NEWSLETTER ON PHILOSOPHY AND MEDICINE

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We offer you our profound regrets and apologies for not having provided advance notice of the change from print to online-only format for the Newsletter on Philosophy and Medicine. Copy for the Fall 2004 issue had been accepted under the presumption of business as usual, that is, paper copy mailed to members some time during the fall. We only learned of the Executive Director’s decision to make the change to online-only format starting with the Fall 2004 issue after the copy for that issue had been submitted to the APA in mid-July. The Fall 2004 issue, which was not posted until mid-January 2005, is only available to APA members who visit the APA website.

Originally, the print version of the Newsletters had been mailed to all APA members free of charge. Then, a few years ago, the APA began to charge an additional fee for the Newsletters. Those who wanted to receive a copy had to check a small box that appeared on the annual dues notice and to add the fee to their payment. The most recent dues notice omitted that box. Some of us failed to notice the change. Others presumed that the omission signaled reverting to having Newsletters mailed as a membership benefit.

The change from a print format to an electronic format was not adequately communicated. Neither Newsletter contributors nor readers were notified in advance of the change to an online-only format. Approximately 4,000 of approximately 11,000 APA members have not provided the APA with an email address, and many of the email addresses that the APA has are obsolete. Nevertheless, the only notification of the change that members received consisted of an email note after the fact. APA members would have been better served by a general mailing that included an invitation for APA members to provide the National Office with an (updated) email address so that they would be able to receive notice of Newsletter postings in the future.

Notification about the appearance of the online-only Newsletters was also inadequate. It would be very useful for readers who receive notice of Newsletter posting to be able to see the Table of Contents. Members could easily be provided with a list of articles along with a mechanism to open articles directly from the posting (e.g., hyperlinks or URLs). Since the APA has the electronic capability to electronically circulate surveys, the office should have the wherewithal to properly circulate the Newsletters’ full Table of Contents with hyperlinks or URLs.

Newsletter availability is another important concern. We have repeatedly urged that the Newsletters posted on the APA website be made available without a membership restriction. This change would not involve any cost to the APA. It would also make the Newsletter contents available to students and to anyone who finds an article through a web or literature search. Open availability would promote greater readership and allow philosophy to play more of a role in ongoing public discussions. This issue is particularly significant for the Newsletter on Philosophy and Medicine because its contents are listed on Medline and PUBMED. Unrestricted availability would allow physicians and students, who are not likely to be APA members, to access Newsletter articles electronically. Whereas the APA Executive Director argued for discontinuing the paper version of the Newsletter because of low interest, he also argued for restricting access to the Newsletters because it is a crucial membership bonus and that making the Newsletters available to nonmembers would lead to a loss of APA members. These claims are contradictory and cannot justify both eliminating the paper edition of the Newsletters and also restricting access to the Newsletters.

Furthermore, we question the authority for making a change of this magnitude without notification of the membership. It is not clear to us that the APA Board actually decided to eliminate the paper version of the Newsletters or that the Board considered or acted on the any of the issues mentioned above. Since these are matters that concern all APA members, they are issues that the Board needs to evaluate. They should also review questions such as: Who will lose access to the Newsletters by the change to an online-only format? What can be done to minimize the loss of access? Why have no Newsletters since the Spring 2001 been posted on the APA website?

Because these issues concern all of us, all of our contributors, and all of our readers, we urge you to communicate your views to the APA Board as well.

Regardless of these drastic changes, we have carried on. This edition of the Newsletter on Philosophy and Medicine is filled with the kind of work that readers are accustomed to find in these pages. It includes papers from two Committee-sponsored sessions along with two interesting submitted papers.

One group of papers comes from panelists at the 2004 Eastern Division Meetings session on “The President’s Council on Bioethics: Political Legitimacy and the Report on Stem Cell Research,” which was organized by David DeGrazia. The first paper, “On the Monitoring Stem Cell Research Report: Report of the President’s Council on Bioethics,” was written by Alfonso Gómez-Lobo, who is actually a member of the Council. Separate papers by Leslie Francis, Timothy F. Murphy, and Hilary Bok present their own critical analyses of the importance of consensus, the membership of the Council, and the content of the report. Together this group of papers provides detailed and informative discussion of the Council’s role and some of the work that it has produced.

The session sponsored by the Committee on Philosophy and Medicine at the spring 2004 Central Division Meeting was devoted to the ethical issues raised by “Home Health Care.”
This session was organized by Mark Sheldon and included presentations by Rosalind Eckman Ladd, Sheri Smith, and Martha Holstein. Ladd’s paper, “Ethical Issues in Home Health Care: The Ambivalent Client,” examines the significance of a client who changes her mind and what significance this has in relation to the issue of competence. Sheri Smith, in “Context Matters: Ethical Issues in Home Health Care,” lays out, in detail, the way the fact that the patient is at home creates unique ethical challenges. Finally, we were unable to obtain permission to publish Martha Holstein’s paper, since a more extended version of it will appear as a chapter in a book that will be published next spring by Johns Hopkins University Press.

Also in this issue are two provocative articles that address enduring issues in medical ethics. “What Price Hope?” by Jeffrey P. Whitman is an interesting reflective discussion of the place of complementary and alternative medicine in the treatment of patients with serious chronic illness. It explores claims of efficacy and evidence and provides an account of the needs that medicine fails to address. “Desires and Values in Medicine” by Chad Bumgardner continues the discussion of the limits of paternalism. He challenges the neat categories that define autonomy in the contemporary literature with interesting examples and questions about desires and personal values.

In sum, this is another exciting issue jam-packed with timely philosophical discussions. We want to continue to offer our readers similarly rich issues in the future. So, we remind you to think of this Newsletter as a place for your announcements, letters, papers, case analyses, poetry, and stories. Please feel free to volunteer a book review. Your contributions and queries should be sent to Rosamond or Mark at the addresses below. Please include your phone and fax numbers and email address.

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FROM THE CHAIR

A Committee Energized by Great Topics for Critical Reflection

David DeGrazia
George Washington University

A half year into my tenure as chair of the APA Committee on Philosophy and Medicine, I would like to take this opportunity to introduce us to our readers and say something about our direction and immediate plans. I joined the group, as chair, in July 2004. The other committee members are Ben Rich (UC-Davis), Gary Seay (CUNY), Hilde Lindemann (Michigan State), Lee Brown (Howard), Mary Rorty (Stanford)—as well as Mark Sheldon (Northwestern) and Rosamond Rhodes (Mt. Sinai School of Medicine), who, as editors of our Newsletter, serve as ex officio members. Next July, Robert Baker (Union University) will join us as Hilde completes her term. My thanks to the outgoing chair, Ken Kipnis (University of Hawaii), for doing such a fine job in his tenure and for including me in committee deliberations for several months before my term began in order to give me a running start.

Before joining the Committee on Philosophy and Medicine, my perception was that its most important functions were to sponsor high-quality panels for each APA divisional meeting and to maintain its excellent Newsletter on Philosophy and Medicine. One half year after joining the committee, my perception remains the same. While leaving the business of producing the Newsletter in the hands of its dedicated editors, I have so far focused more on the business of setting up panels.

Over the years, as an outsider to the committee, I sometimes felt that panels featured too many familiar faces and were, at times, a bit “chummy.” To be sure, the committee’s panels consistently addressed important issues and were of consistently high quality. And, admittedly, my experience was mostly limited to panels of Eastern Division meetings, which I attended. Still, I was a little uncomfortable. With so much talent spread around the field, I thought, maybe we could mix things up a bit more and bring to the table more people who were not among the familiar faces. After I suggested this to the committee, it quickly became apparent that it could be difficult to achieve the desired diversity while also ensuring expertise, or at least excellence, in the specific area represented by a given panel and finding individuals who planned to attend the meeting and were willing to serve! Nevertheless, we have agreed to try harder to mix things up and not to appoint ourselves to serve as presenters on panels—though it makes sense, we agree, to offer the service of moderating a panel we have organized (inasmuch as the service/prestige ratio of moderating is fairly high).

At the recent 2004 Eastern Division meeting, we sponsored a panel entitled The President’s Council on Bioethics: Political Legitimacy and the Report on Stem Cell Research. I believe it is fair to rate the event as a success. Certainly, we had an enthusiastic audience, which filled the medium-sized room and spilled into the hallway—and, more importantly, remained for the four presentations and asked enough questions to stretch the event, easily, to two and a half hours. After introducing the panel on the President’s Council on Bioethics (PCB), I, serving as moderator, turned it over to them.

Alfonso Gómez-Lobo (Georgetown University), who is a member of the President’s Council, addressed the ethics of
stem cell research. Carefully noting that he spoke only for himself, he outlined his moral reasoning about this issue while also illuminating much of the PCB's report, Monitoring Stem Cell Research. Hilary Bok (Johns Hopkins) challenged the PCB on several of its policy suggestions with special attention to the recommendation of a moratorium—as opposed to a ban—on cloning-for-biomedical research (a recommendation made in the earlier report, Human Cloning and Human Dignity). Addressing the charge that the PCB's membership reflects the president's conservative agenda, Tim Murphy (University of Illinois in Chicago) explained that the federal law permits a great deal of latitude in making appointments to advisory committees. Nevertheless, various appointment strategies could enhance public confidence in these committees, he argued, and the bioethics community would do well to devise means of communication that do not depend on prevailing political winds. Finally, Leslie Francis (University of Utah Law School) presented demographic data regarding the PCB's membership and argued that the report on stem cell research could, at best, represent a modus vivendi rather than an overlapping consensus in the Rawlsian sense. For my part, I tried to keep each speaker to twenty minutes and directed the question-and-answer segment of the program. On the whole, the discussion was vigorous, illuminating, and civil. For the benefit of those unable to attend, and those (possibly all) of the presentations will appear in this issue of the Newsletter on Philosophy and Medicine.

This spring, our committee will sponsor one panel each at the Pacific Division meeting in San Francisco (March 25) and the Central Division meeting in Chicago (April 29). Both panels should be of great interest to those working in bioethics, the medical humanities, and related fields. The Pacific panel, to be moderated by Rosamond Rhodes, is entitled The Belmont Report: The 25th Anniversary. The panelists will be Tom Beauchamp (Georgetown University), one of the authors of the Report, Ruth Macklin (Albert Einstein College of Medicine), Alex John London (Carnegie Mellon), Jodi Halpern (Berkeley), and Franklin Miller (National Institutes of Health). The title of the Central panel, which Hilde Lindemann will moderate, is The Limits of and Challenges to Liberalism in Bioethics. The speakers will be Howard Brody (Michigan State University), Agnieszka Jaworska (Stanford), Rebecca Kukla (Georgetown), and Margaret Battin (University of Utah). Speakers for both panels have been invited to submit their presentations, which we expect to be provocative and memorable, for publication in the Newsletter.

Happy New Year!

ARTICLES

On the Monitoring Stem Cell Research Report of the President's Council on Bioethics

Alfonso Gómez-Lobo
Georgetown University

I would like to start some explanations and clarifications. Although I am a member of the President's Council on Bioethics, I do not in any way speak for the Council, and, even less so, for the Bush administration. I speak for myself. I would also like to make clear that I do not receive remuneration for my service on the Council (except for a modest per diem when the Council is in session) and am totally free to dissent from the administration. I should complement that remark by disclosing (something to be expected, of course, if you know what academic salaries in the humanities are like) that I am not invested in the biotechnology industry.

The Council itself, as many of you know, holds its sessions at different public places in Washington, D.C., and the meetings are open to anyone who wants to attend. There is also time set aside for comments from interested citizens, as required by law. The meetings themselves consist, for the most part, of testimony from experts (as can be seen in the Appendices of the Monitoring Report) and open discussion among the members of the Council. These discussions are sometimes quite lively because, contrary to a widely disseminated view, this is a highly pluralistic body. There are deep differences of opinion on some of the most important issues, and the report we are examining clearly confirms this.

The Report

The Report has five basic aims:

1) to explain what stem cells are, to describe their basic types, and to offer some indications with regard to the terminology employed in this domain of science;

2) to clarify and explain the current federal policy regarding stem cell research and to make clear the legal, ethical, and prudential foundations on which the policy rests” (xi);

3) to provide an overview of the ethical and policy debates surrounding stem cell research in the two preceding years” (2002-2003) (ibid.);

4) to offer the non-scientific public an overview of “recent scientific developments in human stem cell research, embryonic and adult, basic and applied”(xi); and

5) “to convey the moral and social importance of the issue at hand and to demonstrate how people of different backgrounds, ethical beliefs, and policy preferences can reason together about it” (ibid.).

At this point in time, I do not need to explain that stem cells have two basic properties: they can differentiate into the cell types of the developed organism, but they can also multiply without differentiation. This second property explains why stem cells have been found (and continue to be found) in organisms that are well beyond the embryonic stage. These are the so-called “adult stem cells.” A better label would be “non-embryonic stem cells” to indicate that, for example, they are found in the cord blood of newborns.

When stem cells were first isolated in 1998, it became immediately clear that they held great promise for the cure of diseases that are caused by the degeneration of cells of a certain type. If stem cells could be induced to differentiate into cells of the destroyed type and transplanted into the body of the patient, cures could be obtained. This is the source of the hope and the hype. The source of the public controversy, on the other hand, is that, in order to obtain embryonic stem cells, human embryos have to be intentionally destroyed. This, in my view, is the heart of the matter, and I will return to it presently.

The Federal Funding Controversy

The Report devotes considerable attention to the funding of stem cell research in order to explain and justify the policy of the Bush administration. That policy consists basically in
allowing practically unlimited funding for research on stem cell lines derived from IVF embryos prior to August 9, 2001. The justification is developed at two different levels, the legal level and the moral level.

From a legal point of view, the decisive fact is that, in 1996, Congress passed the Dickey Amendment that prohibits “the use of any federal funds for research that destroys or seriously endangers human embryos, or creates them for research purposes” (25). This is the background assumption that governs the withholding of funds. Although the law could be interpreted as allowing the use of funds for research on embryos that were previously destroyed using private funds, this probably goes against the spirit of the law because the law itself surely is to be understood as grounded on the moral principle that it is wrong to destroy human embryos.

Why then allow the use of federal funds but only after a certain date? This is where the moral justification kicks in. It is a classical argument concerning complicity with (or appropriation of) evil. It is generally agreed that it is wrong to profit from or make use of the results of a morally wrong action, such as using medical data obtained through coercive or brutal means, as the Nazi doctors did. But it is also generally acknowledged that if the wrong action is distant in time, and no aiding and abetting of that type of action is now possible, then it could be morally permissible to use the proceeds of the action. Using Nazi medical records now (if they are of any use) would not encourage further Nazi research.

A cut-off date then seems to make sense. By setting a cut-off date for the derivation of the stem cell lines, the use of federal funds to encourage renewed embryo destruction is blocked. There would be no financial incentive coming from taxpayers’ money to induce researchers to destroy more human embryos than the ones already destroyed in the past. Embryo destruction, of course, can be engaged in (and is being engaged in at present) using private funds because there is no federal ban on this activity.

All of the above makes sense, of course, only if the principle that it is morally wrong intentionally to destroy human embryos is accepted, and on this the Council has been and is deeply divided.

The Moral Standing of Human Embryos

The Report devotes a section to this topic (3.IV A and B), sometimes using the expression “moral status,” an expression that, in the minds of those of us who are foreign born, conjures up the idea of “immigration status,” a status that an official confers upon one and may be withdrawn. I prefer to frame the question in terms of the inviolability of a human organism at the embryonic stage because this formula avoids both the suggestion of an external (and perhaps, arbitrary) conferral and the obscure notion of degrees of status. But in this I have been in the minority.

