess of reimbursement for their direct expenses for donation. In making that recommendation, however, the guidelines state that it was in part because such payments "raise concerns that might undermine public confidence" in stem cell research. Indeed, they go on to specifically note the "strengths of all the arguments surrounding this issue," which include the argument that substantial payments to egg donors (who bear substantial risks and inconveniences) are not only permissible, but should be required as a matter of good ethics. Thus, the NAS itself is acknowledging that its anti-payment position has more to do with good public relations—avoiding any policies that might cause public controversy over stem cell research—than with ethics.

**A New Primer on Bioethics**
Lest anyone have thought that the events in early 2005 surrounding the withdrawal of artificial hydration and nutrition from Terri Schiavo were a fluke, this more recent story provides additional support for concluding that bioethics discussions in the media can leave a person less than fully informed about what is really going on. And when people find themselves in the situation of wanting a better understanding of such events, they might consider reaching for a copy of Albert Jonsen’s new book, *Bioethics Beyond the Headlines.* Jonsen, Emeritus Professor of Ethics in Medicine at the University of Washington, has played a founding role in the field of bioethics. He has been influential in a number of ways, not least by being a prolific writer. Among other things, he is lead author of one of the most

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11 NRCIM, *supra* note 10, at 85.  
12 See *id.* at 85 – 87.  
13 *Id.* at 87.  
14 *Id.*  
16 He has served as a member of several prominent bioethics commissions, including the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, and the President’s Commission for the Study of Ethical Problems in Medicine.
influential clinical ethics handbooks (now in its fifth edition), and is author or co-author of three scholarly works on the history of bioethics.

*Bioethics Beyond the Headlines* is a change from his usual writings, in that it is directed at the general public. Recognizing that complex bioethical issues are often presented by the media "in superficial and inaccurate terms," Jonsen attempts to provide a more substantive explanation of the most common bioethical issues. The book, a relatively concise 208 pages, is divided into three sections. The first section deals with the core topics of clinical bioethics, including the important role of patient autonomy and its significance in informed consent and in decisions to forgo life support. This section also covers the definition of death, euthanasia, organ transplantation, assisted reproduction and abortion. The second section is devoted to ethical issues that arise not as part of the clinical encounter between a patient and a doctor, but instead out of our efforts to advance our knowledge. Thus, in this section, Jonsen addresses the rules to protect people who participate as subjects in research studies. He also covers the major hot-button topics in medical research, including genetics, neuroscience, cloning and stem cell research. The final section is directed at topics that he describes as being "beyond the usual borders" of bioethics. Here he addresses a topic that is of growing prominence: the ethical issues relating to access to health care (including the inability of many people to afford such care). Another major topic dealt with here is that of "ethical relativism": how should we deal with differences in cultural beliefs (such as it being common among certain Asians to not tell a person with terminal cancer that he has a fatal illness) while still being true to the ethical principles that we generally apply in this country? The final two chapters in this section address animal ethics and environmental ethics.

Obviously, a book of this size cannot provide a comprehensive treatment of such a wide range of topics, nor does Jonsen intend it to do so. He describes the book as a primer, one that will serve as a curious

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19 JONSEN, supra note 15, back cover.
20 The book also has three appendices, providing a "Précis of Moral Philosophy," a "Précis of the History of Medical Ethics," and discussing the "Frankenstein Analogy."
reader’s introduction to this area.\textsuperscript{21} Thus, people who already have a fairly extensive background in bioethics should probably go elsewhere for their next bioethics book. But with regard to his chosen audience, Jonsen succeeds admirably in his goals. The book is written in a clear and engaging style, and nicely blends a description of current issues with quite a bit of the historical background, which has been one of Jonsen’s lifetime interests. Consistent with the title, most of the chapters are constructed around what appear to be actual newspaper headlines, thus allowing Jonsen to demonstrate how a deeper analysis of a topic will enrich the understanding one might otherwise get from merely a headline or sound bite. He generally avoids the common fault of quickly deciding that one or another view is the “correct” one (a practice that of course does not make for exciting news headlines), noting that in bioethics there often is not a consensus regarding the right answer.\textsuperscript{22} There is relatively little jargon or technical terminology; people who are looking for extensive discussions of Kant or deontology will not find it here.

What the reader does get, happily, is the wisdom of one of the leading bioethicists, distilled into a very palatable form. A person could do far worse in selecting their first bioethics book. And, hopefully Jonsen will also succeed in his second goal: he hopes this book will not only provide readers with a background in bioethics, but also encourage them to read further. He wants this primer to “prime” a reader’s interest for such further explorations. And there is an excellent chance that the book will do just that.

