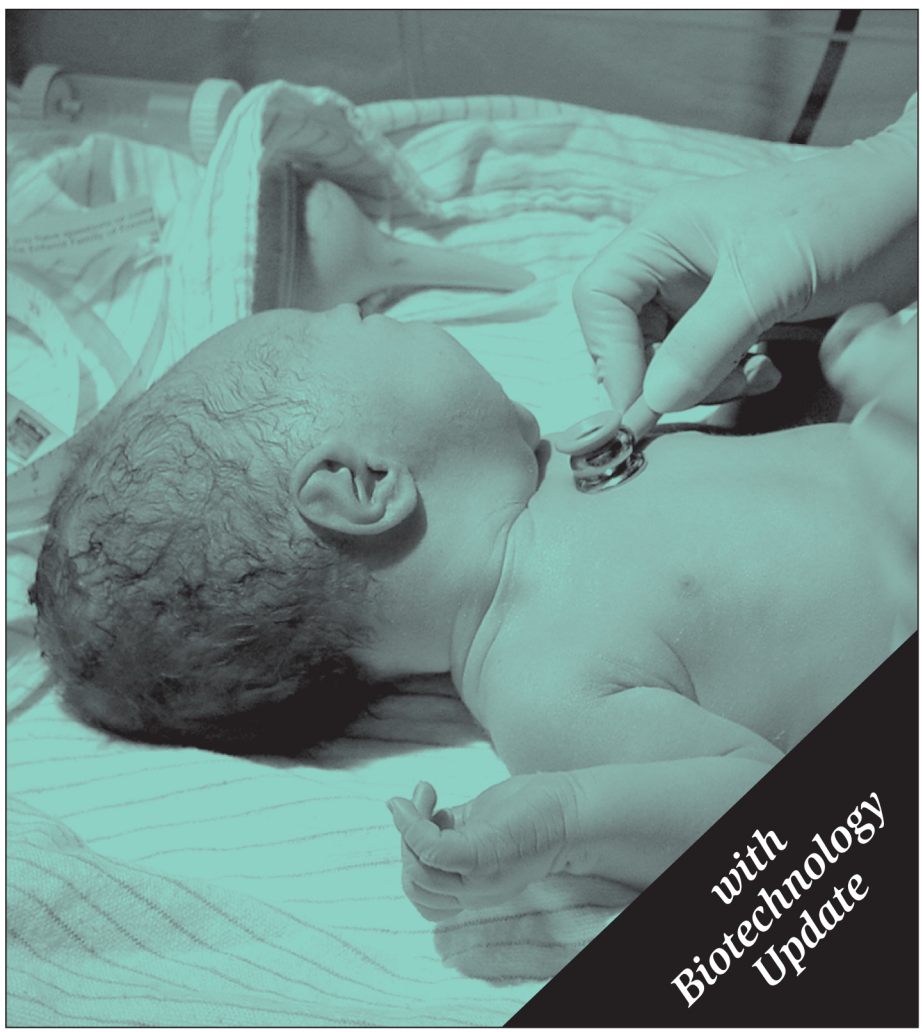
Ethics & Medicine

An International Journal of Bioethics



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EDITORIAL

BILL GATES GETS UNDER OUR SKIN

C. BEN MITCHELL, PHD

This summer Microsoft, the computer software giant, was awarded U.S. Patent 6,754,472, Method and Apparatus for Transmitting Power and Data Using the Human Body.[1] The summary abstract for the patent is instructive: "Methods and apparatus for distributing power and data to devices coupled to the human body are described. The human body is used as a conductive medium, e.g., a bus, over which power and/or data is distributed. Power is distributed by coupling a power source to the human body via a first set of electrodes. One or more devise [*sic*] to be powered, e.g., peripheral devices, are also coupled to the human body via additional sets of electrodes. The devices may be, e.g., a speaker, display, watch, keyboard, etc. A pulsed DC signal or AC signal may be used as the power source. By using multiple power supply signals of differing frequencies, different devices can be selectively powered. Digital data and/or other information signals, e.g., audio signals, can be modulated on the power signal using frequency and/or amplitude modulation techniques."

All of that is to say that Microsoft has harnessed the legal right to use the conductive properties of the human body to link and power a host of electronic devices. Not only does this mean that the wearable computing era is coming of age, but that the melding of body and machine is one giant step closer.

The first application of this technology is likely to be entertainment and communications focused. Mobile phones, MP3 music players, and PDAs will doubtlessly become more integrated with the user's body. Health-related applications will soon follow, including health monitoring devices to keep an eye on heart rate, blood pressure, metabolic rates, fluid absorption, and a nearly endless set of lab values.

With every technology, however, the potential exists for both good and ill. The evil uses of this technology are only limited by one's imagination. At the top of the list are privacy concerns. I recall speaking at a meeting in Chicago on the topic of wearable computing. One of the British scientists on our panel was wearing a device that monitored his health status, including his heartbeat. On the flight to Chicago a man in the seat immediately in front of the scientist happened to be wearing a heart monitoring device. The scientist said he was able to detect his neighbor's heart rate on his own monitor. The scientist wondered whether he had a moral obligation to tell the man that his privacy had been violated. He chose not to do so.

Of course, many of the technical difficulties—including violations of privacy—can be resolved with more sophisticated technologies or encryption tools. But the underlying question remains: Where are the limits?

At stake in this particular patent application are several important ethical concerns. First, how far should we go in exploiting the human body

technologically? "Technology" may be defined as "any tool that extends the human body." Oddly, this patent turns that definition on its head. In other words, the body itself becomes the tool. Second, patent regimes grant a limited monopoly right to the awardee for 20 years. Arguably, this patent is overbroad and contributes to the existing crisis of the commodification of the human body and its parts—and Microsoft is poised to reap the financial benefits. Finally, what are the important moral differences between a technology extending the human body and a technology becoming the human body? This question will continue to become increasingly urgent in the next half-century.

While it would be ludicrous to attempt an answer to these questions here, these types of questions ought to dictate the foci of our moral reflection and research agenda in bioethics for the next several decades. And, since these questions are deeply anthropological, they should be addressed in a collaborative way. Scientists should be part of the conversation, but so ought philosophers, theologians, physicians, sociologists, economists, historians, and many others. Without a multidisciplinary consideration of the appropriation, exploitation, and technologization of the human body, we will not reach satisfying answers.

Ethics & Medicine wishes to encourage not only collaboration by publishing articles by those who represent various disciplines, but also wishes to encourage collaboration by publishing articles written by multidisciplinary teams. Former editor of this journal, Nigel Cameron, has been often heard to say, "Bioethics is the quintessentially multidisciplinary enterprise." Microsoft's patent 6,754,472 demonstrates why this must be the case. E&M

Endnotes

[1] http://patft.uspto.gov/netacgi/nph-Parser?Sect1=PTO2&Sect2=HITOFF&p=1&u=/netahtml/search-bool.html&r=1&f=G&l=50&co1=AND&d=ptxt&s1=6,754,472.WKU.&OS=PN/6,754,472&RS=PN/6,754,472

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GUEST EDITORIAL

Conflicts of Interest in Medical Ethics

EUGENE F. DIAMOND, MD

Medicine is a learned profession that has its own intrinsic ethic. Under this intrinsic ethic, the end of medicine is ordered to a good that is health. Technique and conduct are not value-neutral but rather are ordered to this overarching good, the nature-given end of health. Medicine is a profession precisely because it professes such a goal. Being a professional is more than being a technician. The public profession of medicine as a way of life is an affirmation of the moral nature of our activity. Medicine as a profession is a public declaration of a willingness to devote oneself to others and to serve a higher good. The physician is a moral being who professes and affirms the moral nature of his activity.

We have in recent years seen an attempt to convert our profession to a killing activity. Doctors as abortionists kill unborn children; doctors accept the responsibility to kill patients with or without their consent as in Holland or to engage in the subterfuge of physician-assisted suicide as in the state of Oregon in America. The doctor true to his calling will not violate the taboo against killing. He will not do it for love and he will not do it for money.

This is why medicine must be a profession and not merely a business. A physician guided primarily by the profit motive will have conceded the best interests of his patient in the patient's pursuit of health.

Recently there has been an erosion of some of the safeguards that have accrued to the protection of the patient and the society.

Let us start with information published in medical journals. This information helps shape diagnostic and therapeutic decisions. For a medical journal to be of value, it must publish authoritative, up-to-date information that is free of commercial influence. This requires that the financial associations of authors are disclosed and that these associations do not influence published articles. This is the only way to avoid bias or the appearance of bias based on a conflict of interest. Beyond the authors themselves, this freedom from conflict of interest must extend into the process of peer review. If those who are assisting the editor in selecting articles suitable for publication are not also free from similar financial associations, the possibility of bias is reinforced.[1] Relationships between biomedical companies and research are growing rapidly. Beyond the direct support of research or therapeutic trials, authors may receive consulting fees, serve on advisory boards, own equity, receive patient royalties or receive honoraria for lectures or expert testimony.