The Council did not engage in a focused discussion of the moral status or the inviolability of human embryos. It was considered by some to be a divisive issue on which, in principle, there could be no agreement. Nevertheless, the report includes a summary of arguments for and against the claim that it is morally right to destroy human embryos for biomedical research. There are also some paragraphs devoted to the idea of “special respect” or “intermediate moral status” of human embryos, a thesis that was upheld during the sessions leading to the drafting of the cloning report by several members of the Council, notably by Michael Sandel and Francis Fukuyama. This position leads to the acceptance of “the use of early embryos in medically valuable research in some circumstances” (82). The view that a human embryo is just a clump of cells that deserves no respect whatsoever and may be destroyed without qualms has also been put forth in the Council, especially by Michael Gazzaniga, but, if I recall correctly, it did not find its way into this report.

Another omission worthy of recording is the absence of religious views on early human life (except for a passing reference in a footnote on p. 78). I have been personally adamant in requesting that we not include religious traditions in our deliberations. I reached this position after reading Volume III of the NBAC 2000 report on stem cell research. The conviction I arrived at is this. Religious traditions certainly have much to tell us about compassion and the caring for the sick, but we should realize that the sources of divine revelation in the three major traditions in our midst (Jewish, Christian, and Muslim) all antedate by centuries the discovery of the female ovum in 1827 by Von Baer and the subsequent realization that there is a 50/50 genetic contribution by the mother and the father to their offspring. Without access to these basic biological facts, those traditions have nothing reliable to tell us about the beginning of a human life. The recurring reference to 40 days (or multiples of 40) after conception as marking the beginning of hominization seems to be either a standard application in the Talmud of a canonical number that appears often in the Torah (40 days of deluge, 40 years in the desert, etc.) or is derived from Aristotle’s date for quickening of the male embryo, as is clear in Aquinas and in Muslim scholarship. None of this is helpful today. No religious reasons appear in the report, nor should they.

In my view, public discussion of early human life should be based exclusively on the biological evidence understood within a philosophical framework. Logos, after all, is what we have in common.

The report makes an effort to present, in a simplified form, the dissoi lógoi, “the double (or opposing) arguments,” to use a late fifth century label, on whether human embryos deserve respect or not. The main arguments are well known to professional philosophers and touch upon the metaphysical problem of identity through time. The possibility of twinning (which allegedly ends with the appearance of the primitive streak) plays its standard role in the rejection of trans-temporal identity between an adult and the embryo from which she developed. The common moral background assumption is that a human individual deserves respect at any stage of her life, but on the basis of the twinning argument, some deny that the embryonic stage counts as a stage in the life of a human individual. With this move, the door is open for the standard consequentialist justification of embryo destruction, a form of justification embraced by many members of the Council.

Reading this section of the report, one should not forget that this is not a philosophical treatise from which one could demand rigor and exhaustive argumentation. It is a government document that aims to present to the American public and its leaders the basic moral issues as the members of the Council see them.

The report includes an appendix by Paul Lauritzen offering an overview of the ethics of stem cell research that can be read as tilted, in my opinion, towards the permissibility of embryo destruction. I am personally persuaded by the opposite view and would be happy to address the twinning objection in light of recent research that shows that there is differentiation from day one, and hence very early loss of totipotency on the part of the blastomeres. Although this might seem to be extraneous to the stem cell report, I actually found my way to this interpretation thanks to a key notion explained in the appendix authored by Rudolf J aenisch. The reference to his contribution takes us from the highly disputed ethical
issue discussed by the Council members to the actual monitoring of stem cell research contributed by the experts in the field and summarized by the Council staff.

Two Years of Stem Cell Research

For the general public, this may be the most important part of the report, for it contains a reliable and understandable overview of what has hitherto been achieved in the field and what the prospects are for the immediate future. It is quite useful, I think, to temper the hype, especially with regard to therapeutic applications. I should add that there is an update, prepared by the Council staff, covering the developments between January and November of 2004 that, as of this writing, has not yet been posted on the Council website.

The actual overview of stem cell research is based upon expositions presented by leading figures in the field: John Gearhart on embryonic germ cells, Jamie Thomson (and Tenneille Ludwig) on embryonic stem cells, and Catherine Verfaille on multipotent adult progenitor cells. David Prentice, a biologist who follows the development of adult stem cell research, was asked to provide a comprehensive overview of his area of expertise. Their papers were printed without staff editing, and all the science in the report was carefully reviewed before publication by John Gearhart (Johns Hopkins), Ira Black (Princeton), and Diane Krause (Yale), all of them distinguished scientists who oppose the Bush policy on funding for stem cell research. I mention this revision simply to emphasize that if any non-scientist wants to obtain a reliable picture of what was going on in stem cell research by the end of 2003, the Monitoring Report would be a good place to look for it.

In this connection, let me mention the greatest hype of all, and perhaps the most cruel one: that a cure for Alzheimer’s disease was just around the corner, if only more money had been thrown at embryonic stem cell research. After the publication of the Monitoring Report, the Council invited Professor Dennis Selkoe from Harvard, a leading figure in Alzheimer’s research, to inform the Council, and hence the public, on progress in his field. From the presentation and subsequent discussion, it emerged that the most promising leads have to do with protein inhibitors. At present, it seems, there are no viable research projects to cure Alzheimer’s involving embryonic stem cells. The silence of the Report on this matter was therefore justified.

The Monitoring Report ends with two papers by Silviu Itescu and one by Rudolf Jaenisch from MIT. The latter deals with the process of cloning and has been for me very illuminating, especially because of the clarity with which it presents the almost irresolvable obstacles human reproductive cloning would have to face as well as the key notions of reprogramming, imprinted genes, epigenetic changes, and DNA methylation. This article is, in my opinion, an invaluable resource for the non-scientist.

One Person’s View

Let me finish, for whatever it is worth, with my own position after having been the lucky recipient of a free education in stem cell research. Most of what follows requires detailed argumentation that I cannot provide here.

I am prepared to argue that whatever else we may be, we are essentially organisms; that, in spite of the apparent cogency of the twinning argument, it can be shown that those of us who are not twins (the vast majority of people) are trans-temporally identical with the zygote we once were, and that inviolability has to be co-extensive with one’s existence. Late onset of inviolability is morally inadequate. Later inviolability is of no use to me if it would have been morally permissible to destroy me at an earlier stage of my life.

On this basis, it should come as no surprise that I see as a tragic step for humanity the project of intentionally dismantling humans who find themselves at the embryonic stage, a stage through which I also went, in order to harvest the core components of their organism. I would add that even those who have doubts about their having been an embryo should have reason to pause and rethink the meaning of this drastic and profoundly disrespectful instrumentalization of organisms that are at least biologically continuous with them now. Those young organisms, after all, contain the same genetic program they now possess in all of their cells.

Is this an anti-science stand? I do not think so. It is, in fact, based on the best evidence science conveys to us today about our origins. In this connection, it is rewarding to read the article “Your Destiny, from Day One” by Helen Pearson (Nature, July 10, 2002). Moreover, if embryonic stem cells could be obtained without destroying human embryos, I would strongly support it. In fact, two proposals along these lines were submitted to the December 2004 meetings of the President’s Council, and I would be happy to discuss them with you.

But if therapies are the ultimate goal, we should not underestimate the progress in clinical trials and clinical applications involving non-embryonic (i.e., adult) stem cells. For example, the December issue of the Journal of Cranio-Maxillofacial Surgery reported that a team from Giessen, Germany, repaired the skull of a seven-year-old girl using stem cells from her own fat. The fact that the cells were taken from the patient herself bypasses the problem of rejection and thus the standard rationale for individualized therapeutic cloning. And, of course, there are absolutely no moral problems related to the extraction of adult stem cells if informed consent has been provided.

I hope I have given a fair account of what the Report is about and what my own position on the key moral issue is.

Endnotes


Stem Cell Research and the President’s Council on Bioethics: Of What Value is Consensus?

Leslie Pickering Francis
University of Utah

In my talk as part of this symposium, I took up these interrelated questions: (1) What should be the function or functions of the President’s Council, as it deals with issues such as stem cell research that apparently feature moral disagreement at the deepest level? Should it act as an “expert” scientific body providing peer-reviewed advice, such as the National Academy of Sciences? Should it provide ethical advice, and on what basis? Or, should it function to generate consensus on controversial issues, and in what sense? (2) How has the Council conceptualized its own functions, and what metaethical view(s) might lie behind these...
conceptualizations? (3) What are some of the crucial demographic similarities and differences among members of the Council that might be relevant to claims about the status of any consensus it might generate? (4) If the Council sees itself as functioning to generate consensus, what sense of "consensus" is it using? Is this "consensus" in any interesting moral or political sense?

My argument, in brief, is this. The Council sees itself as trying to provide the president with consensus reports on difficult ethical issues. But its makeup is too remarkably uniform on several important dimensions for the consensus it generates to be interesting as a representative political matter. Moreover, its approach to the analysis of stem cell research suggests that any consensus it has generated with respect to that issue can at best be regarded as a modus vivendi rather than an "overlapping consensus," to put the point in Rawlsian terminology. Its "consensus" report, therefore, is of limited interest as a moral justification.

Tasks for the Council

Bodies such as the President's Council might perform many different tasks. Perhaps the simplest would be to hand to the president "consensus" about the issues under its purview, in such a way that the president know what has been happening scientifically, legally, or in public debates. More to the point for an expert body, the Council might assess for the president the quality and significance of these developments. Like the National Academies of Science, it might give the president "expert" scientific advice—advice that is typically peer reviewed. As an "ethics" council, presumably it could generate expert advice about moral reasoning with respect to the issues it takes up—although it could see itself as engaged in creating scientific reports as well. Following out the model of science, however, any "expert" ethical advice would presumably require professional peer review. Still another task for the Council would be to present the president with legal or policy recommendations about what steps to take on these controversial issues. If it were to undertake this last task, the Council would function more like a political body but in an advisory role.

As it approaches each of these tasks, the Council might—or might not—believe consensus is important. If so, it would need to confront questions about consensus. What must the consensus be about? The identification of issues? The conclusions? Or the reasoning structures used to reach the conclusions? (Multi-judge courts, after all, can reach consensus on the result in a case without agreeing on the reasoning used to reach it.) Who are the necessary parties to the consensus? For example, if the Council were presenting the president with expert scientific advice, perhaps the relevant consensus would be drawn from the scientific community—and not from the political community more broadly, which includes evolutionists and creationists alike. But if the Council were presenting the president with policy recommendations, something more like a democratic consensus might be most relevant. And why does consensus matter in the first place? Is it because consensus reveals that shared views are widespread across society? Because disagreement or backlash is less likely if a recommendation can be viewed as a consensus? Because consensus demonstrates that a decision resulted from a careful democratic procedure? Or because consensus suggests that the recommendations are true?

How the Council Viewed Its Task—Part One

In drafting Monitoring Stem Cell Research, the Council deliberately and specifically avoided making policy recommendations. It took itself instead to be attempting to reach consensus about the current state of the issues regarding such research. In my judgment, however, the Council's deliberations and report reveal deep complexities—and perhaps as deep confusion—about the Council's understanding of its function. These conflicts about the Council's task also surfaced in the session devoted to the Council's work at the recent (fall 2004) meeting of the American Society for Bioethics and Humanities (ASBH), a session that generated rather more heat and perhaps less light in my judgment.

The Council's letter of transmittal to the president reported that it had consulted experts on "all aspects" of the research. Based on this consultation, the Council averred that it had tried to "present the arguments and counter-arguments, faithfully and accurately." The Council expressed the hope that it had demonstrated how "people of different backgrounds, ethical beliefs, and policy preferences can reason together" about stem cell research.

In Monitoring Stem Cell Research, the report itself, the Council describes its members as trying to set personal moral views aside. It emphasized that it was eschewing policy recommendations—although it did make recommendations about federal policy at the present time. In Monitoring, the Council addressed several issues about stem cell research, outlining the arguments from the background papers and from other discussions. The Council saw itself as principally addressing this question: "How can stem cell research be maximally supported without encouraging the destruction of nascent human life for research purposes?" It achieved consensus on two points, that research involving embryos over fourteen days old should be prohibited and that federal funding should continue to be limited to research on lines from already-harvested stem cells without the further destruction of embryos to provide new cell lines. Finally, at the conclusion of the report, Council members express the importance to them of achieving consensus on all aspects of the report—although not necessarily on the justifications for it.

There is yet further evidence that the Council believes that achieving consensus is an important task for it. In its posted mission statement, the Council rejects naïve moral relativism. For a body interested in ethical justification, consensus might be regarded as an alternative stance. Metaethical moral realists, to be sure, may reject consensus in favor of a "right" answer, such as that found in natural law—and there may be as many as five members of the Council who are natural law theorists (George, Gómez-Lobo, and perhaps Glendon, Kass, and Meilaender). Nonetheless, consensus might appear as a metaethical alternative. In their meeting in 2004 devoted to selecting topics for the president's next term—to take a further example of the Council's commitment to consensus—members of the Council sought topics on which there was likely to be agreement, and shied away from topics on which disagreement was likely, such as abortion, or topics on which they lacked expertise, such as justice in health policy more generally.

At the ASBH session devoted to the Monitoring report, the Council chair, Leon Kass, pointed out that the report reflected a consensus—and that the Council was more representative than President Clinton's NBAC had been, in terms of political affiliation.

The Representativeness of the Council

If the Council believes that consensus among its members is important, we might want to know something about levels of diversity on the Council. After all, the fact that consensus exists is only interesting insofar as it results from drawing together what might otherwise have been different. Consensus that is merely agreement among those who already
agree is uninteresting as consensus—if indeed it can be called an “achieved” consensus—although it might be useful to know that people already agreed on the matter in question.

At the ASBH session on Monitoring, the council’s chair, Leon Kass, defended its representativeness with respect to partisan political affiliation. It does not take long, however, to observe that the Council is not very representative in many other respects that might be equally important to the significance of the consensus it achieved. The following data are drawn from the Council’s website, from the respective websites of current Council members, and from the websites of professional organizations.

Currently, there are eighteen members of the Council. All but one (Charles Krauthammer, a journalist trained as a psychiatrist) hold academic appointments—a fact that might lead others to question the Council’s representativeness. Of those, exactly one (Gómez-Lobo) is trained in philosophy (in Germany, at Tubingen), a member of a philosophy department and of the APA. Two members (Dresser and Glendon) are law professors. Six (Fukuyama, George, Lawlor, Sandel, Schaub, and Wilson) have training in political science or political theory/philosophy, a particularly interesting finding in light of what we will see was the paucity of discussion of political philosophy in the Council’s deliberations or in the Monitoring report. One (Meilaender) is trained in Christian ethics. The remaining seven Council members are scientists or physicians, presumably to ensure adequate scientific understanding among Council members; counting Krauthammer, eight of the Council members have scientific or medical training. If bioethics is of special relevance to the Council, no members have specific training in that discipline. Only one member of the Council (Dresser) is a member of the American Society for Bioethics and Humanities. Two other Council members (Kass and Meilaender) have had longstanding associations with the field of bioethics.