**Law and Bioethics**

Since this review is appearing in a health law journal, it seems more than appropriate to say something about the relationship between law

\textsuperscript{21} JONSEN, supra note 15, at 3.

\textsuperscript{22} In a book that covers most of bioethics, there will of course be the occasional misstep. In his discussion of withdrawing care from patients in a persistent vegetative state, Jonsen’s comments might lead a reader to wrongly conclude that there is a wide consensus in bioethics that keeping such persons alive falls within the category of “futile” care. See id. at 37. He also occasionally misstates some legal points: He comments that the legal standard for informed consent in the United States involves determining what a reasonable person would want to be told (whereas in many states, the standard still looks to what information a physician would generally provide). See id. at 43. He states that in the Baby M case, In re Baby M, 537 A.2d 1227 (N.J. 1988), the Supreme Court of New Jersey enforced a surrogacy contract, when it in fact did just the opposite. Id. at 72. But these are very minor faults in a generally excellent book.
and bioethics. Time and again, legal issues pop up in Jonsen's book. Within this book are mentions (generally brief) of: the Uniform Determination of Death Act; the legal decisions regarding Karen Ann Quinlan, Nancy Cruzan, Elizabeth Bouvia, and Terri Schiavo; the Schloendorff v. The Society of the New York Hospital\textsuperscript{23} opinion; the laws regarding refusals of care by Jehovah's Witnesses; the Supreme Court decisions on physician-assisted suicide; the Uniform Anatomical Gift Act and the role of the United Network for Organ Sharing in distributing organs; the Baby M case; Roe v. Wade\textsuperscript{24} and the federal ban on partial birth abortions; and the federal regulations regarding research with human subjects.

Given the frequency with which Jonsen brings up legal issues, it is interesting to note his own viewpoint about the connection between law and bioethics. He addresses this topic in the final paragraph of his first chapter:

Inevitably, the questions of bioethics mingle with the questions of the law. From the beginning of bioethics, legal scholars have joined the discussion. Many cases involving bioethical questions have come to the courts. Legislatures have passed laws that reflect various bioethical positions. So, it is impossible to describe the field of bioethics without reference to "biolaw," and the reader will find many references in the following pages. Despite the prominence of law, a bioethics that seeks to alleviate the human predicament must be, in essence, a philosophical and theological enterprise.\textsuperscript{25}

It seems, then, that he is somewhat apologetic about the amount of law that shows up in the book, viewing it perhaps as a necessary but not always welcome distraction from the philosophical and theological analyses that form the core of bioethics.

Jonsen might be somewhat overstating the case in suggesting that legal reasoning is a largely distinct endeavor from that of bioethical analysis. The two might have more in common, particularly in areas of the law where there is little statutory or similar guidance. Indeed, one of Jonsen's own landmark works—The Abuse of Casuistry: A History

\textsuperscript{23} 105 N.E. 92, 211 N.Y. 125 (1914).
\textsuperscript{24} 410 U.S. 113, 93 S.Ct. 705 (1973).
\textsuperscript{25} JONSEN, supra note 15, at 21.
of Moral Reasoning\textsuperscript{26}—describes how modern bioethical thinking owes much to the religious case-based reasoning known as casuistry that was popular hundreds of years ago. Any first-year law student would no doubt recognize the similarity between casuistry and the type of reasoning that courts undertake in answering questions relating to common law. One of this nation’s leading legal scholars, Cass R. Sunstein,\textsuperscript{27} devoted part of his 1994 Tanner Lectures to reaffirming the importance of casuistry in modern legal decision-making.\textsuperscript{28} He noted that case-based analysis (making legal decisions in a framework that does not involve interpreting a specific "rule" such as a statute) plays a vital role in our legal system, and that we should consider expanding that role.\textsuperscript{29}

Even assuming that legal reasoning and bioethical reasoning sometimes follow similar procedures for coming to decisions, it might nonetheless still be the case that these two disciplines apply those procedures to wholly different types of substantive rules. But perhaps even these substantive differences are not always as great as one might suspect. One of the more fascinating academic legal debates in recent years involved Judge Richard Posner’s presentation in 1997 of the Oliver Wendell Holmes Lectures at Harvard Law School, which he titled \textit{The Problematics of Moral and Legal Theory}.\textsuperscript{30} Posner argued in these lectures that (1) the work of academic philosophers who specialize in moral issues is of little practical help in making decisions about such issues,\textsuperscript{31} and (2) more particularly, moral theory should play no role in making legal decisions.\textsuperscript{32} The \textit{Harvard Law Review} subsequently published Posner’s lectures with accompanying critical responses\textsuperscript{33} from a “Who’s Who” of legal luminaries: Ronald