Recently the *New England Journal of Medicine*[2] and by inference,[3] the *Journal of the American Medical Association* have altered their policies so that

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authors of original articles as well as review articles and editorials will not have any "significant" financial interest in a company (or its competitors) that makes a product discussed in an article. The National Institutes of Health[4] and the Association of American Medical Colleges[5] have likewise relaxed their requirements regarding financial association and resultant possible bias. The key provision is to set an upper limit on the annual sum received by an author in order to have a relationship considered "significant." Currently $10,000 is the de minimus level. Beyond this any holding in which the potential for profit is not limited (such as stock, stock options, or patent holdings) would probably be disqualifying.

The justification for these changes in policy is said to be an inability to impanel an adequate number of authors and/or reviewers to carry out the functions of the journal because so many academicians and clinicians are involved in intertangling financial relationships with pharmaceutical companies.[6]

Inevitably the outcome of the policy will be an enhanced opportunity for the introduction of conflict of interest and a reduced confidence in the reliability of published data. This will extend not only to decision making by physicians and researchers but also to the general public. Almost every major media outlet in the United States has a science editor and staff that cover current medical literature often counting on summaries and releases published for their edification by the journals themselves. Providing this service is a large source of income, for example, to the American Medical Association.

Let us take one example. An article in the *New England Journal* on RU-486 (Silvestre L. et al., *New Eng J Med* 322:645,1990) concluded that RU-486 was "effective and safe." Those who thought the data to be excessively sanguine and reassuring could be forewarned by the revelation in a prominent place that all six authors were employees of Roussel-Uclef which manufactured RU-486 and stood to make huge profits from sales. The knowledge that the so-called "scientific" article was in fact an ill-disguised promotional piece could result in a healthy cynicism on the part of readers. Not only the manufacturer, however, promoted the unfounded enthusiasm as factual, but also the entire publicity apparatus of the pro-abortion lobby and its media collaborationists.

A delegation from the Catholic Medical Association met with the executive director and the editorial staff of the *JAMA* to express our concern that during the previous three years approximately fifteen pro-abortion articles were published and not one anti-abortion paper. Editorial bias was vehemently denied. Subsequently, however, we came into possession of an internal memorandum[7] leaked to us by an AMA employee informing the editorial staff of *JAMA* that, in fact, their policy was as demonstrated, that is, not to publish anti-abortion studies or statistical studies unfavorable to abortion.

If this ideological bias is not to be augmented by a potential for bias based on economic gain, the profession and the public will have been thoroughly compromised.

President Bush was recently called upon to make a Solomonic decision regarding stem cell research. While by no means a perfect decision it did make the important distinction between embryonic stem cell cells (produced from

embryos created for the purpose of being killed to harvest their stem cells) and stem cells produced from adult sources (umbilical cord blood, bone marrow, etc.). While forbidding federal funding of the creation of any new embryonic stem cell lines, the President did concede, in his policy, the continuation of existing cell lines from embryos. These were the fruit of a poisoned tree and, since adult stem cells had outperformed embryonic stem cells both clinically and in the laboratory, it was difficult to comprehend the dogmatic insistence by the scientific community of the superiority of and need for embryonic cell lines.

It turned out that many of the existing embryonic cell lines that were allowed to be preserved were in fact owned by universities and other enterprises that had every intention of profiting from the propagation and distribution of embryonic stem cells for research.

During the debate on cloning[8] in the U.S. Congress, it was revealed that three human cloning patents were pending in the U.S. patent office. The sponsor of the Human Cloning prohibition act, Senator Brownback, pointed out that the notion that we have to kill one person in order to find a cure for another is a false trade-off that disregards advances made in other non-embryonic stem cell sources. Even more frightening is the prospect of people in corporate America owning, trading, buying, and selling (cloned) people as if they were property. This is an issue that must be included in the cloning debate. When Senator Brownback introduced a Human Unpatentability Amendment to outlaw patenting human clones,[9] it was defeated. This occurred on the same day that a team from the University of Minnesota reported on the versatility of adult stem cells and their ability to convert and morph into hundreds of specialized cells within the body.[10]

Jonathan Swift said, "Falsehood flies and the truth comes lingering after, so that when men come to be undeceived the jest is over and the tale has had its effect." The culture of death has for the last thirty years clearly controlled the press and the media and now shows a sinister proclivity toward controlling the scientific literature and thereby the political process. Through the powerful incentive of the profit motive derives the clear conflict of interest between objective scientific investigation and advocate science in pursuit of monetary gain.

The ultimate perversion of the commercialism of medical research would be the sale of body parts for use in experimentation. The reality of a brisk business in fetal body parts as an offshoot of the abortion industry has been exposed by numerous investigative pro-life agencies. These are not mere allegations—actual advertisements containing price lists for human tissues from aborted babies have been discovered in scientific journals. Such offerings as "fetal liver, second trimester fetal kidney, pancreatic islet tissue" each with an attached price list have been discovered (having been placed by so-called laboratories doing business with abortionist sources).[11]

A movement is currently underway to approve the payment by potential recipients for donor organs. Currently the National Organ Transplant Act makes it illegal for "any person to knowingly acquire, receive or otherwise transfer any human organ for valuable consideration for use in human transplantation." The

American Medical Association has called for a study of the possibility of paying donors for organs.[12] The background for this consideration of a radical policy change is, of course, the annual shortfall in the availability of donor organs. The United Network for Organ Sharing database indicates that there are now 75,000 patients waiting for an organ. Among those waiting for a heart or liver transplant one-third will die before an organ becomes available.

The primary source of donor organs will be the so-called Heart Beating Cadaver donors. These are patients who have had an irreversible cessation of total brain function and are being maintained on ventilators in intensive care units. These will constitute a pool of 10,000-12,000 potential donors per year. Despite extensive public awareness campaigns, the ratio of actual to potential donors has not increased sufficiently.[13] One response has been a greater reliance on living donors (kidneys), partial transplants (liver and lungs), and sources of dubious ethical propriety such as anencephalic infants and animals.[14]

Another potential source of transplantable organs is patients who have been declared dead by traditional cardiopulmonary rather than brain-based criteria. The success of transplants using organs from these sources has been limited by problems with warm ischemia. These Non-Heart Beating Cadaver Donor problems fall generally into two categories: 1) Uncontrolled Cardio-pulmonary Death (usually in emergency rooms) and 2) Controlled Timing and Place of Death. This second category follows a method commonly known as the Pittsburgh protocol.[15]

Under this protocol, families who have decided to forego life support are approached to donate organs. Warm ischemia time is minimized by taking the patient to the operating room disconnecting life support there and removing organs immediately or shortly after the pronouncement of death. Ethical issues surrounding the use of Non-Heart Beating Cadaver Donors have to do with the consent process, the question of irreversibility and early declaration of death. There are also intuitive problems related to the fact that the procedure seems staged or contrived in that the patient is declared dead after having been removed from the company of his near relatives and into an operating room.

Market forces have begun eroding the standard of uncompensated donation from living donors by the opportunity to obtain organs outside the United States. Americans are purchasing organs from strangers in China, Peru, and the Philippines, and then returning to the U.S. for post-transplantation care.[16]

Another challenge to the altruistic principles underlying the Act is the increased frequency of kidney donations by patients unrelated to the recipients since a close genetic match is no longer necessary. The possibility exists of illegal purchase and illegal profits beyond the control of transplantation centers.[17]

The movement to liberalize the rules to allow for a freer market in the purchase of organs raises the specter of a bidding war in which less deserving, wealthy candidates for transplantation gain priority over poor candidates lacking the wherewithal to purchase organs. One economist has suggested that less affluent individuals could always take out loans to purchase organs as they now do to purchase automobiles or houses. What happens, however, if the borrower is incapable of repaying the loan? Can we have some mechanism for foreclosing on or repossessing a kidney?