The academic institutions represented on the Council are an unusual mix. Only two Council members (Foster and Wilson) teach at a public university (Texas Western and UCLA). The other Council members teach at private or religious institutions. The private institutions represented are Chicago (Kass and Rowley), Dartmouth (Gazzaniga), Harvard (Glendon and Sandel), Johns Hopkins (Carson, Fukuyama, and McHugh), Princeton (George), Stanford (Hurlbut), and Washington University (Dresser)—all institutions that might be regarded as “elite.” The religiously-affiliated institutions represented are Berry College (interdenominational Christian) (Lawlor), Georgetown University (Catholic) (Gómez-Lobo), Loyola Maryland (Catholic) (Schaub), and Valparaiso (Lutheran) (Meilaender). States represented on the Council are California (2), Georgia (1), Indiana (1), Illinois (1), Maryland (4), Massachusetts (2), Missouri (1), New Hampshire (1), New Jersey (1), Texas (1), and Washington, D.C. (3, counting Kass and Krauthammer’s current affiliations as D.C.). Outside of Chicago, St. Louis, Stanford, and UCLA, only one member of the Council hails from beyond the eastern seaboard (Foster, at Texas Western). One member of the Council (Carson) is African American and four (22%) are women.

I could not ascertain political affiliations of Council members from information publicly available on the web; thus, I cannot verify Kass’s contention that they are politically diverse. I would note that several have associations with organizations recognized as conservative, such as Kass with the American Enterprise Institute and George with the Federalist Society. Quite a number—five, by my count—have interests in natural law theory, an approach to political theory associated with Leon Strauss. By contrast, one (Sandel) is a critic of Rawls, but none would appear roughly Rawlsian in persuasion. Thus, at least five (the Straussians) would appear to have conservative allegiances in political theory, and none would appear to have sympathies with one of the best known liberal political theorists (Rawls) of recent times.

Thus the Council would appear not to be very representative on grounds of race, sex, class, or geographic distribution. It is highly skewed towards elite private and religious institutions. And it has limited expertise in its core fields of bioethics, ethics, philosophy, or health law; and no expertise at all in health policy. Does this matter? If the role of the Council is to achieve consensus amid divergence, it might, depending on the type of consensus sought. If, however, the Council is to be viewed on the model of other expert bodies, perhaps diversity doesn’t matter, but expertise does; there is no effort, for example, to have the Institute of Medicine be “representative” in the political sense in contrast to the sense of calling on the relevant expertise in developing reports. Unfortunately, the Council is limited in the variety of its expertise as well.

Types of Consensus

What kind of consensus were members of the Council seeking in the Monitoring report, and what kind matters? One account of the Council’s consensus is that the consensus in the report gave the president a description of where agreement in fact exists in society. This descriptive task might be particularly important for decisions about federal funding, if we think that federal funding should track public agreement—a view we do not hold for scientific research but might for issues such as funding of abortion where there is deep disagreement. The Council, however, does not contain the kind of expertise such as political scientists who do empirical work that might equip them to develop such reports. Nor did it see itself as representing a kind of popular consensus—if indeed a group with the Council’s makeup could be regarded as any sort of cross-section of viewpoints in the United States.

A different account of the Council’s role is that it attempted to achieve consensus through difference. This seems to be what both Leon Kass and the Council itself thought. On this view, the Council might provide the president with a justification for certain policies—those policies on which consensus has been achieved.

The Rawlsian distinction between a modus vivendi and an “overlapping consensus” is helpful in exploring whether the consensus the Council might try to achieve can be regarded as a justification for the views on which it achieves consensus. A modus vivendi is a mere agreement that allows people with different comprehensive ethical views to continue to function together politically. It provides no deeper justification than the fact of agreement. As I have already indicated, the Council does not have (and does not pretend to have) the kind of expertise that would allow it to report the presence of a modus vivendi across the larger society. And there are certainly questions about whether it contains the kind of representativeness that would enable it to put forth consensus among Council members as a modus vivendi of any broad scope.

An “overlapping consensus” in the Rawlsian sense is a justification that all reasonable citizens in a democratic society can accept, whatever their comprehensive theories of the good. Understanding whether or not there is an overlapping consensus in any respect is a philosophical enterprise. It requires examining the kinds of justifications that can be offered for positions and whether they are shared among reasonable comprehensive views. It also requires examining where justifications are not shared as a matter of public reason, but instead derive only from the comprehensive views in
which they are embedded. The consensus of the stem cell report, by its own characterization, is a modus vivendi; Council members indicate in their discussion at the conclusion of the report that their most important goal was achieving consensus rather than exploring the justifications that might support consensus and how they might do so.

How the Council Viewed Its Task, Part Two—What the Council Did Not But Should Have Done

As an expert body, the Council could have attempted to provide expertise about moral argument. On this view, the Council might have at least analyzed for the president where there is the basis for an overlapping consensus, and where moral disagreements result from different comprehensive views. The Council might have attempted to unearth the assumptions made by and the arguments made for different positions in areas of moral controversy, such as stem cell research. The Council’s role would have been to present the most careful and balanced accounts of the moral arguments in the debate, including where the arguments can be made as a matter of public reason. This admittedly was not the model followed by the current Council, as is apparent in both the background papers and the Monitoring report itself.

The Background Papers

In developing Monitoring, the Council commissioned background papers in both science and ethical theory. There were eight background reports in all, five on aspects of the science of stem cell research, one on state law governing the research, one on the meaning of federal funding, and one on ethical issues. The legal background paper was by Lori Andrews (at Chicago–Kent), perhaps the best known legal expert in the area, and presented a comprehensive survey of state law governing stem cell research, proposed state statutes, and likely constitutional challenges. The paper on the meaning of federal funding, by Peter Berkowitz (from George Mason Law School and Stanford’s Hoover Institution), argues that there is no right to federal funding, that those who would like to see changes in federal policy should seek them through the political process, and that stem cell research is no exception in these regards. It does not, however, present a careful or rigorous analysis of the significance of moral disagreement to political justification, other than advancing the author’s own position that changes should be sought through the political process.

The ethics paper was by Paul Lauritzen (professor of religious studies at John Carroll University). In the paper, Lauritzen contends that the stem cell debate has been too narrowly focused on the moral status of the embryo (to which, by the way, he does not object). Instead, he suggests, the debate should focus on the issues raised by the technology of stem cell research generally: commodification of human tissue, justice in access to the results of research, and reunderstanding what it means to be human. Lauritzen’s view is that both proponents and opponents of stem cell research must take seriously the trajectory of human life and the potential problems involved in extending the human life span. The paper is a summary of the arguments about what it means to be human and is not particularly philosophically deep. As a part of its proceedings, the Council also discussed a paper by Gene Outka, professor of religious studies and philosophy at Yale, exploring whether the “nothing more is lost” principle permits the killing of innocents who would otherwise be sacrificed in any event and can justify the use of embryos for stem cell research. The “nothing more is lost” principle, as Outka understands it, allows use of the fruits of immoral activity if nothing more is to be lost. The Council’s discussion was highly critical of the paper’s analysis of the principle’s breadth.

These papers, and discussions of them, represent the entire background in moral philosophy presented to the Council, at least as a matter open to public observation and discussion.

How the Questions Were Framed in Monitoring

In Monitoring, the Council started with the assumption that embryos ought not to be destroyed for research purposes. It then asked when it is permissible to use the fruits of what will not be brought into existence. Three conditions of permissibility are identified: there must not have been cooperation in the destruction, destruction must not be abetted, and the act of using what has been destroyed must affirm the principle previously violated. In the judgment of the report, government funding expresses support for a policy and thus is problematic if it can be regarded as in violation of one of these conditions. Hence the Council concludes that the Bush administration boundary of permitting federal funding for research with already-created stem cell lines finds ethical support. In reaching this conclusion, the Council analogized this limit to other restrictions on research with human subjects, contending that we set many moral limits on human subject research, and this one is no more problematic than the others. The report stopped short, however, of exploring the nature of support for the analogy. In framing the discussion in this way, the Council accepted as a given that there is no middle ground between those who find the destruction of embryos abhorrent and those who do not (39). But it fails to explore the nature of the arguments for these views, and, hence, either the extent to which they can be part of an overlapping consensus or the significance of making public policy in the face of contending comprehensive views. In fairness, Monitoring does observe that this may be a problem, writing that some have criticized contemporary discussions for failing to pay attention to the appropriate process of policy development. But the report goes no further in considering different accounts or justifications for this process.

The report took this structure as a given. Most troubling, in my judgment, is that it failed to scrutinize the arguments that have been given for framing the problem in this way. Although the Council canvassed various views about the biological features of the embryo that some have found to make a moral difference, it did so in the descriptive manner of an introduction to a (bad) applied ethics text book. It simply lists the points people have made on one side or the other, without doing the work to explore the arguments underlying them. Readers of the report, therefore, are left without any sense of the ethical foundations of different positions in the debate or any tools that might be used to assess them. Thus the reader cannot, based on the report, judge whether a position about stem cell research is—or is not—part of an overlapping consensus based in public reason. Far from contributing to an assessment of the kinds of arguments that should inform public reason, the Council simply assumed that existing arguments must remain entrenched. In so doing, it deepened rather than enlightened the character of our public discussion.

Enlightening the character of public debate, by contrast, was the model for the first President’s Commission, the one from the years of the Carter Presidency. That first Commission provided genuine contributions to bioethics—many still classics today—from people trained in philosophy, economics, law, and other related fields. Unfortunately, the current Council apparently does not see its role in this way.
Representation and Balance on Presidential Commissions

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It was President Ronald Reagan’s 1987 Presidential Commission on AIDS that first drew my attention to the staffing of federal bodies. I objected to several appointees, especially one member who objected to homosexuality as one of the great moral evils of the age; some of the scientist and physician members had no experience with AIDS research or patient care. How was a commission with members like this going to be sensitive to the needs of people with AIDS in the United States? After a period of unproductive wrangling, the original chair left, and the Commission eventually managed to put together a 1988 document that made a number of decent—if overdue—recommendations. I still wonder where the United States might be in the effort against AIDS if that Commission had had other members from the beginning.

The membership of federal advisory commissions is always a sensitive topic, and the current president’s choices are no exception to this rule. Both the procedure for making appointments and the members themselves have drawn fire in George W. Bush’s administration. For example, the Los Angeles Times has reported that the White House asked potential nominees to federal scientific advisory committees about their political views. Some nominees were asked if they favored the death penalty, abortion, and the like. In some cases, the nominees were directly asked if they voted for the current president. Depending on what answers these candidates gave, their names did or did not go forward for further consideration. The Union of Concerned Scientists has called attention to what it described as a pattern of suppression and distortion of scientific findings across the Bush administration. To be sure, scientific expertise in drug addiction, gene therapy, and bioterrorism cannot be measured through political commitments: scientific expertise does not belong to one political party, Republican, Democrat, Libertarian, or the rest. On the contrary, this kind of political profiling suggests that the administration was looking not for disinterested evaluation but for advice compatible with its political agenda.

A few advisory commissions on ethics have done significant and credible work for the government, and we owe their membership thanks for their efforts. These groups include the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research and, more recently, the Advisory Committee on Human Radiation Experiments. For the record, though, it should be noted that even these advisory bodies drew some criticism over their membership. Even so, the current criticism of the president’s bioethics choices has been considerably sharper. Many leading bioethicists have expressed doubts about the credibility of the current president’s Council on Bioethics. For example, Robert Cook-Deegan, Director of the Center for Genome Ethics, Law, and Policy at Duke University, has said: “the credibility of this Council is now deeply damaged, probably irreparably, except in the ‘already converted’ neocon circles. ... it’s too bad. The nation needs a bioethics council that works. I don’t think this one can.”

In part, some of the difficulties of the current Council may be traced to early political missteps. For example, in July 2001, the president was formulating policy in regard to federal funding of human embryonic stem cell research, and he asked Professor Leon Kass of the University of Chicago to make a presentation on the matter, and he also asked Kass to identify someone who held a different viewpoint. Kass invited Daniel Callahan, with the result that the discussion yielded more agreement than disagreement. When it came to representing a broad spectrum, these two eminent scholars were not opposing interlocutors for one another. Later that year, the president went on to create the Presidential Council on Bioethics, and he appointed Kass as its chair. As the White House went about the business of appointing other council members, its staff did indeed ask at least one potential member about her political views. Given this history, the seeds of doubt about fairness in balance and representation were already planted when the Council met for the first time in January 2002.

It was not long before other concerns surfaced. Eric Meslin of Indiana University wondered aloud about the nature of the executive order establishing the Council. In particular, he wondered about the directive that the Council be “guided by the need to articulate fully the complex and often competing moral positions on any given issue, rather than by overriding concern to find consensus.” While this might look like circumvent moral counsel to pay attention to everyone involved in the argument, Meslin wondered whether this very approach would undercut the Council’s actual advisory role. In other words, was the president setting the Council up to be irrelevant, to lose it in academic busy work and inviting it to speak in the kind of academic language lost on legislators and policymakers? Meslin also criticized the executive order for failing to include specific reference to “public members.”

In any case, if the White House was hoping for unanimous judgments from its bioethics advisory body, it was surely disappointed. In its first report, the Council did agree in calling for a ban against the use of somatic nuclear transfer (SNT) for producing children, but the Council divided when it came to human somatic nuclear transfer for research. One camp recommended a moratorium on somatic nuclear transfer for research. The reasons for this moratorium varied; some members of the majority wanted more time for study and for putting regulatory oversight mechanisms into place. Others wanted to use the time to press the case with the public that SNT should never be done. By contrast, the other camp recommended using SNT for research, provided appropriate regulatory mechanisms were put in place.

In February 2004, as terms came round for renewal, the president let two members of the Council go, and—not surprisingly—accusations flew that the White House wanted a more compliant Council. The two let go—William May and Elizabeth Blackburn—were among the members who supported human somatic nuclear transfer for research. Why were they—and not others—singled out?

Leon Kass took to the op-ed pages of the Washington Post to explain. He said William May did not want to stay longer, and Professor May agreed with that account. Kass applauded Blackburn’s expertise and insight even as he took a swipe at her by noting that “her important work kept her from attending many council meetings,” saying this despite the fact that she did not have the worst attendance record. Ultimately, though, Kass remained silent about any rationale for removing Blackburn from the Council. It probably did not help that Professor Blackburn and another councilor had criticized specific council recommendations and said, further, that the Council had ignored analysis they wanted represented in those reports. For her part, Blackburn did not go quietly: she indicated that many choices about and by the Council opened it to perception of bias. Even so, Kass called the
council "easily the most intellectually and diverse of the bioethics commissions to date."15

In other remarks, Kass said that he didn't know anything in particular about the views of the new members of the Council, but his public remarks suggest that their views are more compatible with the administration’s views than those of the two members they replace.16 For example, new member Diana J. Schaub has said that the use of somatic nuclear transfer for research purposes "is slavery plus abortion."17 Another new member, Peter A. Lawler, has publically stated his opposition to abortion.

To protest the decision to let Professor Blackburn’s appointment expire, more than 100 U.S. bioethicists asked the president for a better explanation of what happened, saying the changes compromise the credibility of the Council. The White House offered no reply.

In one sense, it might seem like partisan carping to complain about the personnel presidents turn to for advice, but the membership of federal advisory bodies is not in a strict sense—entirely discretionary. As a matter of law, the President’s Council on Bioethics is subject to the 1972 federal Advisory Committee Act.18 This Act requires membership to be “fairly balanced in terms of the points of view represented and the functions to be performed by the advisory committee.” The Act also requires that committees make “appropriate provisions to ensure that advisory and recommendations...will not be inappropriately influenced by the appointing authority or by any special interest, but will instead be the result of the advisory committee’s independent judgment.”19

From a philosophical point of view, a key issue to be noted is that the terms of balance and function are not specified exactly. As it stands, this language is open to varying interpretation and could accommodate any membership that is not, strictly speaking, completely one-sided or completely unequipped to carry out its duties. In practice, then, there is a lot of discretionary authority when it comes to appointing bioethics advisory groups. Moreover, the language of the Act is such that it is not clear exactly how one could argue that its terms have been violated. Except for egregious instances—say, in which relevant parties had been intentionally excluded, there are ways to appoint an advisory body that is—on paper—balanced, but which, in fact, leans one way or the other. To make this point more plainly, it is not clear that there has ever been a successful challenge to an advisory body on the grounds that its membership violated the requirements of this Act.