\textsuperscript{26}Jonson & Toulmin, supra note 18.
\textsuperscript{27}Karl N. Llewellyn Distinguished Service Professor of Jurisprudence, Law School and Department of Political Science, University of Chicago.
\textsuperscript{29}See id. at 958.
\textsuperscript{31}See Posner, supra note 30, at 1638 – 1692.
\textsuperscript{32}See id. at 1693 – 1709.
Dworkin, Charles Fried, Anthony Kronman, John T. Noonan, Jr., and Martha C. Nussbaum.

These are all wonderful articles, discussing an extremely complicated and important issue, and I will not even attempt to present what would no doubt be an overly-simplistic summary here. The only point to be made here is that several of this nation’s great legal minds strongly disagree with Posner’s conclusions, and believe that moral theory often plays a very significant role in determining what the law is. Justice Fried, for example, states that

I am a judge, and I will reaffirm that my reading, thinking and writing about moral, political and legal philosophy makes a difference to my work. In fact, I regularly test my work as a judge against the arguments that have influenced my thinking about these more academic matters. . . . [M]aterials of positive law are interpreted in light of morality and in the last analysis are accountable to it.

Dean Kronman notes that “Posner badly understates the real, if limited, role that moral reflection can and must play in the decision of cases. . . . In reality, the role judges occupy is one in which the need for moral reflection is steadier and more insistent than in almost any other position.”

In the clash of viewpoints between Posner and his critics, it is especially noteworthy that the examples that are brought up by both sides often are taken from the field of bioethics. Thus, both abortion and physician-assisted suicide end up being discussed. And, upon reflection, this is not very surprising. Issues in bioethics often constitute so-called “hard cases” where we do not have a clear and explicit statute to reference, which will provide an easy answer to a particular question. In part, this is due to the rapid changes in technology that create new

34 Both Professor of Jurisprudence at Oxford University and Professor of Law and Philosophy at New York University.
35 Former Harvard Law School professor and U.S. solicitor general, and Associate Justice of the Supreme Judicial Court of Massachusetts.
36 Dean of the Yale Law School.
37 Judge on the U.S. Court of Appeals for the Ninth Circuit.
38 Professor of Law and Ethics in the Law School, Philosophy Department, and the Divinity School of the University of Chicago.
39 Fried, supra note 33, at 1743.
40 Kronman, supra note 33, at 1761-62.
questions where previously none existed. (We need not have worried about whether having gestated a child or being the genetic mother of a child is a "stronger" sign of motherhood before technology allowed us to have these two aspects residing in two different women). But whatever the cause, it is nonetheless true that to the extent moral reasoning may play a role in legal decision making, it is far more likely to do so in the analysis of bioethics cases than in the more typical case. Thus, the type of analysis that Jonsen provides in his book should be particularly useful to a lawyer (whatever her role) who finds herself confronting a legal issue that falls within the field of bioethics.

Hopefully Jonsen would not object to the notion that legal decision-makers and commentators are indeed frequently paying attention to the very same moral issues that concern bioethicists. And, in Jonsen’s spirit of priming a reader’s interest, I will take this opportunity to briefly provide a few appetizers, as it were: food for thought showing how further reading in the legal literature relating to some of the topics Jonsen addresses can contribute to the understanding of the relevant ethical issues:

Selective Reduction. In his chapter on abortion, Jonsen concludes with a discussion of how assisted reproductive technology has caused a large increase in multiple gestation pregnancies (a woman who is gestating, for example, four or more fetuses) and the unique dilemma of selective reduction. Such pregnancies, given that the female human body was not designed to carry such a large number of fetuses to term, often result in all of the babies having major health problems. By aborting one or more of the fetuses, an outcome can often be produced where all of the babies have a much greater chance of being healthy. Jonsen notes:

Presumably, parents want all of these babies; all fetuses in the multiple gestation are wanted. One or several of the fetuses poses a threat to its siblings. An ethicist opposed to abortion simply would find no justification for selective reduction. However, an ethicist opposed to abortion generally but not universally might find a self-defense justification. However, even then, it would not be clear in most cases which fetus is the aggressor and why. The "aggressor" is selected somewhat at random (and is often the smallest fetus). Indeed, can mere
coexistence in the same womb count as aggression? . . .
Selective reduction is truly an ethical paradox. 41

The selective reduction issue naturally leads one to the
discussions in the legal literature regarding similar "coexistence"
problems. Anyone can benefit from rereading (or better yet, reading for
the first time, if they have not yet had the pleasure) Lon Fuller’s classic
article, The Case of the Speluncean Explorers. 42 Fuller describes a case
in the far future (the year 4300), decided by the fictitious Supreme
Court of Newgarth.