The present system of providing ethical or humanitarian incentives for donation would protect the unbiased distribution of organs based on priority of need.[18]

Brokering criteria in the United States would be impossible to control. If the current prohibition against the sale of organs were rescinded, there would be no legal justification for preventing persons from bypassing the regulated system to compete in an unregulated market. The potential unfairness of such a market and the preferability of enhanced ethical incentives (public recognition, compensation of funeral expenses, or tax credits) would be the better way to sustain broad societal interest.[19]

Finally, in a world of bioterrorism, a fundamental conflict of interest has arisen over the issue of whether biologists should publish work that could be misused. The National Academy of Sciences has set up a panel to study how to prevent the destructive applications of advanced biotechnology.[20] Recent studies on the 1918 pandemic influenza virus at the Armed Forces Institute of Pathology have suggested the potentials for reconstructing the 1918 virus and make it more resistant to the immune system.[21] Similar studies have been published to demonstrate how to engineer microorganisms to spread more readily, resist antibiotics and vaccines and thus be more effective as weapons for bioterrorism. There are serious questions as to whether such information should be made available in journals. A conflict of interest has arisen between bioweapons experts in the government and the American Society of Microbiology as to whether there should be special peer review. Needless to say, scientists are highly resistant to the notion that their work or any important data should be subject to censure for political reasons.

Though the conflicts of interest may not be as demonstrable in a socialized medical system as they are in a capitalist system, they are unavoidable in a privately based system (either fee for service or managed care). The main protection against the intrusion of political and economic issues into medical care is a return to the Hippocratic system of medical ethics that remains viable in all cultures and for all forms of reimbursement.

Finally, another opportunity for conflict of interest consists of so-called "advocate science." This consists in the propounding of so-called "scientific" claims or rejecting counterclaims based not on the quality of objective data involved but rather on a hidden political agenda or a desire for political correctness.

The principal occasion for the employment of advocate science is in research regarding the etiology and the treatment of homosexuality or same-sex attraction disorder. The media have promoted the idea that a "gay gene" has already been discovered and certain professional organizations have not discouraged this assumption. If same-sex attraction were solely genetically determined, then one could expect identical twins to be identical in their sexual attractions. Most studies, however, show that identical twins are discordant in their sexual attraction.[22,23,24]

There are, however, ongoing attempts to convince the public that same-sex attraction is genetically based. Such attempts are politically motivated by the supposition that the public would be more likely to respond to changes in

laws and religious teaching were they to believe that same-sex attraction is genetically determined and unchangeable.

A similar controversy surrounds the issue as to whether the homosexual state is treatable and changeable. In the debate between essentialism and social constructionism, the believer in natural law would hold that human beings have an essential nature—either male or female—and that sinful inclinations such as the desire to engage in homosexual acts are constructed and can, therefore, be deconstructed. Some members of the American Psychiatric Association have gone so far as to allege that attempts to change homosexuals are not only unsuccessful but even unethical. There are a number of therapists, however, who have written extensively that reparative therapy is successful with about 30% experiencing a freedom from same-sex attraction and another 30% improvement.[25,26,27,28] Dr. Robert Spitzer, the renowned Columbia University psychiatric researcher who was largely responsible for the removal of homosexuality from the APA's list of mental disorders has not indicated that his most recent research indicates that sustained change can be achieved.[29]

Other examples of advocate science would include the American Cancer Society's refusal to admit a relationship between abortion and breast cancer[30] despite overwhelming evidence and the National Institute of Health's insistence on the effectiveness of the condom in preventing AIDS. When the question was posed at a large international meeting of AIDS experts how many would be willing to have sexual intercourse with an HIV positive person while wearing a condom, no one[31] in the audience raised their hand.

The evidence strongly suggests that the officialdom of numerous professional organizations such as AMA and American College of Obstetrics and Gynecology has a hidden agenda of apologizing for abortion and upholding the homosexual rights lobby despite any evidence to the contrary and despite the conflicting opinion of many in their grassroots membership. E&M

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COMMENTARY

Inevitable Human Cloning as Viewed from 221-B Baker Street

WILLIAM P. CHESHIRE, MD, MA, FAAN

The latest in a series of attempts to implant a cloned human embryo in a woman's womb continues to fail to produce a viable pregnancy. That announcement from controversial fertility scientist Panos Zavos at a London press conference earlier this year made headlines worldwide. "Successful or not, we are going to do another one and another one and another until we succeed."[1] "The development of human cloning is," pronounced Dr. Zavos in galloping cadence, "*inevitable*."[2]

Dr. Zavos is not alone in claiming that human cloning cannot be stopped.[3,4] Those who disagree, the inevitablists argue, stand in the way of unalterable destiny. Against their certainty of what biotechnology will soon make possible, ethical debates seem inconsequential. For despite arguments against it, human cloning, they say, is unavoidable. It will happen anyway. Cloning technology is becoming feasible, its development irresistible, its application inescapable. The transformation of the imaginable into the possible has, to the inevitablists, dissipated all questions of "whether" and "should," leaving only pragmatic questions of "how," "by whom first," "toward what ends," and "for what price?"

As the pace of cloning rhetoric increases, human dignity seems less noticed, obscured by the dust from the brash stampede of brute inevitability. Trampled under the heels of those embarked on the frenetic quest for biotechnical transhumanism, science's fractured moral compass, relegated to ornamental value, now seems to point only in the direction these scientists happen to be going.

Meanwhile, in a nearby district of London, for anyone familiar with literature, a sanctuary of clear thinking lies a short walk from Dr. Zavos's news conference. Just beyond the traffic, in the second-story window of 221-B Baker Street, one can almost imagine, behind the curl of smoke from his calabash pipe, the amused and ever confident smile of the renowned consulting detective, Mr. Sherlock Holmes. The perspective from Baker Street is as timeless as are the short stories of Arthur Conan Doyle. In considering how Sir Arthur's protagonist might have responded to the "interesting, though elementary"[5] prospect of inevitable human cloning, a surprising analysis comes to light. Before Mr. Holmes has finished his first pipe, the claim of inevitability will have collapsed beneath the wisdom of even a fictional personality, whose deductions are "simplicity itself."[6]

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Let it be clear that this writer, although an admirer, has not actually met Mr. Holmes and therefore cannot speak for him on bioethical matters. The aim of the following discussion rather is to examine the case for inevitable human cloning from the perspective of 221-B Baker Street, drawing from the wisdom of Holmes and Watson to suggest fresh insights into a quandary unknown to their time.

There is in Western literature no finer exemplar of the practical value of keen observation and astute deduction than Sherlock Holmes. His companion Dr. Watson regularly noted his "passion for definite and exact knowledge"[7] as well as "his brilliant reasoning power [that] would rise to the level of intuition."[8] Wrote Watson, "His zeal for certain studies was remarkable, and within eccentric limits his knowledge was so extraordinarily ample and minute that his observations have fairly astounded me."[9] Holmes was, moreover, "deeply attracted by the study of crime, and," as Watson records, "occupied his immense faculties and extraordinary powers of observation in following out those clues, and clearing up those mysteries which had been abandoned as hopeless by the official police."[10]

Sherlock Holmes was no stranger to the intimidations of inevitablism. In *The Final Problem*, Holmes received a visit from the villain of villains, Professor Moriarty, who taunted him with the threat of "inevitable destruction," adding,

> "Tut, tut!" said he. "I am quite sure that a man of your intelligence will see that there can be but one outcome to this affair. It is necessary that you should withdraw. . . . You stand in the way not merely of an individual but of a mighty organization, the full extent of which you, with all your cleverness, have been unable to realize. You must stand clear, Mr. Holmes, or be trodden under foot."[11]

If Holmes had given in to evil, there could have been no story. Nor in this case would he have earned the praise of Dr. Watson, who confided that, "I had often admired my friend's courage, but never more than now."[11] The story's unfolding proved Holmes's struggle with his sinister adversary to be most difficult, requiring the utmost wit, and courage that resulted in triumph only at the cost of great personal sacrifice.