In addition to federal requirements, the nature of the advisory body’s tasks can also suggest standards to guide the selection of members. The charge to the Presidential Council on Bioethics is broad, to say the least, and its mandate is flexible enough to justify the appointment of almost any single member or group of members without worrying that—through that appointment—the body’s goals cannot be met. Specifically, the president has charged the Council to advise him on bioethical issues and—in the course of doing so—to undertake fundamental moral inquiry into the human and moral significance of developments in biomedical and behavioral science and to explore ethical and policy questions related to these developments.20 The Council is also expected to provide a forum for a national discussion of bioethics, to facilitate a greater understanding of bioethical issues, and to explore possibilities for useful international collaboration on bioethical issues. As there are many ways to meet these goals—especially the charges that do not ask for legislative or policy recommendations on specific matters—the membership of the Council can be composed in many different ways that do not impede its stated functions.

Despite legislative and procedural caution about observing balance in advisory bodies, it is almost impossible to underestimate the way in which political concerns guide the choice of membership. From a political point of view, presidents are cautious creatures and frequently unwilling to move to the vanguard of new social ventures or research. For example, in 1986, the U.S. Surgeon General produced an AIDS report that recommended, among other things, AIDS education starting in grade school. The report also cautioned against excessive testing programs with the sole purpose of identifying people with HIV infection. These recommendations and others like them caused considerable consternation in President Reagan’s political base. Enter the political need for another set of recommendations from the administration. While one might assume that a presidential advisory body on AIDS would be a natural development within an administration faced with a novel epidemic of communicable disease, it is not clear that the Reagan administration wanted the very Commission it eventually put in place. In fact, one commentator observed skeptically that “the Commission was created to deflect attention from the administration’s own inepic policy response to AIDS.”21 It is no wonder, therefore, that the George H. W. Bush White House went on to appoint members who could be expected to pay attention to the moral and social concerns of the president’s constituency.

Whether it is Congress or the president appointing advisory bodies, their creators will certainly pay attention to the political risks of doing so, asking themselves whether there is more political gain or risk from these bodies, bioethics advisory groups included. One way to contain what risks there are is to appoint members who—while meeting the stated purposes of the advisory group—will not rock the political boat more than necessary. It would be odd for a president to seek counsel from people whom he expects to put him at political risk with the voters who put him in office. It is true that advisory bodies can offer the president a certain amount of political cover. Since their recommendations are not binding, advisory bodies can float ideas in order to gauge their political reception. If the ideas are not well received, the president can always distance himself from the group’s views—but, in general, one should not expect recommendations to differ radically from the political soil in which they have grown.

One way to minimize substantial political risk is, of course, to sideline advisory committees into public education or other less controversial areas.22 It can be wondered if the Presidential Council on Bioethics is not drifting more and more this way. The second Council report offered an overview of the science and ethics of human embryonic stem cell research, an overview of the scientific and ethical issues involved. In 2003, the Council issued Beyond Therapy: Biotechnology and the Pursuit of Happiness, which plunked down a number of concerns associated with technological tools used to enhance human life and to extend the lifespan.23 In 2003, the Council also issued Being Human, an anthology of texts from short stories, poetry, memoirs, and novels, because these readings “can contribute to a richer understanding and deeper appreciation of our humanity, necessary for facing the challenges confronting us in a biotechnological age.”24 Whatever its next projects, most of the Council’s efforts to date have not involved specific advice to the president in regard to legal and policy matters. To be sure, each major bioethics advisory body has embraced some degree of responsibility for public education, but as George Annas has put it, the Council now seems to be in the business of conducting a national seminar.25 There is, of course, a lot of expertise that could be represented on federal advisory bodies in the name of public education, but balance and representation in membership

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really does matter here, too, especially when it comes to framing particular issues, or even in making judgments about which samples of literature best represent the ethical issues at stake in bioethics. So far, most commentators looking at governmental advisory bodies have asked whether bioethics is good for government, and in this regard there is—appropriately—lots of concern that advisory bodies be constituted in a representative and balanced way. But another question is at stake, too: Is the government good for bioethics? As a matter of drawing public attention to the goals and methods of the field, the answer appears to be an unequivocal and legitimizing yes. But it should also be asked whether governmental advisory bodies are the best way for bioethics as a field to conduct research and communicate with public and policymakers alike. I ask this question, of course, in full knowledge that the main professional association of bioethics in the United States does not adopt positions on burning political issues of the day. That is, it cannot adopt a position that says, in effect, it is opposed to federal sponsorship of human embryonic stem cell research, the use of somatic nuclear transfer to produce babies, or any other matter. When it comes to offering deliberate judgments from professionals active in the field, this bioethics association stands mutely on the sidelines, confined by its by-laws mostly to educational exchange. I mention this professional silence because governmental advisory bodies, while useful, should not be the only sources of deliberated and considered advice from bioethics, especially when it comes to public education. As matters stand, there is a communication gap between bioethics as a field and the public it hopes to serve.

Looking to presidential advisory bodies as the most important or primary mechanism through which to help conduct public education and determine public policy strikes me as a case of asking too very little from the profession. I believe there is a case to be made for communicating fully deliberated views to the public, legislatures, and policymakers in order to make it less susceptible to the political winds of the moment. Presidents surely have need for real advice from advisory bodies from time to time, but they will ask for this advice only when there is enough political gain in doing so. A more mature bioethics is one in which its leaders offer their collective and deliberated counsel when it is ready and not simply in response to requests that are sometimes only a part of a larger political strategy.

I want to offer one note of caution, too, in regard to bioethics theory and its sense of ethical problems. Key texts of bioethics typically treat the "state" and "government" as an idealized Platonic form, as if there were no ethical questions to be asked about how legislatures, agencies, departments, and institutions do their work. A great deal of bioethics theory treats the state as a morally neutral system of levers, which may be pushed or not, depending on the appropriate uses of government. For example, one looks in vain in most texts for counsel about the moral ambiguities of working through institutional and political organizations in all their complexity, about the ethics of compromise, or standards of institutional integrity. I mean no disrespect to the pioneers of bioethics, but it really is time that we start asking more fine-grained questions about how government works to avoid complicity with dubious compromises, to avoid partisan erosions of public goods, to examine what it means to accept help from parties with dirty hands, and so on. And—as I have been suggesting all along here—I think we also need to ask what it means to have fairly balanced views on federal bodies that purport to be representative and equal to their tasks.

The work of federal advisory bodies frequently radiates beyond its original purposes. Legislatures sometimes look to their work for guidance when coming to decisions, and courts can draw on them in their decisions. In other words, the reports that come out of federal advisory bodies have a political effect. In order to ensure that this political effect is not also a partisan effect, it is important to have balance in the viewpoints represented on the federal committees. The perception that a commission's work is guided by partisan politics will surely turn its efforts into political football.

In light of all the concerns I have raised about representation and balance in governmental advisory bodies, I will close by offering one specific recommendation: in direct proportion to the importance of a topic under consideration—whether it is national security or human embryonic research—governmental advisory bodies ought to ensure that the leadership of an advisory body compromises people from opposite ends of the political spectrum and that they are people who can be trusted to represent their moral views with vigor. Sometimes this condition can be met by appointing co-chairs of a committee, and other times this condition can be met by the appointment of strong members who are willing to swim against a political tide and to vote against the majority in the name of intellectual integrity, even when they know that they will end up on the losing side of the vote. Sometimes this condition can be met by leaving in place members who rock the boat, even if they miss some meetings now and then. Without this kind of representation and—therefore—balance, it will be hard, indeed, to trust that these advisory bodies work in the nation's interest.

Chicago, December 2004

Endnotes

1. I refer here to Cardinal John J. O'Connor of New York, who, in his battles against non-discrimination policies in New York, said: “We do not believe that homosexual behavior should be declared lawful or that such behavior should be elevated to a protected category.” Nat Hentoff, “Profiles (Cardinal O’Connor, Part II),” New Yorker (March 30, 1987), 50.


3. See, for example, Elizabeth Shogren, "Researchers Accuse Bush of Manipulating Science," Los Angeles Times (July 9, 2004).


5. See also James Hughes, “Human Enhancement on the Agenda,” http://betterhumans.com/Features/Columns/Change_Surfing/


7. Among the first assignments of the committee was to discuss the 1843 short story, “The Birthmark,” by Nathaniel Hawthorne.


20. See http://www.bioethics.gov
22. I don't discount the importance of this effort in any way. The chair of the National Bioethics Advisory Commission rightly put it this way: “...we believe that an ongoing national conversation about these issues is a critically important component of policy development.” Harold T. Shapiro, “Preface,” National Bioethics Advisory Commission, 1998-1999 Biennial Report (Bethesda, MD: National Bioethics Advisory Commission, 1999), iii.
23. President's Council on Bioethics, Beyond Therapy: Biotechnology and the Pursuit of Happiness (New York: Regan Books, 2003). By and large, this report proceeds by piling up possible social effects of these practices, but it makes no legal or policy recommendations. In fact, it avoids answering questions like whether and to what extent social changes in these areas would amount to a compelling reason to intervene against reproductive choices or technologies used to enhance or extend our lives, for whatever limitations these texts might have, it is unclear that the current members of the advisory council are not equal to the task.
24. The President’s Council on Bioethics, Being Human: Readings from the President’s Council on Bioethics (Washington, D.C., 2003), xvi. I will mention in passing that the Council identifies no principle for the selection of these texts or why these texts and not others are relevant to the issues at hand. More to the point here, there are no policy recommendations anywhere in sight.
27. See, for example, Institute of Medicine, Society's Choices: Social and Ethical Decision Making in Biomedicine (Washington, National Academy Press, 1995).

The President's Council on Bioethics and Stem Cell Research

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The President’s Council on Bioethics’s work on stem cell research consists chiefly of two reports: Human Cloning and Human Dignity (July 2002) and Monitoring Stem Cell Research (January 2004). The second of these, as its title suggests, consists chiefly of a summary of recent stem cell research, which I am not competent to assess, and a decent statement of various arguments for and against the moral permissibility of stem cell research. It provides a reasonable summary of many of the moral issues raised by stem cell research but does not attempt to decide which view of these issues is correct. For this reason, it is hard to argue with. Instead, I will focus on the Council’s report on cloning, and specifically on their discussion of somatic cell nuclear transfer, which they refer to as “cloning-for-biomedical-research.”

Somatic cell nuclear transfer works as follows: you take an unfertilized egg and remove its nucleus. You then take the nucleus from another adult cell and insert it into this enucleated egg, thereby creating an egg with the same DNA as the donor of the adult cell. You then manipulate the egg in various ways to induce it to start dividing. At this point, you have a cloned blastocyst. Presumably, you could then do any number of things with this blastocyst, but, for the most part, people have focused on two: either you can implant it into a woman’s uterus in order to create a cloned baby, or you can use it for biomedical research, like (for instance) deriving embryonic stem cells. We cannot keep human embryos alive outside a woman’s womb for longer than fourteen days; embryonic stem cells are generally derived when the embryo is about six days old. Strictly speaking, cloning-for-biomedical-research and stem cell research are two different things. On the one hand, not all stem cell research involves somatic cell nuclear transfer. Research into adult stem cells obviously does not, nor does research into embryonic stem cells derived from excess IVF embryos. On the other hand, somatic cell nuclear transfer might, in principle, be used for biomedical research that does not involve the derivation of embryonic stem cells. However, thus far, the main purpose to which somatic cell nuclear transfer might be put, other than producing cloned babies, is the derivation of embryonic stem cell lines.

The most important moral issue raised by cloning-for-biomedical-research is that, like any derivation of embryonic stem cells, it involves the destruction of nascent human life. Those who believe that, from the moment of conception, nascent human life merits the same protections that we give to, say, human infants, will for this reason regard the derivation of embryonic stem cells as murder, whether or not it involves a cloned embryo. But cloning-for-biomedical-research adds an additional wrinkle. When we derive stem cell lines from
excess IVF embryos, we destroy those embryos, but those embryos were not created at our behest. Absent our intervention, they would either be destroyed or, at best, frozen indefinitely. But when we use cloning-for-biomedical-research to derive stem cell lines, we create embryos for the express purpose of deriving embryonic stem cells from them, thereby destroying them.

Given this extremely brief sketch, one might think that there would be two main positions on cloning-for-biomedical-research. On the one hand, most of those who believe either that human life merits the protection we give to infants from the moment of conception, or who object in principle to the deliberate creation of embryos for use in procedures that will destroy them, presumably think that cloning-for-biomedical-research should be banned. On the other hand, those who believe that a six-day-old blastocyst does not merit the same sorts of protections we give to human infants, and that it is permissible to create them for a purpose that will involve their destruction, possibly on condition that that purpose not be frivolous, would support allowing scientists to proceed with cloning-for-biomedical-research.

The Council’s report came up with two recommendations. One, which received seven out of seventeen votes, was to allow cloning-for-biomedical-research to proceed, possibly subject to regulation. But the other was not, as one might have expected, that it should be banned. Instead, ten members of the Council recommended a four-year moratorium on cloning-for-biomedical-research.

It is not clear what the point of such a moratorium would be. A moratorium makes most sense when something that we expect to happen during the course of the moratorium will affect the choice we make, and when we think that we should not proceed until that something has occurred. But it is unclear why one might take this view of the case at hand: what might happen in the next four years such that we should not decide whether or not to proceed with cloning-for-biomedical-research until it has happened. Here are some possibilities:

First, one might support a moratorium in order to allow time for the government to develop suitable regulations on cloning-for-biomedical-research. However, the Council understood the option of permitting cloning-for-biomedical-research to go forward to include permitting it as soon as suitable regulations could be developed; therefore, a desire to allow time for the development of those regulations cannot be what led members to support a moratorium over the option of permitting cloning-for-biomedical-research to go forward.

Second, we might hope that the ethical issues will be clarified in some way that will make it obvious how we ought to proceed, or that will at least allow us to make a better decision than we can make now. This might be sensible to think in the case of some new technology that raises genuinely novel questions that we have not yet thought through. Thus, if some new scientific discovery made it possible to arrest the aging process at, say, age 40, thereby granting human beings something close to immortality, it would be a good idea to stop and think through the implications before proceeding. However, cloning-for-biomedical-research does not raise novel moral issues that we have not yet considered. We have already discussed the moral issues involved, like the status of human embryos, extensively, and I can see no reason to think that we will develop some radically new insight into these questions in the next four years.

Third, some of the members of the Council cite the need to allow democratic deliberation to proceed, in the hope that we as a society can reach consensus on the issues raised by cloning-for-biomedical-research. I do not think that this consideration shows that we should place a moratorium on cloning-for-biomedical-research. The issues involved have already been the subject of extensive public debate. No doubt there are people who are not yet familiar with the ins and outs of stem cell policy, but that is surely not because they have not had sufficient time to think, or because the issues are too new. Nor is there any obvious reason to think that the outcome of four more years of debate would be a consensus—this has not happened in the case of abortion, which, like cloning-for-biomedical-research, involves the question of the moral status of human embryos.