The facts involved a party of amateur cave explorers who end
up being trapped underground as a result of a landslide. 43 They are able
to remain in communication with the outside world. 44 Learning that it
will take at least 10 days before they can be rescued, they talk with a
committee of physicians, which advises them that given their lack of
food and water, it is unlikely that they will be able to survive until the
rescuers reach them. 45 They then ask if, were they to kill and eat one of
themselves, could they could survive long enough to be rescued. 46 That
question was “reluctantly” answered in the affirmative. 47 The explorers
all agree to throw dice to determine who is to be eaten, but in the
middle of the process of doing that, one of them decides to withdraw
from the arrangement. 48 The others force him to participate, and he
ends up being the loser; he is killed and eaten. 49

After the successful rescue, the survivors are tried for murder.
Fuller’s article presents the opinions of the several justices on the
fictitious supreme court. 50 He constructed each opinion so that it
represents a particular point of view regarding where the law comes
from. 51 Fuller’s thoughtful analysis of jurisprudence allows the reader
to explore how much (or how little) some views of law-making (such
as the natural law approach) might overlap with the type of ethical
decisions about right and wrong that Jonsen wrestles with in his book.

41 Jonsen, supra note 15, at 83.
43 Id.
44 Id. at 617.
45 Id.
46 Id.
47 Fuller, supra note 42, at 617.
48 Id. at 618.
49 Id.
50 See generally id.
51 See generally id.
Fuller’s article continues to engage us more than a half-century after it was written, regularly producing new commentary in the legal literature. As recently as 2002, it was employed in analyzing a case involving the separation of conjoined twins, which raises issues very similar to those surrounding multiple gestations.\(^52\)

*Withdrawal of Artificial Hydration and Nutrition.* In discussing the judicial review of Terri Schiavo’s case, Jonsen notes the following:

Every [Florida] court recognized that much law existed about similar cases and that, indeed, the U.S. Supreme Court had ruled on a similar case. In 1990, it concluded in the similar case of Nancy Cruzan that “a State may apply a clear and convincing evidence standard in proceedings where a guardian seeks to discontinue nutrition and hydration of a person in persistent vegetative state.”\(^53\)

Jonsen is of course correct in noting the relevance of the *Cruzan*\(^54\) decision to the legal analysis of Terri Schiavo’s situation. And given that obvious relevance, it is especially interesting to note the paucity of references to that landmark opinion in the otherwise massive amounts of media coverage that led up to Terri Schiavo’s death on March 31, 2005. For example, between January 1 of that year and Schiavo’s death, the *New York Times*\(^55\) and the *Washington Post*\(^56\) each published only two news articles by its reporters even mentioning the *Cruzan* case.

The minimal attention given to that case during the Schiavo media frenzy is especially surprising, given how much there is to learn from *Cruzan*. In the Schiavo case, two of the most controversial issues appeared to be (1) the allegedly lax burden of proof standard being


applied by the Florida courts in deciding what Terri Schiavo would have wanted done, and (2) the allegedly barbaric nature of allowing someone to die as a result of withdrawal of artificial hydration and nutrition. *Cruzan* squarely addressed both of those issues.

With regard to the burden of proof issue, the *Cruzan* decision was actually rather controversial back in 1990. It determined, by only a 5-4 majority, that it was acceptable under the Constitution for a state to require “clear and convincing” evidence of a person’s wishes before allowing life-sustaining medical care to be withdrawn. And, tellingly, it was the more conservative block of the Court—including Chief Justice Rehnquist and Justice Scalia—whose views were on that winning side. Justice Rehnquist’s opinion for that majority accepted that a state, in effect, could err on the side of life (where have we heard that concept recently?!) by imposing the more demanding burden of proof. The more liberal dissenting four Justices would have not allowed a state to impose such a strict standard; their view was that this type of standard improperly kept people alive too long, unconstitutionally violating their interest in having their wish to die—even if only supported by merely a preponderance of the evidence—respected.