In regard to the question of human cloning, Holmes would likely beckon, "Let's now explore the parts that lie behind it."[8] "Come, Watson! . . . The game is afoot."[12] In the race to clone the first human being in history, much of the preliminary footwork has already been accomplished in existing biotechnology. Methods that were developed to improve the efficiency of in vitro fertilization (IVF), such as intracytoplasmic sperm injection, electrofusion, and cytoplasmic transfer, so closely approximate somatic cell nuclear transfer technology that the same equipment and technical skills already in operation in IVF laboratories around the world are already available, virtually unregulated, and could easily be redirected to human cloning experiments. Following the 1996 cloning of Dolly the sheep,[13] and the 2001 announcement that Advanced Cell Technology had cloned human embryos by transferring nuclear material from the cells of an existing person into donated human eggs stripped of their nuclei,[14] some have conjectured that it may be simply a matter of time before cloned human

beings are brought to term. Already South Korean scientists have established an embryonic "cloning academy."[15] Commenting on the inexorable trajectory of human cloning technology, Columbia University reproductive physician Mark Suer speculated that, "If you had a good cell biologist, you could do this with two people. You could do it in a small closet. . . . It will be done by someone, somewhere."[16]

Nontrivial technical obstacles to human cloning remain, however, no matter how much hubris aspiring cloners bring to their efforts. Some of the bizarre variations on these experiments reveal the tenacity with which the goal of human cloning has been sought. Following Advanced Cell Technology's unpublished 1998 experiments in which human cell nuclei were inserted into cow eggs to create bovine-human hybrid embryos, former National Bioethics Advisory Commission Chair Harold Shapiro remarked, "As the technology continues to burst forward with such stunning speed, one has to be very modest about what one can expect to do to control and regulate one's basic principles." Bracing against the gusts of inevitability, Shapiro added, "We know that it would be very difficult but not impossible to stop something that we are against."[17]

To concede that the arrival of technical opportunity must be the prelude to large–scale, inevitable human cloning would be to overlook the decisive role of ethics. Opportunity correctly understood is an invitation to responsibility. Holmes and Watson acknowledged this when their client, entrusted with the precious Beryl Coronet, recognized "the immense responsibility which it entailed upon me."[18] In another story, it was Holmes's reputation for being a man of "honor and discretion" that drew the heir to the throne of Bohemia to 221-B Baker Street entrusting the detective "with a matter of the most extreme importance."[19] From the perspective of Baker Street and beyond, ethical restraint, not brazen indulgence, guides noble conduct.

The prospect of cloning a human being would have no doubt fascinated Sherlock Holmes, who thrived on applying his habits of observation and deduction to crimes no one else could solve. Holmes confided to Watson his "love of all that is bizarre and outside the conventions and humdrum routine of everyday life."[20] Deeply attracted to the extraordinary, Holmes spent his life "in one long effort to escape from the commonplaces of existence."[21] Watson noted that only the most remarkable of problems challenged Holmes's powers of analysis[22] and disclosed that, "he would devote weeks of most intense application to the affairs of some humble client whose case presented those strange and dramatic qualities which appealed to his imagination and challenged his ingenuity."[23]

Not only the cloning, but also the zealous cloner seeking celebrity, would have captivated the attention of Holmes, who aspired to preeminence in his own field. "I know well that I have it in me to make my name famous," said Holmes privately. "No man lives or has ever lived who has brought the same amount of study and of natural talent to the detection of crime which I have done."[24] Yet Holmes sought to do good and consistently placed the interests of justice and beneficence ahead of his own personal gain or safety. Dr. Watson described him as "unworldly," adding, "I have seldom known him claim any large reward for his inestimable services."[23] According to Watson, "he was ever as ready to

bring his aid as his client could be to receive it."[25] In contrast to scientists whom Lord Robert May, President of Britain's Royal Society, recently characterized as "cowboy cloners,"[1] Sherlock Holmes the gentleman detective exemplifies intellectual passion tempered by dedicated adherence to moral principle.

The contours of Holmes's ethics conformed to the culture of Victorian England, which, despite its social failures in some areas, generally recognized a universal moral authority in the God of the Christian Bible. Though Doyle was himself an agnostic, his Jesuit education may have helped shape the moral ethos out of which Holmes, in observing nature, deduced evidence of the goodness of God:

> Our highest assurance of the goodness of Providence seems to me to rest in the flowers. All other things, our powers and our desires, our food, are all really necessary for our existence in the first instance. But this rose is an extra. Its smell and its color are an embellishment of life, not a condition of it. It is only goodness which gives extras, and so I say again that we have much to hope from the flowers.[26]

Among Holmes's cases this Victorian worldview enabled Hugo Baskerville to acknowledge "the infinite goodness of Providence,"[27] and Jefferson Hope with confidence in the reliability of ultimate justice to declare, "Let the high God judge between us."[28] The citizens of such a worldview tended to cultivate an attitude of humility, which is no less a virtue in the current age of biotechnology.

Even Sherlock Holmes with his well-developed sense of self-importance would have been perplexed by the contemporary belief in the nearly absolute liberty of personal autonomy unencumbered by intrusions of obligations to a higher good, or to God. An exalted view of personal liberty that lets individuals choose their own moral law apart from the common recognition of any natural order invites enterprises such as human cloning. A self-determined people may feel at liberty to clone themselves, and perchance to control the genetic makeup of their offspring.

Cloning has been offered as a way to recreate talented people. If he were not fictional, perhaps someone might want to clone Sherlock Holmes. Such flattery would quickly dull, for once selected as special, the proliferation of so many genetic copies of Holmes would render him no longer the only one of his kind. Individuals are plainly much more than assemblages of genes. Detective fiction elaborates how persons are also the products of their origin, their environment, their choices, their experiences and relationships. In reality, persons are not things to do with as one likes, but are living beings of inestimable worth. They are unique souls. Populating Scotland Yard with multiple Inspectors Lestrade would not necessarily resolve the London crime problem. Although clones of Professor Moriarty might not be destined to turn out wicked, the thought of someone set on manufacturing multitudes of Moriartys would be profoundly unsettling. As Holmes said in *The Adventure of the Dancing Men*, "We have let this affair go far enough."[29]

The privilege to clone humans, at least to the embryonic stage of life, has been widely defended on the grounds of scientific freedom.[30-32] But an absolute

freedom to investigate and manipulate nature, including human nature, would mean that any technological act inevitably could be permitted. Sherlock Holmes would be quick to point out that, "it is as well to test everything."[33] What is here subject to testing is the dogma of technological fatalism, which claims that, if a conceivable technology is scientifically possible, then it ought to be pursued as a moral imperative in order to direct its applications toward useful ends, because in time it will be developed anyway.[34]

To this Holmes might respond, "You know my methods. Apply them!"[35] When Dr. Zavos claims that, because human cloning is inevitable, he should keep trying until he succeeds, the observer does not need a magnifying lens to notice the breach in logic. Even if bringing a human clone to term were proven to be possible—a feat the laws of nature have so far denied—Dr. Zavos attempts to deduce an "ought" from a "can." For Holmes "the world is full of obvious things"[36] that not everyone observes. It is obvious to ethical investigation that a statement of "one can" simply does not justify the conclusion "I ought."

In the case of human cloning, "can" argues more persuasively for a verdict of "ought not." Serious safety concerns have been raised, since most cloning experiments in nonhuman animals have yielded defective or nonviable offspring.[13] Dolly the sheep, for example, had to be euthanized last year because of progressive lung disease and premature arthritis.[37] Cogent ethical arguments have also been put forth showing that cloning would affront human dignity and result in innumerable harms to human flourishing.[38-40]

Just as, in Holmes's day, countless wrongs were committed within "the dark jungle of criminal London,"[41] inevitability arguments emerge from the philosophical jungle in many forms. Some zoologists warn that the extinction of the tiger is inevitable, but it would be clearly wrong to hasten the efforts of tiger poachers on the grounds that tigers will one day die out anyway.[42] Holmes in a different context once remarked, "You may remember the old Persian saying, 'There is danger for him who taketh the tiger cub.'"[43] There may also be unforeseen dangers to taking the lives of cloned human embryos.

The appeal to inevitability, whether from Professor Moriarty or from a modern biotechnological fatalist, to the mind of Sherlock Holmes would be stimulating if not instructive. Holmes once chuckled to Watson, "When I said that you stimulated me I meant, to be frank, that in noting your fallacies I was occasionally guided towards the truth."[35] The fallacy of inevitability is that it reduces to an empty bluff. Masquerading as an ethical theory, the appeal to inevitability is a veiled excuse to abandon ethics. The concession to inevitability suspends ethical judgment and substitutes for human decision an autonomous technology existing as an end in itself, and with human beings as its means.[34] Indulging in human cloning experiments would hurl research well beyond the pale of traditional scientific freedom and into brave new territory that Arthur Conan Doyle could not have foreseen. The freedom to engage in whatever might be technically possible would be, in effect, a freedom drained of the moral obligations to humankind and to research subjects that history has taught must accompany the scientific enterprise.[44]

To his credit, Dr. Zavos is an imperfect technological fatalist in that he advocates some ethical oversight of the practice of human cloning. But once it

has been decided that human cloning is permissible, it becomes difficult to find logical grounds for resisting further appeals to technological fatalism to justify extending access to cloning technology for any purpose held to be inevitable. The slippery claim of inevitability outlines ethical criteria that too easily dissolve into what is merely possible.