Even if we could expect further public discussion of these issues to make real progress in the next four years, this would not imply that we should not proceed with cloning-for-biomedical-research in the interim. Obviously, it is better to make significant policy choices after extensive public debate. However, sometimes there are real costs to waiting until such a debate has concluded. In such cases, we normally think that the government has the right to proceed. Thus, for instance, we went to war in Iraq before we had concluded a thorough public debate on the merits of doing so. Like cloning-for-biomedical-research, the invasion of Iraq raised serious moral issues, issues that concern not just this particular war but the general question whether we should invade other countries absent either an imminent threat to ourselves or our allies or an unfolding humanitarian catastrophe. In this case, as in the case of cloning-for-biomedical-research, proponents of moving ahead with the proposed policy justify their views by pointing to the costs of waiting. And while one might question that decision on any number of grounds, it would be odd to base one’s disagreement on the general claim that we should never do something that a significant minority of the citizenry thinks is wrong without first allowing public discussion and deliberation to conclude. Sometimes the cost of inaction is high. Since constraints on research into stem cell therapies delay therapies that could save lives, cloning-for-biomedical-research is, arguably, one of those cases.

If we cannot anticipate a major ethical breakthrough, and if we should neither require nor expect democratic deliberation to lead to some sort of consensus, the obvious remaining possibility is that progress in scientific research during the next four years might allow us to see the issues more clearly. If we allowed cloning-for-biomedical-research to proceed for the next four years, we might learn something useful about what it can and cannot do. But imposing a moratorium on cloning-for-biomedical-research would rule out this source of useful information, so this cannot be what proponents of a moratorium are waiting for. We might hope that pursuing embryonic stem cell research in animals would enlighten us. However, it is already clear that animal studies are very promising. Some members of the Council expressed the hope that research with adult stem cells might show embryonic stem cell research, either with or without cloning-for-biomedical-research, to be unnecessary. But this is unlikely. Adult stem cells and embryonic stem cells are not just one sort of thing, stem cells, taken from two different sources. They are very different kinds of cells with very different properties, and there is, as far as I know, no reason whatsoever to think that adult stem cells will turn out to be capable of doing whatever embryonic stem cells can do. Moreover, in testimony before the Council, researchers in both adult and embryonic stem cells said that they find it useful to compare the two, and that banning research into either embryonic or adult stem cells would significantly impede research into the remaining type of stem cell.
To clarify these points, consider a few purposes for which cloning-for-biomedical-research seems very likely to be necessary.

* Autologous stem cell lines. When you inject stem cells or their derivatives into someone, you are essentially performing a transplant. As with organ transplants, you have to worry about how the person's immune system will respond to these cells, and, in particular, about whether it will reject them. Scientists are working on a number of ways to address this problem, but by far the most promising is to use embryonic stem cells with the recipient's own DNA, which the immune system will obviously accept. Now, how would a doctor go about finding embryonic stem cells with a specific person's DNA? Even if that person has an identical twin, that twin would not be an embryo. The odds of an embryo with that person's exact DNA turning up as an excess IVF embryo and being donated to research are vanishingly small. The only practical way of getting embryonic stem cells with a specific person's DNA is to create one using cloning-for-biomedical-research.

* Research into genetic diseases. Embryonic stem cells, in general, allow us to do more powerful research into embryonic development than we could do otherwise. Using stem cells, scientists can observe aspects of the process of development and differentiation in ways that would be neither moral nor feasible with living, developing embryos. But cloning-for-biomedical-research allows us to take this a step further. Suppose a scientist wants to understand exactly how a given genetic mutation produces a given disease. If she is restricted to using excess IVF embryos, she will need to wait until an embryo with that mutation turns up; if the mutation in question is a rare one, this could take quite a while. If she uses cloning-for-biomedical-research, on the other hand, she need only locate someone who has the mutation in question and use his or her DNA to develop a stem cell line. Moreover, scientists could use genetic engineering to create two genomes, one with the mutation, and one without. Using cloning-for-biomedical-research, they can then generate two stem cell lines that differ only in that one has the mutation in question and the other does not. This would allow them to see exactly when and how the two lines diverge in their development, without needing to worry about the possibility that their divergences were due to some other genetic difference. And this would be an extremely powerful tool for understanding some genetic diseases.

These are some of the obvious scientific benefits of using cloning-for-biomedical-research. Both require stem cells derived not from excess IVF embryos but from cloning-for-biomedical-research. They are speculative in the sense that we might discover that embryonic stem cells cannot be used for these purposes successfully. But their promise is quite clear as things stand. What is required is to do the necessary research to see whether or not they do work. But this is precisely what a moratorium would prevent us from doing. There might be good reasons for thinking that such research is immoral and should not be allowed to proceed at all. But there is no obvious reason to think that we will be in a better position to make that determination four years from now than we are today. For this reason, I do not understand why the ten members of the Council who voted to recommend a moratorium thought that it, and not either a ban on cloning-for-biomedical-research or a decision to allow it, possibly subject to regulation, was the best policy option.

However, it is not clear that all ten of the Council members who voted for a moratorium did think that that was the best option. Page 228 of the Council's report contains the following passage: "Were we to indicate where we stand on the ethical and prudential assessments of the two forms of human cloning, each considered independently, we would line up as follows:"—seven for allowing cloning-for-biomedical-research to proceed subject to regulation, three in favor of a moratorium, and seven in favor of a ban. "Where we stand on the public policy options—in which both cloning-to-produce children and cloning-for-biomedical-research are necessarily considered together—we shall indicate below, in our recommendations." It was in these recommendations that seven members of the Council voted for a moratorium and seven to allow cloning-for-biomedical-research to proceed.

This passage implies that what accounts for the fact that seven members favor a ban on cloning-for-biomedical-research considered in isolation but went on to vote for a moratorium is that, for the purposes of the latter vote, cloning-for-biomedical-research and reproductive cloning were considered together. But it is not clear why considering the two together either weakens the case for a ban on cloning-for-biomedical-research or strengthens the case for a moratorium. The only obvious way in which considering both forms of cloning together affects the arguments at all is that it makes relevant one consideration that concerned some members of the Council: the fear that cloning-for-biomedical-research might make reproductive cloning easier. But this consideration would seem to strengthen the case for a ban, not to weaken it.

Nor does the text of the report clarify the reasons that led the seven members of the Council who favored a ban on cloning-for-biomedical-research considered in isolation to endorse a moratorium instead. After the passage just cited, in which seven Council members express support for a ban, the report moves to a discussion of other issues. When it returns to the Council's recommendations, the only options considered are permitting cloning-for-biomedical-research and imposing a moratorium on it. The option of banning cloning-for-biomedical-research has simply vanished and is not considered again.

The reasons the Council gives in support of this proposal focus primarily on the claim that we, as a society, have not yet reached a consensus about the morality of cloning-for-biomedical-research, and that, therefore, more deliberation and debate is needed before we proceed. But the Council does not explain either why we should expect that further deliberation will allow us to reach consensus, or why we should wait until we do. It does not attempt to weigh the desirability of reaching consensus against the delay into research that might save lives.

More interestingly, it does not explain why those members who favored a ban when cloning-for-biomedical-research was considered in isolation voted in favor of a moratorium instead. As I have noted, considering cloning-for-biomedical-research and cloning-to-produce children together rather than separately would strengthen the case for a ban. Moreover, while the report presents reasons for thinking that a moratorium is a good thing, it does not present reasons for thinking that a moratorium is a better option than a ban. While pros and cons of both positions are presented earlier in the report (pp. 220-223), the section of the report that explains the rationale behind the moratorium (pp. 231-246) neither compares it to a ban nor explains why, in the view of those Council members who supported it, it was the superior option. Thus, it does not help us to see why those Council members who originally supported a ban on cloning-for-biomedical-research voted for a moratorium instead.

For these reasons, I cannot help wondering whether the seven who favored a ban in isolation might not have preferred it as a policy option but decided to vote with the three who
favored a moratorium rather than recommend the option they thought best. If a majority of the Council did not, in fact, think that a moratorium was the best policy option, their views about cloning-for-biomedical-research would be more consistent. But this possibility would raise a different set of questions about how they understand the work of the Council.

If one were, say, a member of Congress trying to put together a majority in support of one’s views, then it might make sense to vote for a moratorium even if one thought that the most justifiable option would be a ban. A vote in Congress determines what the law will be, and so it might make sense for a supporter of a ban on cloning-for-biomedical-research to vote for a moratorium if her choices were either to vote for a ban, in which case her side would lose and cloning-for-biomedical-research would be permitted, or to vote for a moratorium, in which case cloning-for-biomedical-research would be prohibited for four years, allowing advocates of a ban more time to make their case.

However, the President’s Council is not a legislative body. It is an advisory council whose purpose is to illuminate the arguments for and against various policy options and, if possible, to recommend those they think best. In this context, it is not at all clear why one would vote to recommend a policy one did not believe to be the best available. Doing so does not clarify the issues, it does not result in the recommendation of those options that Council members think are the best; and it arguably undermines the Council’s stated purpose of providing the president and the nation with the best advice the Council can give, and of enhancing public debate of the issues they take up.

Some Council members might have believed that some good consequences would follow if they obtained a majority in favor of a proposal that did not allow cloning-for-biomedical-research to proceed. There are many ways in which members of the Council might, and presumably did, appropriately take the consequences of their report into account. They might, for instance, try to figure out how to put their points in such a way that ordinary people, not just bioethicists, scientists, and policy analysts, could enter into the argument. They might worry that some point might be misconstrued in ways that would be harmful and try to explain clearly why it should not be taken in that way. They might discuss some point at greater length than they would otherwise have done in the hope that a longer discussion would provoke a more illuminating public debate. Any of these ways of allowing concern for the consequences of their report to affect its contents would have been perfectly appropriate.

But it would not be appropriate for concerns about the consequences of the Council’s report to affect members’ decisions about which policies to recommend. If Council members are concerned about the consequences of actually adopting some policy option, those concerns have presumably entered into their judgment about which option is best. But if, having decided that some option is best, they choose to endorse a different one because they think it important to get a majority in favor of some option other than allowing cloning-for-biomedical-research to proceed, or because they believe that some unfortunate message would be sent were the Council to split evenly between those who favor allowing cloning-for-biomedical-research to proceed and those who favor banning it, with three swing votes in favor of a moratorium, then that seems to me wrong on two counts.

First, I think that any Council member who voted for a moratorium on these grounds is mistaken about how much influence the Council’s recommendations have. I am not trying to minimize the importance of the Council’s work in general; I think that the Council’s reports have done a good deal to stimulate public debate. But the precise breakdown of the Council’s votes for or against a particular policy option seems unlikely to have much impact.

Second, for members of an advisory council to misstate their conclusions in order to achieve some desirable consequences is to mistake both the nature of advisory bodies and the role of public intellectuals. The role of an advisory council, as I understand it, is to offer the president and the nation the best advice they can give, not the advice that its members think will lead to the best results. The role of public intellectuals is to illuminate the arguments for and against various positions and to advocate those they prefer by explaining their reasons for thinking them best. It is not to advance the conclusions that seem to them to produce the best consequences when they do not think that those conclusions are justified.

I may be wrong to wonder whether some members of the Council might have voted to recommend a policy they did not think was best. As I noted above, the text of the report does not explain their reasons for preferring a moratorium to a ban, and so I have had to try to reconstruct them. But if some members supported a ban but voted for a moratorium, then I believe that they abdicated, to some extent, the role they were best suited to play: not to exercise political influence but to contribute their best thinking and judgment to the debate about stem cell research. If, on the other hand, they did favor a moratorium over a ban, all things considered, it would have been useful had they explained their reasons more clearly.

Endnotes

1. Someone who believes that human blastocysts merit the same protections we give to human infants but that this claim can be justified only by appealing to views that she thinks public policy should not be based on, for instance on religious views, might not endorse such a ban. For instance, a Catholic who thought that a ban on cloning-for-biomedical-research could be justified only on the basis of her religious beliefs, and who also had a strong commitment to the separation of church and state, might oppose a ban on cloning-for-biomedical-research.

What Price Hope?

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Serious illnesses, and perhaps especially serious chronic illnesses, often present their sufferers with difficult physical challenges, as well as existential challenges that go to the very core of their being. The physical challenges by themselves can be daunting, involving maladies such as acute pain, motor impairments, sensory deficiencies, incontinence, and shortness of breath, to name but a few. Despite the enormity of some of these physical challenges, however, the challenges to one’s personhood may present the greatest difficulties. People tend to identify themselves by the work they do or the roles they take on in either their private or public lives (e.g., a mechanic, a teacher, a salesperson, a little league coach, a father or mother, a church volunteer), and serious illness can often compromise a person’s ability to fulfill these roles. The resulting disruption of the individual’s life—loss of job, inability to participate fully in the life of one’s community or family—can furnish the materials for an existential crisis of the highest
Assessing CAM

Turning to the assessment of the effectiveness of CAM therapies, the first thing to note is that very little data exist. Despite the National Institutes of Health’s charge to seriously investigate such therapies, there are still few studies aimed at systematically evaluating many alternative therapies. Of course, the same holds true for some of the practices involved in conventional medicine. Particularly when the etiology of a disease is not well understood, even if the clinical symptoms are clearly demarcated, conventional treatments may be based on incomplete and/or ambiguous data. In more instances than physicians may wish to admit, conventional therapies and their practitioners are mistaken at best and charlatans at worst.

I should also add that I am someone with a chronic, progressive neurological disease (multiple sclerosis) and, for the past eight years, have found it necessary to use a wheelchair for mobility. As someone with a serious chronic illness, I have experienced what I refer to as the tyranny of CAM therapy. Whenever one is ill, getting better or finding a cure is a natural desire. Family and friends also naturally desire a cure for you, or at least symptomatic relief. Unfortunately, conventional medical treatment cannot always effect such an outcome. For some diseases (and mine is one of them), conventional medicine may help the patient “manage” the disease and offer some minimal symptom relief, but it is unable to effect a cure or give total relief. As a result, well-meaning friends and family often ask me why I do not try other, nonconventional, holistic remedies. After all, what do I have to lose? When I offer the confession that the therapy in question is untested (at least in a scientifically rigorous manner) and therefore has dubious effectiveness, often the person will produce some sort of evidence in favor of his or her suggested therapy—an article in the popular press, anecdotal evidence from a friend, a testimony found on an advertisement for the drug or treatment in question. If I try to gently reject the person’s evidence as logically or scientifically inadequate, the reaction is almost universal disappointment, but it is a disturbing kind of disappointment. The person’s disappointment is often directed as much toward me as toward what I perceive as a dubious medical treatment. The conclusion sometimes drawn (either implicitly or sometimes explicitly) is that I am being close-minded, or that I am ungrateful for the person’s help, or even that I do not really want to get better. I have seen this reaction time and time again, and I freely confess I may be partly to blame in too abruptly rejecting a genuine offer to be helpful. Nonetheless, I have come to view CAM therapies as a kind of tyranny that I must constantly confront, which further fuels my skepticism of them.

Still, as Eisenberg and others have documented, these alternative therapies remain popular with significant numbers of people, many of whom cannot be labeled as irrational, illogical, or otherwise deficient in their ability to reason. I know many highly educated, professional people—lawyers, college professors, teachers, bankers, business leaders—who swear by the effectiveness of chiropractic treatments, acupuncture, and herbal supplements, among other modalities, to cure or relieve a host of maladies. My initial, skeptical response notwithstanding, the phenomenon of CAM merits a more balanced and reflective hearing than I originally imagined. In this spirit, I see three primary questions that need addressed at the beginning of any analysis of alternative medicine. First, how do we assess the claims of CAM therapies? Second, how and why does CAM threaten conventional medicine? Third, what makes a therapy “alternative” as opposed to standard care?