And in 2005, what was the relevant law in Florida applicable to Terri Schiavo’s case? Florida’s statute explicitly required that there be “clear and convincing” evidence of a patient’s wishes before life-sustaining care could be withdrawn. In other words, Florida applied the strict standard that was at issue in the *Cruzan* case, a standard that – but for the swing vote of a single Justice fifteen years earlier – might not have even been constitutionally permissible. How odd, then, that during the Schiavo case much of the media took no notice of the fact that an evidentiary standard that strongly favored the “pro-life” viewpoint, and that barely survived being upheld by the Supreme Court, was suddenly being characterized by many as too generous in allowing people to die.

The *Cruzan* Court had also spoken to another of the most controversial issues regarding Terri Schiavo: the acceptability of allowing someone to die by withdrawing artificial hydration and nutrition. Simply stated, that Court had determined that this issue was not even very controversial back in 1990. Withdrawal of artificial hydration and nutrition was to be treated in the same way as withdrawal of any other form of medical care. Eight of the nine Justices accepted this conclusion. Indeed, even Chief Justice Rehnquist—rarely considered a wild-eyed liberal—writing for the majority, appeared to acknowledge that the Constitution probably protected a person’s right to have artificial hydration and nutrition withdrawn.
Again, how odd that relatively little attention was paid to these facts by much of the media. Surely it was relevant that a practice that fifteen years earlier was considered non-controversial, even constitutionally protected, by some of the most conservative members of the Supreme Court, was now being recharacterized as some type of cruel invention for killing people off.

The Cruzan decision—each and every one of the various opinions—remains a source of much wisdom, no matter what one’s political leanings might be. That fact makes it even worse that there has been so little serious discussion of it in the major media, even as there are calls for “tightening up” the burden of proof for allowing care to be withdrawn from future patients. The issues addressed in that case, regarding the appropriate burden of proof, were difficult ones back in 1990, and still remain difficult ones, even today. How to “properly” make a decision for someone when we are not sure what she really wants done remains a vexing problem, whether we treat it as one of law or ethics. Whatever we decide, we will be doing a wrong to some people by doing something to them that they would not have wanted done. 57

Determining When a Person is Dead. One of the few issues that was relatively non-controversial in the recent debate over Terri Schiavo was the fact that she was not dead. This is the first substantive topic that Jonsen addresses in his book. 58 And even though many of those who advocated withdrawing artificial nutrition and hydration from Schiavo might have felt that she should be considered dead (she was perhaps “as good as dead”), and thus presumably her wishes would then be irrelevant, such arguments were rarely made. To a significant extent, that is because the debate about where to draw the line between life and death took place decades ago, and is largely settled: a person with a functioning brainstem and a beating heart does not meet the legal definition of death in any state of the U.S.

But oddly enough, there is still an ongoing controversy about one aspect of the definition of death. Jonsen notes the relatively recent practice of obtaining organs for transplantation not only from people who are declared dead under “brain death” criteria (their entire brain has irreversibly ceased functioning, even though their hearts continue to beat), but rather who die as a result of their heart ceasing to beat. These people used to be called non-heart-beating donors, although the

58 JONSEN, supra note 15, at 26-27.
newest terminology refers to this practice as *donation after cardiac death* (DCD).

In spite of there being specific statutory guidance on this issue—almost all states have adopted a version of the Uniform Determination of Death Act ("UDDA")—there is a significant controversy about whether organs are regularly being removed from DCD donors prior to the time that they meet the legal criteria for being dead. The growing legal literature on this issue addresses many of the same questions that philosophers would ask. Are there fundamental concepts we have in mind—concepts that are embedded in the UDDA—when we decide that someone is dead? The current protocols for removing organs in the DCD context allow a person to be declared dead even though that person could later end up being brought back to life. They allow persons to be declared dead even though they might still have continuing brain function. We are again discovering that core ideas about the nature of our being, long thought settled, can revive themselves to present challenging new issues.

**Conclusion**

Over the coming years, issues in bioethics will no doubt continue to attract a great deal of media attention, and play a growing role in public policy debates. Jonsen's book is an excellent starting point for beginning an exploration of this field. And hopefully it will lead many readers to a further and deeper inquiry—delving into *both* the philosophical and legal literature, each of which has much to contribute to "alleviat[ing] the human predicament."60

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