Shall the world, then, be overrun by clones? Hardly. Feigning delirium in *The Adventure of the Dying Detective,* Holmes quipped, "Indeed, I cannot think why the whole bed of the ocean is not one solid mass of oysters, so prolific the creatures seem."[45] Only madness disregards limits. Aspiring cloners may continue their experiments in undisclosed locations. But the widespread practice of human cloning, leading to allocation of federal research funding, patenting of altered clone lines, implementation of eugenic agendas, and broad cultural acceptance, are by no means *faits accomplis*. Ethically prudent choices, particularly if codified preemptively in law and treaty, can resist the cumulative assaults of realizable opportunity. Though confronted by persistent inevitability, ethics can still serve the common good. Even inevitable wrongs can by ethical action be postponed or restricted, thereby limiting the reach and extent of evil.

Had Arthur Conan Doyle lived to witness the advent of human cloning, perhaps he would have written a Sherlock Holmes adventure story about an unknown clone. In that story, Dr. Watson might react to human cloning as something ghastly wrong, but Mr. Holmes would more likely find fascination in questions of mistaken identity arising from DNA testing. Doyle has created in Sherlock Holmes the supremely rational individual. "I am a brain, Watson," said Holmes. "The rest of me is a mere appendix."[46] "All emotions," noted Watson, "were abhorrent to his cold, precise but admirably balanced mind. He was, I take it, the most perfect reasoning and observing machine that the world has seen."[10] When Holmes, in surveying the scene of a crime in *The Adventure of the Abbey Grange*, exclaimed, "Every instinct that I possess cries out against it. It's wrong—it's all wrong—I'll swear that it's wrong,"[47] he was responding not to a moral offense but to the anomalous fact of an extra wine glass. Instinct for Holmes resides at the level of pure reason.

Reason alone, however, cannot complete the story. Reason must be motivated by purpose, and purpose must be oriented by value. The solitary fact of a wine glass has value precisely because it can be traced to a malevolent act. Even Holmes was appalled at the sight of untimely death.[48] Holmes's avid antipathy to emotion, moreover, divulges an inconsistency that points to meaning beyond simple computation, for passionate resistance is itself an emotion.

What the reader learns from Holmes is that a coldly materialistic view of the world cannot satisfy. Holmes's total reliance on his exceptional rational faculties is to the exclusion of heartfelt intuition which apprehends truth deeper than logic. In deduction Holmes delights, but in compassion he is bound to disappoint. This is why many people might not prefer a Sherlock Holmes as their personal physician, and why Sir Arthur supplies Dr. Watson for essential dramatic contrast. 221-B Baker Street is incomplete without a Watson to complement its Holmes.

Unlike other technologies, human cloning takes for its raw material the

mortal substance of living human beings. With the sentiment befitting a good Dr. Watson, many people instinctively recoil in response to the genetic copying of individuals or the calculated annihilation of embryonic human life, even if their explanation lies beyond logical description. Commenting on human cloning, bioethicist Leon Kass has drawn attention to the validity of such visceral responses and their basis in human moral intuition with the warning, "Shallow are the souls that have forgotten how to shudder."[49]

The full view from 221-B Baker Street, therefore, involves the complementary judgments of reason and moral intuition. Both reject unethical human cloning and its alleged inevitability.

Many proponents of human cloning research, in the interest of harvesting embryonic stem cells, are willing to overlook the problematic question of the moral status of the human embryo. Still others have urged restraint, maintaining that so-called "therapeutic" cloning, which entails the creation of living human embryos intended for destruction, sacrifices early human lives that should be respected as possessing the special moral status shared by all human beings.[40] Although the tiny embryo might not at first glance appear to be human, if one reasons backward, and considers the full human life span from old age through adulthood, adolescence, childhood, infancy, fetal and embryonic life, a biologic continuum is plainly evident.

If Holmes were to lift his "lantern and magnifying lens"[50] and gaze closely at the human embryo, what might he deduce? "Let me see if I can make it clearer," said Holmes investigating another matter in *A Study in Scarlet*.

> Most people, if you describe a train of events to them, will tell you what the result would be. They can put those events together in their minds, and argue from them that something will come to pass. There are few people, however, who, if you told them a result, would be able to evolve from their own inner consciousness what the steps were which led up to that result. This power is what I mean when I talk of reasoning backward, or analytically . . . . to begin at the beginning.[51]

The course of human life also is a train of connected events. Reasoning back to the beginning of life, logic encounters the wondrous embryo. From maturity to youth, from old age to embryo, the human being is indubitably the same being at every phase of development in life, seamlessly united to her existence throughout her life span. That the human embryo is a very young human organism is an elementary deduction. Likewise, the mind of Holmes appreciated that, "from a drop of water, a logician could infer the possibility of an Atlantic or a Niagara without having seen or heard of one or the other."[52]

In conclusion, embryonic biotechnology has advanced at such an astonishing pace that some have predicted the development of human cloning to be inevitable. Arguments based on inevitability, although intended to sway public opinion and policy toward unpopular agendas, must be understood to represent an appeal not to ethics but to the abandonment thereof. Similarly, the argument that opposition to human cloning is useless derives not from valid moral reasoning but from transparent rhetorical intimidation.

As long as there are people who appreciate literature and ethics, inevitablists will not have the final word. That science and society must choose is inevitable, but that choice is not predetermined. An investigation of the case for human cloning from the perspective of 221-B Baker Street suggests the need for great caution. Arguments for prohibiting human cloning are ethically compelling.[38-40] And there is, as Holmes advised Watson in *The Hound of the Baskervilles*, "not a moment to lose!"[53]

Aspiring human cloners would do well to heed the words of Sherlock Holmes, who declared, "When a doctor does go wrong he is the first of criminals. He has nerve and he has knowledge."[54] May biomedical knowledge always be nurtured by wisdom and applied with humility, for efforts that honor human dignity are never futile. E&M

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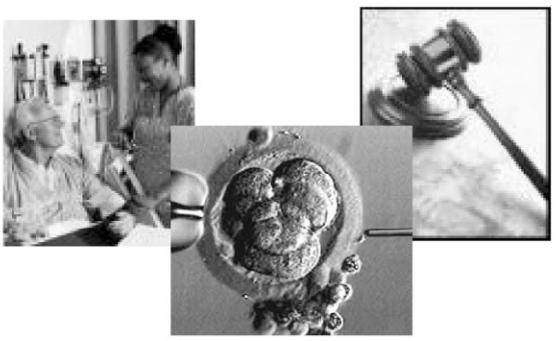

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TERMINAL SEDATION, TERMINAL ELATION, AND MEDICAL PARSIMONY*†

Y. MICHAEL BARILAN, MD, MA

> Agonies are one of my changes of garments.
> —Walt Whitman, *Leaves of Grass*

> Whatever its name, the drug had elevated Patrick's consciousness of pain, while at the same time leaving him utterly detached from the pain itself; it had made him feel like an indifferent observer of someone else. And in elevating his consciousness, the drug did far more than relieve his pain.
> —John Irving, *The Fourth Hand*

I. Introduction

This paper examines the potential role of mind-altering drugs in terminal care. Such drugs—mainly tranquilizers and opoids—are already in widespread use. 'Terminal elation', which will be defined as the use of mind-altering substances or techniques for purposes other than sedation and pain relief, has received skimpy attention.

Psychoactive drugs are prohibited in many societies for all sorts of reasons, and even patients with conditions that might benefit, such as multiple sclerosis or AIDS, really have to struggle to be able to try them. My intent here is not to call into question our attitude to drugs in general. This paper is based on the assertion that terminal care is a special case. Over and above our natural compassion for the dying, terminal care is the only situation in which many patients, caretakers and laypersons consider killing as a therapeutic option. If the arguments for terminal sedation and euthanasia prevail over 'slippery slope' arguments, we need not worry about the spillover of illicit drug use either.

Patients' autonomy is about patients making their own choices. Every choice is made from a set of alternatives. Is it ethical to practice and to legislate euthanasia, physician-assisted suicide or terminal sedation as long as the use of psychoactive substances is not a practical alternative for the patient to choose? I think it is not.

If *unwanted death* of the innocent is one of the worst moral outcomes possible, then we must not overlook the possibility that the use of psychoactive substances can change the life of dying patients in ways that will make them want to go on living. No matter how harmful those drugs might be, their use is not likely to be more deleterious than preventable death. If the patient is willing to accept a mind-altering therapy in lieu of euthanasia, his or her death would seem a futile alternative, even a coerced one, for lack of choice.

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In this light we need not explore the different effects mind-altering drugs might have: euphoric, stimulation of pleasures, suppression of moroseness, etc. The choice of elation and the appropriate balance of influences will become crucial issues only after we incorporate this line of therapy in our concept of terminal care. Only then will we be able to define the particular brain functions we wish to enhance.