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Ardent proponents on each side of the dispute generally view the RCT as the gold standard of assessment, making room for other, more holistic and patient-centered, forms of subjective evaluations by patients. Perhaps we should no longer feel medical practitioners need to be more open to qualitative, nature, these effects are more often measured in qualitative terms (which seem necessarily subjective) instead of using the methods of objectively verifiable, quantitative analysis favored by the RCT. The difficulty in assessing CAM can seem even more daunting when one adds in the possibility of the placebo and/or other hidden, nonspecific effects as a contributing factor in making the patient feel better.

As a result, viewing the RCT as the sine qua non for assessing medical therapies necessarily renders the efficacy of CAM suspect. Yet many would argue that reliance on the methods of Western science and the RCT represents a kind of value judgment. Perhaps when it comes to evaluating CAM claims, medical practitioners have to be more open to qualitative, subjective evaluations by patients. Perhaps we should no longer view the RCT as the gold standard of assessment, making room for other, more holistic and patient-centered, forms of assessment.

In any case, would more or better data on CAM resolve the dispute between the various practitioners? I doubt it. Ardent proponents on each side of the dispute generally operate within different frames of reference. What data exist for assessing CAM are not generally the kind of data science-based, conventional medicine would find legitimate, let alone convincing. Part of the reason for conventional medicine’s rejection of CAM stems from these different frames of reference. Yet part of the rejection also stems from the perceived threat CAM presents to physicians’ patients and medical practices. This perceived threat leads to the second question I raised earlier: How and why does CAM threaten conventional medicine?

The Threat of CAM

The first and most obvious threat CAM poses to conventional medical practice centers on resources. Patient demand for alternative forms of medical therapy means increased competition for already scarce medical resources. The depth and breadth of this demand was first revealed in Eisenberg’s disturbing findings (disturbing for mainstream, conventional medicine). Among other interesting facts, Eisenberg and his colleagues discovered that, in 1990, approximately sixty-one million Americans used at least one of the sixteen unconventional therapies they studied, and approximately twenty-two million saw unconventional medical providers for treatment of a principle medical condition. Furthermore, in 1990, one in three American adults used unconventional therapies, and the number of visits made to unconventional medical providers exceeded the number of visits to all primary care physicians nationwide. In addition, the U.S. Congress has appropriated money to the National Institutes of Health to “support rigorous research on complementary and alternative medicine (CAM), to train researchers in CAM, and to disseminate information to the public and professionals on which CAM modalities work, which do not, and why.” This appropriation amounted to $113.4 million in FY 2003, up 8.4% from FY 2002. Arguably, this is money that might be used for research into more conventional types of therapies.

But the perceived threat of CAM is more than merely monetary. Many physicians see CAM providers as threatening their authority as the gatekeepers of accepted medical practice. Particularly in the current era of managed care, physicians are expected to make decisions on the effectiveness and efficiency of any potential treatment modality for their patients. Without physician approval, insurance underwriters will not cover a given medical treatment. Most CAM providers work outside of this system of physician approval and insurance payments, employing a fee for services model that had been the dominant payment model for physicians in the past. Additionally, some patients supplement their conventional physician care using CAM therapies without fully consulting their physicians. Drawing again from Eisenberg’s report, in 1990, most patients who used a CAM provider did so without the recommendation of their doctor (89%), and 72% of CAM users did not inform their doctor of their use of these therapies.

Notwithstanding the potential harm to patients when they keep their conventional physician uninformed as to their use of CAM, these practices by patients impinge on physician authority and autonomy.

A further perceived threat is the result of a kind of philosophical conflict between CAM and conventional medicine. The conventional view of medicine reflects the ideal of Western science that there should be a uniform method in medicine and medical research. This view of medicine as a subset of science is clearly expressed by Marcia Angell, former editor of The New England Journal of Medicine:

> Perhaps the most important hallmark of science is its utter reliance on evidence. Furthermore, the evidence must be objectively verifiable. This reliance on concrete evidence distinguishes science from all other human endeavors. …Medical conclusions are no different from other scientific matters, because the body is a part of nature.

Angell’s view, as expressed here, harkens back to an earlier debate in philosophy and the philosophy of science, in particular, the concern over how to demarcate genuine science from pseudo-science, and the related epistemological concern over how to demarcate meaningful propositions from nonsensical propositions, often found expression in the criterion of empirical, objective verifiability. If we accept the position that objective, empirical verifiability demarcates genuine medical practice from pseudo-medical practice, then, of course most CAM therapies fall beyond the pale. And it really is this fundamental philosophical difference that seems to underline much of the debate between CAM and conventional medical practice. Not to overstate the controversy too much, but some see the basic tenets of Western science (which is to say good and proper science) at stake in this dispute over CAM.

Of course, this view raises the question of whether or not the practices and methods of Western science are somehow the right or best methods (or at least somehow better than
other methods of inquiry), particularly within the domain of medicine. And, while I confess to being sympathetic to the view that they are generally the best methods, particularly vis-à-vis the practice of medicine, I admit this view is increasingly under siege and is no longer assumed as a truism in our postmodern world. This leads to the final of the three questions I began with, viz., what exactly demarcates a therapy as alternative or complimentary as opposed to standard, conventional care?

**Alternative Therapy or Standard Care**

As I began to outline above, the question of distinguishing a medical therapy as alternative or complimentary rather than standard conventional practice is embedded in a larger philosophical debate that goes back a century or more. In medicine, this debate manifests itself in the move away from a holistic approach to medicine to a more value-free, scientific approach.17 Physicians began to increasingly view patients in a more fragmented way, focusing on a diseased organ or biological system rather than on the illness as experienced by the patient with its array of physical, psychological, and spiritual components.18 In making this move away from a holistic approach, medical practice was moving in step with what was becoming the mainstream scientific view. And this mainstream scientific paradigm was very much influenced by the positivist stance.

The logical positivist emphasis on empirical verifiability as the hallmark of good science engendered a sharp distinction between the objective and the subjective. Good science, and therefore good scientific medicine, relied on value-free, neutral, unbiased observation. In such scientific practice, the observer made every effort to be totally separated from the object observed, lest his or her personal biases affect the observed outcome. Subjective value judgments were eschewed as far as possible in good science and in good science-based medicine. The personal reports of the patient, being subjective and largely unverifiable, were no longer the “privileged” data in diagnosis and treatment. In their place, the laboratory report became the “privileged” data and indicated what was really happening to the patient.

The sharp distinction between the objective and the subjective realms that positivism encouraged (privileging the former over the latter) also tended to lead to a fairly radical form of reductionism in science and in medicine. The assumption was that all of nature operated according to certain objectively observable and discoverable laws. There was a certain unity to science, and part of the goal of scientific study was to uncover this unity. The fundamental laws that governed the motion of planets were ultimately the same as the fundamental laws of chemical reactions, which can then be connected to the laws governing biological organisms.18 On this assumption, physics and biology are ultimately connected to one another. In medicine, these ideas led to the establishment of research-based medical schools (e.g., Johns Hopkins being the first) and increased emphasis on the science of medicine with, according to some, its attendant reductive components.19

However, in philosophy of science, there has been increasing debate over the primacy of this model of scientific inquiry. This debate began in earnest with the publication of Thomas Kuhn’s book The Structure of Scientific Revolutions.20 In this book, Kuhn argued that an examination of the history of scientific inquiry and discovery revealed that there really was no single, unified method in science. Instead, scientists adopt a certain “paradigm”—marked by their acceptance of a particular conceptual worldview, which embodies various methods, beliefs, and values. This paradigm represents “normal science” for them. Over time, however, certain anomalies arise in their research programs, and, eventually, these anomalies become so numerous that the current paradigm can no longer accommodate them. A crisis ensues, which is resolved by a revolution in which the old paradigm is replaced by a new paradigm. The replacement of the Aristotelian model of physics and the geocentric universe by Newtonian mechanics and the heliocentric universe of Copenicus and Galileo provide examples of just such revolutions and paradigm shifts, argues Kuhn. The lesson to draw from all this, according to Kuhn, is that there is no one method in science. The unity of science and scientific method was, and is, a myth.19

Applied to medicine, this new conception of science gives credence to the view of some that there is no one right method for providing medical care, such as the method embodied in conventional, science-based medicine. If no one method can define good medical practice, this leaves open the possibility that some of the medical practices falling under the heading of CAM potentially have equal claim to being considered good medical practice. So perhaps the attempt to distinguish a therapy as alternative as opposed to standard medical care represents a certain close-minded hubris on the part of conventional medical practitioners. In fact, we can observe some loosening in this distinction between alternative and conventional therapies in the recent past as practices that were once considered alternative and suspect have become a part of main-stream, conventional medicine (e.g., the current acceptance of osteopathic medicine along with the increasing use of acupressure and bio-feedback modalities as conventional treatments, to name just a few).

The distinction between various therapies has changed over time and no doubt will continue to change. That fact is partly to blame for the difficulty everyone seems to have in providing a suitable definition for CAM. CAM therapies represent a kind of moving target, and zeroing in on them can be challenging. A therapy such as the treatment of an ulcer today may become standard practice at some future time. While I am predisposed to favor conventional, scientific medicine, I do not think we can dismiss all CAM therapies out of hand. Neither can we uncritically accept them, however. What then is the proper response to CAM therapies and their claims? Based on my own critical reflections, as a chronically ill person struggling to reconcile my philosophical skepticism concerning the claims of CAM with my own desire for a cure, I see three main lessons we might draw from the issues I have raised here.

**The Phenomena of CAM: Lessons to Learn**

The first lesson concerns the limits of conventional medical treatment. All of us—medical practitioners, patients, the public—need to recognize and accept the very real, and sometimes sobering, limits of medical treatment (and of life itself). Not all diseases and medical maladies are responsive to conventional medical treatment, or any medical treatment for that matter. This lesson is a hard one to accept, especially in the face of disability, disease, and death. When we face these eventualities, we have a difficult time believing that nothing else can be done medically to mend us or prolong our lives. Our society tends to operate under the assumption that if we study a disease long enough, and throw enough resources into finding a cure, we can defeat virtually any disease (and even death itself).12 The remarkable successes of modern medicine have greatly contributed to this assumption. Operating under this assumption masks a reality we must all face sooner or later: not all conditions and diseases can be cured, and, for all of us, death is the ultimate destination. Still, we are loath to accept this reality, and herein lies some of the
allure of CAM. When modern medicine can do no more to help us, there may be nothing irrational in choosing to pursue a nonconventional remedy, whether it be an herbal cure, acupuncture, meditation, or prayer (especially in conjunction with conventional therapies).

This natural and reasonable inclination to pursue CAM therapies on the part of some patients should not necessarily threaten conventional medicine. Honest practitioners of modern conventional medicine recognize the role that intuition and subjective judgment play in practicing the "art" of medicine—even scientifically-based medicine. Modern medical techniques greatly aid physicians in the diagnosis, prognosis, and treatment of disease, but the judgment of the physician, which is a product of his education, experience, wisdom, and knowledge of the patient, seems necessarily subjective. That patients seek second opinions, even treatment, from nonconventional practitioners should come as no surprise given that medicine is not entirely an exact science. Nor should this threaten physicians. Rather, they need to accept this turn towards CAM on the part of some of their patients, educating them on the potential harms while encouraging truthful disclosure by their patients when they seek out alternative therapies. This disclosure is particularly important in order to protect the patient from any adverse reactions between conventional and alternative treatment plans.

The second lesson to take from these reflections is how little the public, including patients and some doctors, really know about so many CAM therapies. This ignorance on the part of the public needs to be remedied if we are to avoid needless harm to ourselves and to society at large. Part of what is required are more studies and tests on CAM therapies, something the National Center on Complementary and Alternative Medicine has undertaken. Despite the objections of some, these tests need to be as scientifically rigorous as possible, with special attention paid to the role of placebo and other nonspecific effects in CAM therapies. While I am aware that a great deal still needs to be investigated and better understood concerning the efficacy of conventional medical practice to include the role of placebo and other nonspecific effects in these therapies, that does not mean we should not hold CAM therapies to a rigorous, scientific standard. All medical practice, conventional and CAM, should be held to the highest scientific standards possible.

The public has a role to play here as well. The public needs to become more scientifically literate and logically astute, especially if they are to guard against medical misinformation and charlatans. Greater scientific literacy will help the public assess the claims of conventional medicine, as well as CAM, and should make all of us better informed participants in our own medical care. Unfortunately, even a moderate level of basic medical literacy often seems lacking. For example, most acute illnesses are self-limiting, and even most chronic illnesses experience remissions. What this means is that most ill people are going to get better even if they do nothing. Therefore, not all patient improvement is attributable to medical procedures, whether of a conventional nature or CAM. And yet, how many people are generally aware of even this simple fact? The number of people who swear by the efficacy of Echinacea to treat the common cold indicates a certain ignorance in this regard. Yes, they get better taking Echinacea, but they would get better in the same amount of time without the drug.\(^\text{23}\) Echinacea clearly has no effect in treating the common cold, and yet many otherwise intelligent and well-educated people still persist in taking Echinacea. Why is that? Answering this question leads me to my final lesson concerning the phenomena of CAM.

When we are ill, whether from the common cold, a chronic, debilitating condition, or a life-threatening disease, CAM therapies and their practitioners respond to two felt needs of many patients. The first need, which I have already alluded to, is the need to do something about the illness. We are generally not content to "let nature take its course" but look to intervene in some manner, no matter how dubious its actual effect. So the cold sufferer takes Echinacea, the person with chronic fatigue syndrome goes to the acupuncturist, the terminally ill cancer patient goes to a faith healer. The second need is even more crucial for most people, and, while related to sickness and wellness, it is not a straightforward medical need. For that reason, it is a need that conventional, science-based medicine, with its emphasis on the disease process rather than the ill person, has sometimes lost sight of, namely, the patient's need for someone just to talk to them. Oftentimes what the sick person desires most is a friend who understands and is willing to listen to them, someone who sees them as a person rather than a disease. CAM practitioners, either knowingly or unknowingly, tend to recognize and satisfy this felt need of the patient—even though they are not medical treatments by the standards of conventional medicine.

As a patient and a philosopher, I am still deeply skeptical of most of the claims of CAM; however, I also recognize that CAM practitioners can have a powerful and positive impact on patients. The practitioner who spends time listening to the patient and assessing his or her condition holistically on the basis of the patient's own subjective reports (rather than by appeal to impersonal scientific tests, such as blood tests, CAT scans, etc.) establishes a bond with the patient that can have a positive effect on the patient's health. However, accomplishing this kind of bonding is increasingly difficult in today's environment of managed care, with its emphasis on efficiency and the need to process many patients in a relatively short period of time. Really listening to patients, respecting their subjective self-evaluation, providing a sympathetic ear, and establishing a level of trust based on mutual respect and even friendship are not standard medical treatments and are not recognized as such by most insurance underwriters.

So what is the lesson here? I do not believe modern scientific medical practice should give up its science, but physicians can continue to do a better job of accommodating the "nonmedical" needs of their patients. The needs I refer to are nonmedical in the sense that they do not fit under the rubric of standard medical practice, but they are not nonmedical in the sense of having no impact on the health of the patient. They can have a profound effect on the patient's feeling of well-being and level of general health, and I would argue that sometimes the apparent efficacy of CAM can be attributed to the CAM practitioners' willingness to fulfill this need.