Indeed, we know little of the effects of 'mind-altering' drugs on the very ill. 'Suicide machines' of the kind developed by Dr. Kevorkian receive widespread support in spite of the fact that they have not been evaluated in clinical trials either. Introducing new therapies into terminal care is ethically and methodologically challenging. Lack of scientifically rigorous knowledge, however, should not excuse us from carrying out basic science and clinical research on the potential of mind-altering drugs in terminal care.

Although every new therapy might be dangerous or unpleasant, the concept of harming the dying is far from clear. It is well established that *typically* death as a side effect of morphine is not 'harmful' to terminal patients. Suppose we arrive at the bedside of a terminal patient when he is just about to receive terminal sedation or euthanasia. We offer the patient a hallucinogenic drug. He is fully informed about it, and he *wants* to try it out. What sort of harm can ensue? In the worst-case scenario, the doctors immediately sedate or kill the patient according to the original plan. On the other hand, if the patient is content, we have given him the greatest gift he or he can ever get, a few more days or even weeks of tolerable—maybe even rewarding—life.

In this paper I will try to lay foundations to a philosophical analysis of this intuitive argument. I will first explore the possible roles of 'terminal elation' as an extension of the well-established practice of 'terminal sedation.' Then I will discuss the use of psychoactive drugs within the broader context of realizing life plans with the assistance of medicine. The 'life plan' in question, is actually a 'death plan'.

II. Three Interpretations of 'Terminal Sedation' and 'Terminal Elation'

Fourteen years ago the term 'terminal sedation' was introduced to the professional literature (Enck, 1990). Suggested guidelines for terminal sedation were published some time later (Cherny and Portenoy, 1994, Rousseau, 2001). Clinical studies, which were uncontrolled and open, have found that patients usually die within one to four days from the onset of sedation (Ventafrida et al., 1990; Morita et al., 1996; Stone et al., 1997; Fainsinger et al., 2000; Broeckaert, 2002).[1] However, an accepted definition of 'terminal sedation' is still lacking (Chater et al., 1998; Morita et al., 2002).

Intuitively, terminal sedation is usually understood as an active intervention on behalf of a physician during the last phases of terminal illness. The purpose is the mitigation of intractable suffering and the soothing of the dying process. Ethically, terminal sedation is commonly located along the yardstick of end-of-life decisions, somewhere between aggressive palliation and physician-assisted suicide.

Pondering the matter in depth, one may delineate a few competing interpretations of the term 'terminal sedation':

1. *Controlled sedation, which is induced in order to relieve extreme and otherwise intractable suffering* (Fonderas, 1996, Rousseau, 2000). Sedation is a universal medical practice with no intrinsic connection to terminal care and to the dying process. Informed consent is usually not requested prior to sedating a panic-stricken patient during the induction of mechanical ventilation, or to a person suffering from acute and severe burns. The patient is sedated to a desirable degree and for a specific length of time, towards the end of which his or her need for further sedation is reevaluated. According to this interpretation, terminal sedation merely means a session of sedation that coincidentally takes place in the context of terminal care.

2. *Deep sedation from which the patient is deliberately kept from awakening until he or she dies*. This is also done in order to save the patient from extreme and otherwise uncontrollable suffering. From the patient's perspective, it is not much different from active euthanasia since terminal sedation 'disables' the personhood of the patient completely and permanently. Some regard this form of sedation with a Cartesian twist. The sentient soul is put away while the corporeal body is nourished or even ventilated thus distinguishing sedation from homicide. The caring team becomes a housekeeper of an evacuated and decaying, but still living corpse, while the soul is in a state of disengaged absence.

3. *Deep sedation as an indirect form of euthanasia*. The patient is sedated and left to dehydrate, starve or even suffocate. The sick and unconscious body does not receive the care it biologically needs for survival. The provision of care to a dying and unconscious body is perceived futile and possibly degrading. Some refer to this form of sedation as 'slow euthanasia' (Billings and Block, 1996). Other ethicists argue that it is significantly different from assisted suicide, because the intention is sedation rather than death (Cavanaugh, 1998, p. 379). It is noteworthy that a recent study found that mere sedation does not shorten the lives of terminal patients (Sykes and Thorns, 2003).

4. *The use of psychoactive drugs in order to eliminate suffering during the dying process, 'terminal elation.'* As stated in the introduction, 'terminal elation' refers to the use of drugs or other techniques in order to produce an alteration in the state of consciousness for non-sedative and non-pain relief purposes. By extension, this term would cover all forms of manipulating the content or structure of consciousness, such as cultivated in hypnosis or ethno-medical trances, with or without drugs. Some modes of therapy such as SSRI antidepressant drugs affect consciousness and personality. I will not discuss them here since the changes in personality are a side effect, not the intended

> therapy or its goal. Moreover, many of these patients (arguably most of them) obtain relief from depression without finding their personality altered.

The first three interpretations of 'terminal sedation' refer to the effect on the level of consciousness. Sedatives and other psychotropic drugs can also influence the content of consciousness and induce euphoric, tranquil or hallucinogenic states of mind that replace anxiety, pain, and all that constitutes psychological anguish. Retractable suffering is not necessarily a prerequisite for the induction of terminal elation. One may opt for 'terminal elation' instead of other forms of symptom control. Terminal elation may relieve suffering directly, or may help the patient add content to his consciousness in ways that make life desirable for him *in spite* of suffering.

III. Preliminary Bioethical Criticism of the Above Interpretations and the Concept of Medical Parsimony

Physicians have administered sedatives since time immemorial as part and parcel of comprehensive medical care. Doctors stupefied the condemned prior to execution as well. This example is rare and bizarre, yet paradigmatic of the first interpretation. The caring physician is helpless in the face of death and sedation has nothing to do with the cause of death. Albeit that sedating a patient who is dying of most natural diseases may hasten death, there is no reason why this should differ from the administration of painkillers at the deathbed. In actuality, ample doses of opiates exert profound sedation. Two considerations (beyond the well-known issues of aggressive pain relief to the dying) are due in this scenario. First it is imperative to titrate the sedatives to the required level, not too shallow and not too deep, and to deliberate the next sedative regimen when the effect is about to peter out. Schotsmans (2000, p. 101) calls this practice 'controlled sedation.'

The second moral consideration is to weigh the benefits of sedation against the losses in lucidity of mind. It is unlikely that a patient with acute burns misses much by being asleep for a day or so. On the other hand, the last days of life often bear personal, metaphysical and legal significance of the highest degree. A dying person can reconcile with a family member, confess to a terrible sin or change a will. Magendie, for one, believed it was dehumanizing to deprive someone of consciousness at the hour of his or her death (Fulop-Miller, 1938, p. 211). Although the climate of opinion has much changed since the nineteenth century, there is no reason to suppose that Magendie's views are not relevant to some people or cultures today. Besides, a patient may wish for sedation on Sunday when her suffering is overwhelming, and accept or even wish for conscious dying on Monday when pain is in remission. The second and third interpretations ignore this possibility. A patient cannot regret her own euthanasia, but in the case of euthanasia the irreversibility of death is a mere side effect. If simple sedation provides adequate relief of suffering, an autonomous wish for irreversible sedation encroaches beyond mere palliation and raises issues concerning the ethics of suicide in general. I will return to this point later on in the context of 'death plans.'

Most of the literature on terminal sedation implicitly or explicitly embraces the second interpretation. It is clear in this context that the decision to sedate is almost always final and irreversible. Often this is also the request of the patient who becomes anxious by the very idea of being woken up in order to check the need for further sedation. His only wish is to 'end it once and for all.'

Opinions vary as to whether the second interpretation of terminal sedation differs much from euthanasia, and whether caregivers should care for the unconscious life by means of alimentation, mechanical ventilation, etc. Both issues depend on each other. One may believe that separating consciousness from bodily functions is inapplicable to the dying human being and that the withdrawal of consciousness inevitably hastens death by aspiration, thrombosis, and other medical complications of the vegetative state. Things become more complicated when one tries to distinguish between sedation as palliation of suicide by neglect from starvation due to the cessation of 'futile' nourishment. Cross-cultural studies suggest that self-induced death by neglect and starvation is the most common form of euthanasia (Blok, 2001, ch. 12), so called 'Voodoo Death' (Eastwell, 1982).[2]

I do not intend to discuss here the meaning of causality at the deathbed. Nor do I wish to dive into the debates over intending and foreseeing or about the principle of double effect. I only want to point out that killing patients has never been a goal of medicine; rather it has always been the outcome to be avoided. Supporters of euthanasia typically regard killing as the last resort in achieving a fundamental goal of medicine, namely the alleviation of suffering; they do not find death a goal in itself. Later in this article I will discuss the opinion that medicine should not only vanquish suffering at any price but also help the patient control the way in which he or she dies.