Now, I am not so naive to believe that our system of managed care is going to radically reform in such a way as to make such an accommodation on the part of conventional medical practice easy. If anything, taking time to enrich the physicians' interaction with their patients will become only more difficult as health care costs continue to rise.\(^\text{24}\) So part of the solution to this conundrum may lie with patients. What I mean by this is that we as patients need to recognize that not all of the problems associated with illness are medical problems amenable to a medical solution. Particularly when it comes to chronic and/or life threatening illnesses, often there is no magic drug or therapy that can effect a cure. Yes, living with such illnesses requires medical support, but it requires other kinds of support too. Loving friends and family, membership in a church or other religious/spiritual support, an attitude of optimism and hope—all these things may be as important as,
or more important than, the latest drug or the newest medical therapy. For better or worse, these things are not generally found in the doctor’s office, and we as patients should not expect to find them there.

Do CAM providers offer this kind of support to their patients? I suspect they sometimes do—even if the CAM provider’s solicitousness represents more of a false come-on rather than genuine caring—which explains much of their appeal. Are CAM providers the only ones who can offer this kind of support to ill people? Obviously, they are not. So where does all this leave me, the chronically ill philosopher? What conclusion do I draw from this analysis of CAM? First, I intend to live my life without recourse to the unproven and generally false hope that CAM offers. Second, I will also live my life with the recognition that conventional medicine has little to offer me in the way of a cure (at least so far). However, I do not live without hope. I live my life with the hope of being surrounded by a loving family and good friends, with the hope of doing good work in the world and making a difference in the lives of others, however small. Finally, I live my life with the hope that in the end I can say—with the Roman poet and philosopher Horace—"I have had my hour."

Happy the man, and happy he alone,
He who can call today his own:
He who, secure within, can say,
Tomorrow do thy worst, for I have lived today.
Be fair or foul or rain or shine
The joys I have possessed, in spite of fate, are mine.
Not Heaven itself upon the past has power,
But what has been, has been, and I have had my hour.

Odes, Book 3, xxix—Translated by John Dryden

Endnotes


5. Eisenberg, et. al., 248. Some have disputed the accuracy of Eisenberg’s figures, persuasively arguing that his numbers are falsely bloated. See Timothy Gorski, “Do the Eisenberg Data Hold Up?" Scientific Review of Alternative Medicine, Vol 1, No. 3 (Fall/Winter 1999).

6. The lack of data for evaluating CAM claims may be attributable to ignorance on the part of most physicians and patients, but it is a prevailing perception among many people, and so therefore becomes reality for them.

7. My point here is not meant to impugn conventional medical practice as mere guesswork. There is a great deal of scientific data backing up conventional medical therapies, and physicians’ “hunches” are heavily influenced by that data and their experiences. Nonetheless, medical science is not an exact science (what applied science is?), and both physicians and especially patients should recognize that fact.


9. Eisenberg, et. al., 250. As noted above, some dispute the accuracy of Eisenberg’s data (see note 5), but, nonetheless, the demand for CAM seems to be increasing.

10. Ibid., 251.


13. Eisenberg, et. al., 249.

14. Potential adverse drug interactions or other adverse outcomes from different treatment protocols by different practitioners present a growing danger to patients in these dual settings.


16. The goal of philosophy known as the logical positivists, with A. J. Ayer as its most well known English speaking proponent, held the view that a proposition had to be empirically verifiable to have any meaning. See Ayer’s Language, Truth and Logic (NY: Dover, 1952). Karl Popper, while not exactly of the same school of thought as the positivists, sought to demarcate science from pseudo-science using the criterion of empirically falsifiable. Only genuine scientific theories were falsifiable; pseudo-theories were not. See Popper’s Conjectures and Refutations (Harper and Row, 1968).

17. The Flexner Report of 1910, which argued for a more research-based approach to medicine, was instrumental in effecting this change.

18. The earlier quotation from Marcia Angell represents an acceptance of this unified approach to science and medicine.


21. Clearly, I have greatly simplified Kuhn’s argument here, and there are others who contributed to this new conception of science and scientific inquiry. Paul Feyerabend, who argued that no rules should govern science, particularly comes to mind. I should also note that Kuhn himself modified his views in his later writings, and, yet, the ideas that I have outlined here retain their influence over many.
22. Witness the funding appeals of so many organizations seeking donations to study various diseases. They ask the public to send money so that society can defeat or cure heart disease, cystic fibrosis, cancer, lung disease, muscular dystrophy, etc.


24. And, yet, there are physicians (even those working in a managed care setting) who do find the time and energy to interact with their patients in meaningful and positive ways—so the task is not impossible.

Desires and Values in Medicine
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It is clear that autonomy is an important component of personhood and that our desires are tied to our autonomy in an important way. Just how they affect our autonomy is not so clear and has been the focus of much philosophical research. Defining personhood is a necessary part of the discussion of autonomy and the understanding of moral responsibility. In the medical context, judgment of autonomy, or lack thereof, guides the medical professional to act either with or against the patient’s desires.

Harry Frankfurt’s famous paper “Freedom of the Will and the Concept of a Person” makes two major assertions. The first is that a person is defined as one who has a desire for one of her desires to become effective—a kind of “second order desire” he calls a “second order volition.” The second is that a person’s will is free only when her volition matches what she actually does. Freedom of the will is the ability to choose from among one’s first order desires the one that moves her to action. Frankfurt is on record as a compatibilist, but he claims in his paper that his concept of a person is neutral in regards to determinism.

By his account, free will is determined on an act-by-act basis. For example, I may, of my own free will, take the trash out when I do not want to take the trash out. At the same time that I do not want to take the trash out, I do want to take the trash out (because I want the trash taken out and I’m the only one around to do it). Of these two first order desires, the one that I want to want is my will if it becomes effective. If I do not fulfill my volition and I don’t take the trash out, Frankfurt asserts that I have not acted of my own free will (I didn’t fulfill the desire I desired to fulfill), though I have still acted freely (I did what I wanted to do, on the first order at least). His distinction between freedom of action and freedom of the will is important to his argument.

Throughout this ordeal, I have been a Frankfurtian person. Whether I’ve taken the trash out or not, I have had a second order volition about my two conflicting desires. The ability to reflect on my desires is what distinguishes me from an animal that may desire to do things but cannot lay its desires out and pick among the ones that conflict. I wanted one of the two to be the one that moves me. In a sense, I preferred one.

If laziness won out and I did not take the trash out, I still had that volition to do otherwise, which, according to Frankfurt, is what personhood is all about—though, I would be a person without free will in regards to the disposal of my garbage. Had I not cared about which desire became effective, then I would be a “wanton.” As a wanton, my two desires still exist alongside each other, but I do not have a preference as to which one I bring to fruition (the trash would likely never get taken out, and I would not care even though it makes me unhappy and I want it gone).

The idea of a wanton thus conceived is problematic. Frankfurt claims that it is not impossible for a wanton to exist with rationality and second order desires, but it is difficult to imagine an individual who has the capacity both to want and not want something but does not see in one of them an outcome that is more desirable for her. Frankfurt says the wanton would just go with the strongest impulse, perhaps deliberating about how best to achieve the accomplishment of fulfilling the strongest desire but ignoring the question of her will.

Returning to the tale of the trash that has yet to be taken out, how could it be that I do not want to take the trash out and want to take the trash out but do not care which desire moves me to action? Given that I do care, giving into laziness will be upsetting to me because I am still left with the trash. However, if I do not care whether wanting to take the trash out or not wanting to take the trash out moves me, then could I have really wanted them both? If I do not care, then it is hard to conceive of myself honestly wanting to take the trash out.

Take another example, from medicine. Suppose a patient wants to have a life-saving operation and does not want to have a life-saving operation because it is frightening. In fact, most people who face an operation have the same conflicting desires. No one wants to have surgery, though most people do want to do what it takes to be healed. The patient’s volition is that she wants the desire for the operation to move her to get on the operating table. However, she is actually moved by her desire not to have the operation—it is just too scary for her to do what she knows is best for her, what she wishes she could bring herself to do. Can a wanton be described using these same circumstances? Can she want to have the operation to save her life, and not want to have the operation because it is scary, and still really not care about which she will act on? The wanton, conceived as a marble bouncing randomly through a maze of desires, seems more like an automaton. Frankfurt concedes that the individual who matches his description of a wanton with reason and second order desires is unlikely to exist.

Imagining a wanton is easier in the case of animals and children than it is in adults towards their behavior about household chores, for example, or even Franklin’s favorite example of drug addiction. The distinction between the person (unwilling addict) and the wanton (unconcerned addict) is most believable in the case of drugs because included in the concept of addiction is the idea that one’s autonomy is already wounded. The unwilling addict has the desire for her will to be not to use drugs. Again, this volition establishes her as a person. Similarly, the willing addict wants to use drugs and wants to want to use drugs. The wanton, though, has no volition, so her simultaneous desires to use drugs and not use drugs do not matter to her.

Drug use leads to more, however, than a simple desire—drug addiction is a powerful biochemical force. The drug addict’s decision to use drugs and thereby sacrifice her autonomy is akin to the case of the person faced with an armed robber. The robber demands from her, “your money or your life.” She can respond in one of two ways: refuse and be killed, or surrender the money and be left to live. She wants to both deny the robber her money and to remain unwounded. It is not impossible that she makes the first choice, but the
claim that she is as free to choose that as she is to choose to save her life is dubious.

Similarly, when the drug addict feels the pangs of “hunger” for her substance, she still has the ability to resist. Substances can create physical cravings—desires to escape pain, chills, anxiety, frustration, and other symptoms. Not being able to resist the desires they create may be a matter of weakness of the will, but her will is still capable of strengthening itself to the point of deciding against using the drug. In other words, drugs do not hijack a person and act for her. In the face of pains from withdrawal, or even simple discomfort, she is just not as free to resist as she is to give in. One thing about which Frankfurt is clearly correct is that “the enjoyment of freedom comes easily to some. Others must struggle to achieve it.” In “Autonomy, Duress, and Coercion,” James Stacey Taylor puts it somewhat differently and more accurately: “Impairments to autonomy can differ in degree.” For the addict and the robbery victim, bringing one of their two desires to action is profoundly difficult and the other is quite easy. In these cases, where fulfilling one of two desires will result in immense pain, or death, Frankfurt is correct that the ability to exercise free will is limited.

It does not follow from the idea that one does not care which of her desires leads her to action (as in the case of the wanton) that she is unaware of all of them, higher ordered or otherwise. The individual who does not care which desire has the strength to make her act has, as a higher order desire itself, the desire not to care. She may want to be without worry or anxiety about the future self she is harming. A person may, of her own free will, be a drug user, a criminal, or an all around horrible person. But she is still a person. She has autonomy regardless of how she resists or does not resist the internal forces doing work to limit it. As the popular song goes, “don’t make me over, I’m all I want to be.”

What we commonly regard as desires are desires of the first order. The personal difficulty we face when our first order desires conflict can be resolved when we reflect on our higher order desires—when we consider what we “really want.” Frankfurt notes that “unresolved conflict among someone’s second-order desires [puts one] in danger of having no second-order volition.” This, Frankfurt continues, will either “paralyze his will” or cause “his will to operate without his participation.” Furthermore, if one cannot resolve conflicts between his second-order desires and continues to move up the hierarchy of desires infinitely considering which of his higher order desires he desires, then he again “destroys himself as a person.”

Frankfurt states this problem of regress as if it were a possible psychological condition an individual might have. But other critiques of Frankfurt’s theory have claimed that the problem is with the theory rather than the individual. Higher order desires are just desires themselves, and just as a first order desire would need a volition to make it one’s will, so would a second, third, fourth, and fifth order desire. The hierarchy of desire, then, becomes infinitely high, and one cannot be sure that she is doing what she wants to want, ad infinitum, to do. For this reason, Herat Shamindra writes, “the hierarchical model needs to be grounded in something other than mere appetites, if it is to account for autonomy.”

By autonomy, he means the self-governance associated with freedom of the will. Still, in this sense of “self-governance,” Frankfurt and Shamindra agree that autonomy is central to the concept of a person. In “Autonomy and Hierarchy,” Michael Bratman discusses the possible resolution of intra-personal conflict in terms of values. Citing Isaiah Berlin’s discussion of pluralism, he notes that within individuals there are often conflicting values, just as there are among individuals. An individual who values her work, for example, may have to make a sacrifice in regard to that value because of another value, such as spending time with her family. Looking from the perspective of what we value, we create judgments about our desires, and from there we decide which is truly desirable.

Aristotle might cite habituation as the basis for one’s values, but, in addition to upbringing and habit, values differ from desires in that they assess what is important to oneself. Gary Watson argues in “Free Agency” that our values emerge from self-reflection, and it is when our values govern our action on our desires that we are free.

Bratman considers Watson’s claim that the average person’s actual deliberation is about what to do, not which desire is motivating her, to be an important point. Bratman and Watson are correct: most people, no matter how sophisticated, do not stop to consider the hierarchy of desire but rather rely on “background structures” that are complex, personal, and not immediately apparent to the individual upon whom they are working.

Wanting to have a desire and wanting to have a first order desire be effective distinguishes desires from volitions of the second order. The doctor who wants to know what it is like to experience drugs, from Frankfurt’s example, has a second order desire independent of his second order volition. The doctor wants to want to experience drugs, but he does not want his desire to experience drugs to make the real experience of drugs happen. He wants to know what it is like to be one of his patients, but he does not want to be afflicted with their condition. In this case, it seems that his desire to empathize with them is not a desire for drugs at all. If he really wanted to have the desire for drugs, then he could call up his volition and get hooked. Perhaps the hypothetical doctor has patient-related values—he values having empathy for his patients, but he values more his life free from the kind of conflict and suffering for which they seek his help.

If we insert values into Frankfurt’s discussion of hierarchy, then we might conclude that when individuals resolve conflicts among their desires based upon the “policy-like attitudes” that Bratman describes as shaped by their values, they have acted of their own free will.

Returning to the problem of regress, if I desire to take my drug of choice, but I also desire not to take it, Frankfurt contends that deferring to my higher order desire not to desire the drug makes me a person. Imagine that I can line my first order desires up, and then try to match a higher order desire to the correct one. But what if I have two higher order desires that conflict? It is possible that I want to take the drug and I do not want to take the drug, and I want to want to take the drug and want not to want to take the drug. This situation can be reconsidered in terms of values. Now, when my desires are laid out on the table, I reflect upon what is important to me. The pleasure of using drugs may be important to me, as well as a future in which I live a better (and freer) life. The latter of these choices is what I value most; the former is just what will gratify me for the moment.

Here, the hierarchy of desire still exists, but the inner debate about what I truly value exists on only one level. I may not live up to my own values, and thereby injure my own autonomy, but I will have acted freely in either case.

Of course, people are often “torn” by their values, and their values are often matters of desire. I may value spending time with my family and value the important project I’ve been working on. At any moment, I can do only one or the other, and picking between them may not be as easy as deciding
what I really want to do. When we consult our values and reach an internal resolution, we may find that something important to us has been lost in order to preserve or promote something else of equally legitimate importance.

Frankfurt and Berlin would likely go to philosophical blows over the matter of determinism. Frankfurt holds that the wanton has no freedom over her will—her actions are determined by the unchecked desire to do what is immediately rewarding to herself—but Berlin would claim that the wanton is sacrificing one value for another because she is unable to translate her desires into the value that would best serve her autonomy and well-being. Berlin would likely describe the will in terms of appetites and values, both of which are pointed toward outcomes.