So how to rank medical alternatives, such as the three interpretations of 'terminal sedation'? To answer this question I wish to propose a bioethical law of medical parsimony. Medical parsimony requires the limiting of the powerful tools of biomedicine to the least radical intervention possible when coping with a medical challenge.[3]

A radical intervention influences more body parts, or its influences last for a longer period of time, or produces greater alterations in bodily function or sensations, and is more polluting to the environment than the alternatives. Additionally, acts that are controversial, ethically or professionally, would be less parsimonious than common practice; risky procedures are less parsimonious than less risky ones. Note that the law of parsimony does not address the *ultimate* goal of therapy. Avoidance of surgery in acceptance of shortened life expectancy is not *medically* parsimonious. Similarly the decision of whether a hopeless patient should fight for every breath or pray for death is not a question of parsimony either. For every medical goal, the less radical, the less destructive, and the less controversial act is parsimonious.

The maxim of medical parsimony, therefore, states that physicians who face *equally* effective strategies have a *prima fascie* duty to recommend the most parsimonious one. Medical parsimony dictates that as long as the first interpretation of 'terminal sedation,' which is the least expansive one, is possible, the other interpretations, which are more radical, should be avoided.

Do caregivers have to comply with patients who request less parsimonious treatments? I think this takes us beyond the subject of this article (Barilan 2002, 2003). Nor do I intend to discuss how different aspects of parsimony, such as being economical and being environmentally friendly, sum up to a meaningful valuation. For the meantime, I will point out the well-established principle that doctors should not comply with requests for euthanasia when less radical palliative solutions are available.

Considering 'terminal sedation' in the light of medical parsimony, it seems that the first interpretation is superior to the second because it achieves the same medical goals by more parsimonious means and agenda. Its aim is most restricted, namely to reduce consciousness to the level of tolerable life, the time-range of the action is the most limited, and the internal morality of the action is on par with the least controversial modes of terminal care. It follows, I contend, that as long as the more parsimonious options have not deliberated, the discussion, let alone the execution, of less parsimonious acts such as euthanasia, is morally wrong.

The manipulation of consciousness beyond the minimum level required to fend off suffering satisfactorily, however, cannot be curatively or palliatievely meaningful. At the biological level there is nothing to do since the patient is hopelessly dying; at the symptomatic level there is nothing to do either. Once the patient has no symptoms, there are none to palliate.

The third interpretation of terminal sedation may appeal to those who care about nuances such as the distinction between doing something and merely allowing it to happen. The sedating physician does not perform an act that kills the patient; he merely leaves him to die of the natural history of both the comatose state and the disease process. The third interpretation fuses terminal sedation with euthanasia. This paper considers terminal sedation as a distinct entity, so I will not dwell on that interpretation further.

It is unlikely that terminal sedation is provided to patients who do not suffer but merely wish 'not to be there.' Medical parsimony is implicit in the fact that contemporary practice does not offer terminal sedation to the chronically ill, but only to the dying. The bioethical literature does not discuss patients who desire 'terminal sedation' merely for escaping the dying process, akin to the situation of women who opt for cesarean delivery with the explicit intent of avoiding natural labor.

The rule of medical parsimony tells us to always employ sedation rather than euthanasia, and to prefer consciousness-sparing treatments to sedation and death; both neutralize the human person.

IV. Terminal Elation and Medical Parsimony

The pre-moderns from different cultures knew well how to concoct soporific potions, usually a mixture of herbs in alcohol so as to blunt the pain associated with anesthesia-free surgery. This art reached its peak during the nineteenth century with the discovery of ether and chloroform. Among the few effective things the nineteenth century doctor could do for his patients was the administration of such home-made preparations, for example, cannabis seeds

in port wine (Smith, 1990, p. 17). Contemporary pharmacotherapy seems to have lost the art of incomplete-general anesthesia—what was called 'states of insensibility' and similar, even subtler alterations of consciousness. High-ranking academicians had little faith in the recipes coming from popular medicine which they labored to marginalize and regulate. Harvard Professor Bigelow declared in 1876 that since anaesthesia must be 'easily attainable, complete and safe,' stupefaction by morphine, cannabis and the like is 'unpredictable,' 'partial' and 'unsafe' (Stratmann, 2003, p. 6). This position, which ignored traditions of refined anaesthsia, although partial and prone to error, still looms unjustly over the deathbed of many patients.

Altered states of consciousness are known and developed by numerous cultures worldwide. In most cases trance is induced without pharmacological intervention whatsoever (Bourguignon, 1973, Goodman, 1990, Harner, 1972). Use of hypnosis in terminal care has received skimpy coverage in the medical literature (O'Connell, 1985; Martin, 1983; Haley, 1973, pp. 300-6). Obviously, mere compassion produces elation and comfort. Pharmacological elation need not and should not substitute direct and sincere human care.

The reasoning behind 'terminal elation' appears neat. Why turn off consciousness, if one can eliminate suffering through 'enhancement' or other alterations of awareness? Moreover, some psychotropic substances alleviate disease-mediated symptoms other than pain. Cannabinoids allay nausea and reduce anorexia and cachexia (Grinspoon and Bakalar, 1997). Opiates alleviate dyspnea and so forth (Bruerra & Neumann, 1998). Nitrite oxide is routinely offered to women in labor. For reasons unknown to me, this gas, which according to one of its first users 'induces almost a delirium of pleasurable sensations without subsequent dejection' (Wright, 1997), is not part of terminal care. 'Terminal elation' also empowers autonomy, since the sedated patient cannot participate in shared decision making over his or her care. She must be woken up first, and this might be a distressful experience.

Hallucinogenic drugs are employed by some cultures in therapy and palliation (e.g., Dobkin de Rios, 1972). Anthropologists Levi-Strauss (1963, ch. 10) and Taussig (1992, ch. 9) debate the role of symbols in shamanistic obstetric analgesia among the Indians of the Amazon basin, but they both agree about the effectiveness of these mind-altering techniques.

Skilful use of mind-altering substances and methods is mastered by many 'primitive' shamans and practitioners, but it has been neglected by biomedicine. The introduction of 'terminal elation' into terminal care will certainly require extensive training and research for which the outcomes are too early to predict.

Stanislav Grof and Joan Halifax (1977) published the only detailed clinical research about the use of hallucinogenic drugs with terminally ill patients in a Western hospital.[4] Although their pioneering work lacks design and rigorous analysis, it introduced a number of points for further consideration. First, they reported adequate symptom relief though they did not focus on patients whose suffering was considered refractory to the best supportive care available. Second, they observed that many terminal patients were in need of psychotherapy in order to die peacefully. If this observation is corroborated, it would be wrong

to deny at least some of the dying the psychological and spiritual input they need and possibly want. Evidently psychotropic drugs may not be necessary for such work. The patient, however, must command some level of tolerable consciousness in order to accomplish it.

Drug-induced 'trips' might become extreme experiences, as one user of hallucinogens described it as 'forty foot waves crash over you for several hours while you cling desperately to a life raft which may be swept from under you at any moment.' Is this the kind of experience terminal patients crave?

One reply would be that many medical interventions bring about extreme consequences if used injudiciously. Medicine does not shun therapies that involve horrible side effects. In administering 'terminal elation' the caring team should only aim at the minimal level of 'elation' necessary for the control of suffering and in the safest way possible. Biomedicine is dedicated to projects that are no less bold and much less promising.

Another reply would be that it is nevertheless unethical to force a choice between suffering and sedation or even death on those patients who would prefer the 'trip' if they were informed about it as a serious and achievable option.

Non-parsimonious 'terminal elation' is the deliberate cultivation of altered states of consciousness in order to realize existential or spiritual experiences during the dying process, and not as mere last-resort means to avoid suffering.

In the first possibility, 'terminal elation' is one means among others to the relief of suffering. In the second possibility, 'terminal elation' is an end in itself, an integral part of a 'good death.' Non-parsimonious 'terminal elation,' however, calls upon us to reconsider the role of medicine at the death-bed.

The wishes of the patient play a central part in the process of medical decision making. Contemporary concepts of autonomy acknowledge the duty medicine has to assist the patient in meeting his or her 'life plan' (Brody, 1987, p. 48ff.).

It seems that many people strive to realize individual 'death plans' as well. 'Death plan' is not a euphemism for suicide. Nobody chooses his or her own life. We are alive because others, namely our parents, brought us into this world. We find life as a given and then proceed to develop our own 'life plans.' Similarly, the idea of a 'death plan' is not about someone who is given life but prefers death. Rather, it is about those who find death and dying forced upon them and then develop their own concept how they wish to die.