What we desire, when we desire anything at all, is an outcome. If I desire to eat ice cream, for example, I am looking forward to the outcome of satisfying my taste buds. I do not want the outcome, however, of the calories affecting my health. This is where my values conflict. Is it the satisfaction or the avoidance of a few extra calories that is most important to me?

The outcomes we desire that are most important to us are more complicated than simple tastes and vanity. When I want my garbage taken out, I want the outcome of a sanitary, garbage-free place in which to live. When I face the operation, I value the outcome of my health being restored. When I am tormented by my conflicting desires to use drugs and not to use drugs, I value the outcome of being a free, autonomous person who is not ruled by the chemistry of suffering. It is the outcome that fits with our values that we desire on the first order of the hierarchy, and when we move ourselves in accordance with our values, we are moving freely and of our own free will.

Medical professionals have the difficult task of not only assessing their patients’ autonomy but also their values. Sometimes the hierarchy of their desires will become a web of conflict in which the autonomous, proactive involvement in their well-being is trapped.

When deciding to act against any of the patient’s desires, or what the patient perceives as her will, the physician must determine and examine the patient’s values through the resources, when available and timely, of psychological counseling, knowledge of family members, and prior experience. Similarly, physicians must assess the values of the medical profession when their own desires about how to best serve the patient conflict.

A well-trained, compassionate physician is herself not immune to the anxieties patients feel about certain treatments or to the fears of pain that treatments can cause. Doctors and their patients care about the outcome of the treatments in which they are involved, of course, but when they want what will destroy what they value, such as a longer life or a shorter period of suffering, the doctor-patient relationship must be used to examine the hierarchy of desire, the value system upon which it is working for or against, and the patient’s autonomy in the past, present, and future.

Endnotes

Ethical Issues in Home Health Care: The Ambivalent Client
Rosalind Ekman Ladd

Introduction
When I ask home care professionals what their most perplexing ethical issues are, one of the most frequently-mentioned issues concerns clients who change their minds. Ever mindful of the ethical requirement for informed consent, caregivers are frustrated by the individual who accepts treatment willingly one day but refuses it the next day.

The change of mind client may be particularly unsettling for home health care nurses, for they have the opportunity to come to know clients over a period of time in their home and family settings, and so may feel that they know the person and his or her wishes better than they would in a hospital setting. Thus it comes as more of a shock to hear a reversal of previous choices. What does the client really want? How can I know? Will there be another change of mind tomorrow?

There are two forms of changing one’s mind. One involves a change from a past consistent pattern of choice. The change seems sudden and non-characteristic. Based on the evidence of past preferences, one is tempted to say, “I know she doesn’t mean that.” The second form of change of mind involves a pattern of flip-flopping, repeatedly expressing different choices at different times. Each of these forms presents conceptual and practical problems.

The typical knee-jerk response to either form of change of mind is to question competence. According to some theories, a sustained pattern of choosing is a necessary condition of competence, that is, an absence of flip-flop behavior and perhaps even an absence of change of mind. Inconsistency is taken as legitimate grounds for questioning competence.

In what follows, I want to challenge the relationship between inconsistency and incompetence. I will do so by trying to understand more fully the idea of “what the client wants” and the kind of autonomy required for someone to give informed consent for medical treatment. My thesis is that if we introduce some form of feminist relational autonomy, we can put the inconsistency of change of mind or flip-flop choices into a context in which ambivalence about treatment choices is both understandable and within the realm of the rational and competent.

Consistency, Competence, and Relational Competency
The standard argument underlying the questioning of competence on the basis of change of mind goes like this: to be logical requires consistency, for example, affirming or choosing p or not-p. To be inconsistent is to choose p and not-p and therefore is not logical. To be competent requires being logical; therefore, being inconsistent is a sign of incompetence.
In the case of the widower, the client should be regarded as a self-in-relation, one who is and should be influenced by family and others. His reasons for a change of mind should be explored. If a different choice is made in response to changed circumstances, then this is an expression of competence. The important thing to remember is that a change of circumstances may include a change in relationships: perhaps he has reconsidered the degree to which he is a burden on his family or he has recalculated the cost-burden ratio of the quality of life with treatment versus the extra time it might afford him.

According to the independence view of autonomy, a person is encouraged to choose what is in his or her own best interest. But some individuals take self-sacrifice as a high value and see it as being in their own self-interest. Relational autonomy, as I understand it, recognizes and honors the value we put on our relationships with others. Whether it is a matter of nature or a product of socialization, it is true that some individuals derive a great deal of satisfaction from choosing in ways that are self-sacrificing. Should we spoil it for them by imposing a misconceived standard of independent autonomy?

The Practical Problem

These reinterpretations of typical cases, however plausible, still do not answer the practical questions: How do we know what the client wants? How should we respond? There are a number of principles one might consider adopting.

A. Always go with the choice for continued treatment and continued life. This reflects the condition written into most forms of the living will that the choice to discontinue treatment may be revoked at any time, even by a patently incompetent person. For those who accept this principle, a request for treatment always trumps. This may feel comfortable to the physician who takes the goal of medicine to be saving lives, but it does not reflect honestly the idea that competent persons may refuse treatment.

B. Always go with the current expressed wish. This has the advantage of being “easy,” or at least avoiding a confrontation by pointing out the inconsistency with past choices. But this is, in many situations, impractical, especially in a situation of continued treatment, where going on and off a medication may be dangerous or may compromise the efficacy of the whole course of treatment. The importance of this principle, however, is to remind us that treatment must be accepted voluntarily by a competent person and should never be forced or administered while the person is actually protesting. It offers an opportunity for exploring the person’s reasons for the protest and assessing whether this may be a genuine change of mind, which may be supported with very thoughtful reasons, or a display of “flip-flop” decision-making, which indicates a deep underlying ambivalence.

C. Ask for reasons in order to determine whether or not a particular choice is a competent one. In theory, this is an excellent principle; in practice, there are difficulties in exploring the issue without exerting undue influence. Simply questioning a decision may be taken as a kind of disapproval. More importantly, under the physical and emotional stress of illness and life-death decisions, many perfectly competent people would be hard pressed to be able to articulate reasons or engage in a prolonged discussion of the issues.

D. Choose a time to designate as the time of a genuine decision. For example, a patient with cystic fibrosis, well aware of what the future holds, decides in advance not to accept respirator support at the end of life. When the time comes and breath is short, she may ask for help in breathing. If the medical team can remind her of her decision and promise sedation to eliminate suffering, she is likely to reaffirm the original decision. Patients and families who are well informed
about what to expect at end of life are less likely to panic and to try to reverse a previous choice.

The downside of this principle is that we do not want to make it impossible for people to change their advance directives, to make them irrevocable. The usual criticism, that we cannot know ahead of time what we will be feeling and wanting as we approach death is well taken, and, if we take informed consent seriously, we need to leave open the possibility for someone to give or revoke consent.

None of these “solutions” to the practical problem of knowing what someone wants acknowledges the deep ambivalence about values that I have argued is a part of the human condition. Deciding on the basis of any one of these principles assumes either that a decision can be made for all competent persons outside of their expressed wishes (Principle A), or that a competent person’s choice, once made, remains consistent over time (Principle C), or that to be competent is to comply with the laws of logic and be able to provide reasons that lead logically to a particular conclusion (Principle B).

Conclusion

What lessons can be learned from this discussion? If my analysis is right, then the home health care nurse who is faced with clients who change their minds will approach them with understanding and empathy rather than frustration or exasperation. The nurse can initiate a conversation to help clients recognize the conflicting values that account for their ambivalence. Having recognized that, the next stage is to think through what must change in order for one value to really outweigh the other and allow them to resolve the ambivalence.

Context Matters: Ethical Issues in Home Health Care

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Ethical issues rise for everyone involved in home health care, including patients, their families, and professionals. This discussion, however, will focus on the issues for nurses who work in this context. This analysis will utilize a methodology developed with Rosalind Ladd and Lynn Pasquerella for our book, Ethical Issues in Home Health Care. In our work, we argue that an analysis must address three factors: the particular circumstances of the patient and caregiver, individuals’ relationships and related responsibilities, and the consequences for relationships.

The first of these three factors, the context in which an issue arises, will be the focus of these comments. I will describe two ways in which the context is ethically relevant in home health care: 1) the general features of the home health care context, and 2) the significance of this context for nurses who face ethical conflicts. Since the evaluation of morally-relevant factors and the decision to privilege specific factors over others in a particular case requires ethical judgment, I will conclude with an initial sketch of a concept of ethical judgment.

The Home Health Care Context

In general, there are several important differences between the hospital setting and the home health care context. When the setting for delivering care shifts from hospital to home, the responsibility for care largely shifts from health care professionals to nonprofessional, family caregivers or friends; the role of family relationships takes on greater significance; and new concerns about rights and values may arise. All of these changes have an impact on the ethical problems that must be faced by professionals and families.

First, concerns about the physical setting for providing health care often emerge about safety. Hospitals and health care professionals generally can control the safety of the hospital environment. It is clear, however, that health care professionals are not able to exert a similar kind of control in a client’s home. Individuals who are no longer hospitalized can make decisions that may risk their safety, from treatment choices to decisions about whether to live alone or with someone else, judgments concerning the day-to-day management of their homes, and basic choices about how to run their lives. Clients can, for instance, decide to live with someone who neglects them, or take risks with their own health and well-being, or be content with a home that is basically unsanitary or unsafe, or tolerate dangerous behavior from family members, and so on.

Secondly, when patients are sent home from the hospital, families, or, in some cases, friends, are expected to become caregivers, to follow medical instructions, and to provide whatever assistance is necessary in caring for the patient. This can be a source of ethical concern for nurses if a member of a family or a friend is negligent, refuses to adhere to medical instructions, or attempts to interfere with professional care. When there are questions about the ability and willingness of family caregivers to provide the care required, there may be critical questions about the adequacy of the care they are giving, or even the feasibility of home health care. Since nurses have a responsibility to determine whether to intervene on behalf of a client, the behavior of the family caregivers can raise serious issues for nurses.

Perhaps the most significant contextual feature of home health care is the role of families and the significance of family relationships. On the one hand, maintaining meaningful relationships is of special importance, especially in the circumstances of illness, and, most importantly, in the context of home health care. This is an important ethical goal that should inform the actions of professional caregivers who are involved in home care. On the other hand, concerns about a client’s relationships may arise when a family member is manipulative, or a relationship is destructive or harmful in some way to the client. While in the hospital setting, the role of the family is limited, but families usually have a substantial role in home care. Professional caregivers are in charge in the hospital setting, but the home is under the control of the client and/or the family.

A further difference arises in the context of home health care. Recognizing and supporting important ethical rights and values may be especially challenging in the home health care setting. The client’s right to make significant decisions may be impaired when the client is dependent on family caregivers or friends, and nonprofessional caregivers may be ignorant of basic rights or inclined to disrespect those rights. For example, family members may attempt to override decisions about treatment made by the client. Most significantly, when dying clients have decided to forego resuscitation measures, families may call a rescue unit and demand resuscitation. Though competent clients retain their moral and legal decision-making authority in this setting, professionals, as well as families, often have concerns about poor judgment and decision-making in a setting in which clients control the physical setting, the care plan, and the choice of their caregivers. Finally, maintaining other basic ethical requirements, such as confidentiality and privacy, is challenging in the home setting.

Most important is the fact that home health care nurses, though part of an interdisciplinary team, are ordinarily the only
professionals in the client's home when a decision must be made. This factor may present the nurse with unique ethical concerns about providing adequate care in the context of a home that presents obstacles to ideal nursing practice. The nurse may also have to confront troubling issues about the health and well being of family caregivers themselves.

**Context Matters**

To illustrate the significance of these differences in a physical setting, the role of nonprofessional caregivers, and the import of family relationships, let's consider the case of a patient receiving kidney dialysis and wound care in a hospital setting. Can you imagine any of the following scenarios in this context?

- The patient is not provided with the special diet ordered by her physician.
- The patient does not get the medications ordered, or may get them, but not according to the schedule devised by her physician.
- Though she requires wound care, professionals involved in her care are unable to maintain sanitary conditions.
- Her care is assigned to someone believed to be drunk most of the time.

Hospitals have developed policies and procedures that generally prevent these situations from occurring and provide remedies when they do occur. For example, if there are concerns about the sanitary conditions in a hospital setting, these conditions can be immediately addressed and corrected. Concerns about the adequacy of care are referred to the appropriate supervising authority, and legal mechanisms are implemented where necessary.

All of these scenarios, unimaginable in the hospital setting, occur in the context of home health care. Although there are policies and procedures for addressing issues such as neglect or elder abuse, many of the concerns about safety or the behavior of family members do not rise to the level that precipitates official action. Consequently, there may not be clear remedies for these concerns about the adequacy of home health care. The following case is not atypical.

**Case: Imperfect Care**

A nurse reports: "My client is a woman with kidney disease who receives dialysis three times a week. I am seeing her because she needs daily wound care for pressure sores. Her daughter, who has a history of alcohol abuse, recently moved in to take care of her. This is not working very well. The daughter is often drunk when I arrive, and I think she is neglecting her mother. When I tried to raise this issue with the client, however, she said her daughter takes good care of her. Should I do something more to protect this woman from her own daughter?"

Addressing the ethical concern raised by this case requires careful thinking about the home health care setting, the nonprofessional caregiver, and family relationships.

Clearly, such relationships are valuable aspects of people's lives, but, here, that family relationship has added influence and significance since this woman is dependent on her daughter. Given her kidney disease, she requires medication and must adhere to specific dietary restrictions, and she needs transportation to her dialysis treatment appointments. She is at risk of developing an infection in her wound if the requisite standards of cleanliness are not maintained. All of these considerations underscore the important role her family caregiver must play. The nurse is right to be concerned about the daughter's capabilities and her motivation to conscientiously act as her mother's caregiver. Should she do anything more to protect this woman?

Any competent adult has the right to decide to live where she wants and under whatever conditions she deems desirable. Unless there is a reason to believe that this woman is incompetent, or that her decisions are coerced or uninformed, there is no justification for intervening further. Based on her own comments that her daughter takes good care of her, we can infer that the client is satisfied. She seems to value her daughter's companionship more than her own comfort and well-being, and apparently she wants her daughter to continue to live with her despite the difficulties. That is her right.

At the same time, this consideration of her rights and the consequent risks she accepts should be informed by an ongoing evaluation of the physical context and the caregiving provided. Questions remain about this specific context: What is this woman able to do for herself? What help is available for her if a problem arises with her daughter's care? Are there other family members or friends, even neighbors, who can be enlisted to check on her or to assist with caregiving? How can the risks be minimized? These questions demonstrate the contextual details that are essential to good decision-making in ethics.

**Ethical Judgment**

Determining which factors are most important in an ethically problematic situation calls for ethical judgment. Ethical judgment involves: motivation to do the right thing; sensitivity to recognize ethical issues, comprehension of major moral ideas, principles, and values; unbiased culturally competency; reasoning ability; and experience in reflecting critically on ethical problems and solutions. Individuals can develop their capacity for ethical judgment. The ability to exercise ethical judgment is indispensable when nurses, patients, and their families grapple with the ethical issues emerging in the context of home health care.

**Endnotes**

4. Ibid., 11-12.
5. Ibid., 4.
6. This case is based on an example used in Ethical Issues in Home Health Care, 14.
7. Ibid., 14.