Terminal elation may thus serve two purposes. First it eliminates or marginalizes the kind of suffering which is disruptive of the 'life plan' of the patient (parsimonious elation). Second, 'terminal elation' may be part of a 'rational death plan' itself. Many patients dream of dying in a pastoral and blissful ambience. For example, a wish to see one's departed or faraway dear ones at the deathbed might be a motivation to hallucinate (non-parsimonious elation). The use of opium in the induction of meaningful dreams was explored by nineteenth century physicians (Jay, 2000). It has been abandoned since: 'The prohibition on drugs takes its legitimacy from the idea that drugs are an obstacle which must be overcome on the way to a civilized society' (Jay, 2000:

p. 245). If our society is confident in the strength of its civilization to such a degree that the taboo on murder is suspended for the sake of the dying, the prohibition against mind-altering drugs for the dying should be put aside as well.

In sum the concept of 'terminal elation' challenges us in two different ways. First we are provoked to consider the parsimony of different strategies of terminal care. Second, we are challenged by the possibility that some people may wish to design a death 'under the influence.'

V. Death Without Suffering and Terminal Elation as a Component of Good Death

The above discussion of terminal sedation actually implies that terminal care is a mere means to a single end, which is death without agony. There is, however, a different attitude to dying, and it seeks death in preconceived ways, not merely to avoid pain and suffering *during* the dying process. This attitude is exemplified by the medieval tradition of *ars moriendi* (Lock, 2002, p. 294-8, Blok, 2000, ch. 10). Probably this is what Loewy & Springer Loewy (2000, ch. 4) describe as 'the orchestrating of the end of life.'

People might wish to harness psychoactive drugs to orchestrate their life and to seek relief from hitherto unruly medical or psychological problems (Shenk, 1999). In this paper, however, I wish to focus on terminal care since this is the only kind of suffering for which complete sedation is an accepted practice and killing has gained wide support as a measure of relief.

Death without suffering may be taken for an ordinary hedonistic goal, the realization of which should be pursued vigorously, but parsimoniously as well. In the context of palliative care, the word hedonistic may sound pejoratively. But, technically, this is the appropriate word. Popper (1962:284) already pointed to the primacy of the elimination of suffering over the achievements of positive satisfactions in life. As argued elsewhere (Barilan, 2004, Barilan, 2005), the reality of terminal care teaches us that people are not hedonist, and that a truthful interaction with reality matters more than mere states of consciousness. However, since hopes, dreams, and similar states of minds do not undermine our relationship of truth with the world, hallucinations and subjective euphoria do not necessarily violate it either. Humans master an extraordinary capacity to integrate symbols and 'fictions' (e.g., vivid presence of biblical persons) in their mesh of reality. Terminal patients should not be an exception, particularly when the purportedly 'fictional' happiness in question alleviates suffering and prevents premature death. In this manner, terminal elation contributes to real life, rather than detracting from or substituting for it.

The orchestration of one's deathbed implies the striving for the realization of 'categorical desires' (Williams, 1973: p. 85ff) with regard to one's own death and dying.

I think that many authors who write about euthanasia as a human right or as a dignified way of dying, actually express such trends. Being dead, and being dead in a particular way, become a personal goal similar to enabling

one's children to graduate from college. It is different from the hedonistic desire to fend off suffering. It seems to be the only motivation behind advanced directives that require that the patient not be treated in case he or she enters an irreversible vegetative state. Many people commit suicide in order to avoid senility or dependence on machines. They do not necessarily fear the subjective experience of dementia. Rather, some demented patients appear to be in a state of blissful ignorance. But not having such a life is a prime categorical desire for many. Therefore, euthanasia may be sought both as the last resort of palliation and as an end in itself, a categorical desire not to live certain forms of life.

This paper does not intend to discuss euthanasia. Therefore I will propose two sets of arguments in favor of 'terminal elation,' one for those who approve of euthanasia ethically and one for those who condemn it. I hope both parties should accept 'terminal elation' at least in its parsimonious form, namely as a last resort before terminal sedation.

My first premise is that killing is not a parsimonious act. Death is total, irreversible, and symbolically loaded. According to the rule of medical parsimony, one should give a preference to the more parsimonious option. It follows that terminal elation, which is apparently less radical than killing—it is not total, it is reversible and is less charged symbolically—should be offered to terminal patients as well.

Support of euthanasia is at least partially based on respect for the personal autonomy of patients who make their own decisions. The broader the range of options, the more empowered the autonomy of the decision-maker becomes. The absence of 'terminal elation' from contemporary terminal care, therefore curtails autonomy. This is even more troubling considering the possibility that some self-inflicted deaths would have been avoided had terminal elation was available to desperate patients.

Addressing those ethicists who oppose euthanasia seems more difficult. I will first show that the case for 'terminal elation' does not entail an argument for euthanasia. An altered state of mind is considered an acceptable side effect of certain therapies such as hypnosis; its place as a deliberate medical goal is yet to be discussed. Death is never considered an acceptable side effect.[5] The case for aiming at something which is not tolerable as a side effect is much weaker than the case for choosing a tolerable side effect as an aim for therapy.

Since 'terminal elation' is not more radical than some widely accepted side effects of therapy, so it is not too radical to take it as the very goal of therapy, particularly when the alternative is intractable suffering.

VI. The Non-Parsimony of Terminal Elation Reconsidered

As we have seen in the second section, intractable suffering is a prerequisite in all three interpretations of terminal sedation. How should we respond to patients who seek 'terminal elation' in order to orchestrate their death, rather than to avoid any particular suffering?

The leading question would thus be, how radical is terminal elation? Is it possible to justify 'terminal elation' even in a euthanasia-free world? It

appears that the less radical we find 'elation' in general or 'terminal elation' in particular, the more likely we are to accept its medicalization.

According to the ethos of Protestant and of industrialized capitalism (arguably the leading ethos of the world's most affluent nations today) and Islamic tradition as well, terminal elation might be radical indeed. Loss of sobriety and 'disinhibited behavior' are considered profound degradation of human dignity, possibly worse than death. 'Sobriety,' 'disinhibited behavior,' and similar terms need careful definition and study. For the time being, let us take them at their face value and let us assume that they are frequent outcomes of 'terminal elation.'

Another problem might be that a significant alteration in one's state of consciousness may amount to an alteration of personality and possibly of the 'person' of the patient as well. Zohar (1991) and Heyd (1995, ch. 4) contend that it is impossible to benefit someone by altering his or her person, simply because the new person is not the one intended for benefit. Hence, 'terminal elation' cannot benefit the patient anymore than 'terminal sedation' or even euthanasia.[6] Rather, by eliminating the previous person, the act of 'elation' counts among the most radical medical interventions extant. Those who regard the human person as the locus of agency and human dignity might even take it for killing.

I think, however, that it cannot be established that 'terminal elation' changes the person of the patient to such a degree. Extreme pain and other manifestations of illness have no less a profound impact on the person (Scarry, 1984). Nevertheless, the pain-smitten patient is treated as continuous to the person he had been, prior to his or her disease.

Many non-Western cultures take it for granted that people change their state of consciousness, as naturally as they change clothes. Grob and de Rios (1992) list and discuss many fundamental differences between wanton 'drug abuse' in the American urban setting and 'managed altered states of consciousness' known to us from 'tribal,' societies. Their research shows that the difference lies in the cultural, social, and personal circumstances of using the same drugs, not in any particular state of consciousnesses or certain pharmaco-dynamic effects as such. Not every altered state of mind amounts to loss of person and human dignity by any one's standards. A medical setting or a dignified dying at home is quite different from reckless street life.

I wish to conclude this paper with two propositions, which I believe are cogent regardless of cross-cultural issues. The first proposition is that death is a hard fact, while an altered state of consciousness is a subjective experience whose factual grounding is tenuous. Why not embrace a permissive attitude to people's wishes and valuations with regard to purely phenomenological experiences? Because death is so powerfully real, irreversible, hollow and tabooed, we are hesitant to kill someone even when he sincerely wishes to be dead. But the induction of a subjective state of mind is something different, at least as long as the person involved does not consider his altered state of mind as a significant change of his own self. If the patient does not experience a deviation from an acceptable state of mind, and neither does he consider the change in his consciousness ethically significant, why should other people

bother? Why not respect patient's autonomy and allow those who are interested in 'terminal elation' to have it? It is quite possible that the phenomenology of the patient, which actually is the sole constituent of his state of consciousness, is different from what we project it to be. Evidently the same cannot be said about death and killing.

Moreover, and this is my second proposition, it seems that the powerful aura bestowed on psychoactive drugs by authors such as Huxley and by the drug frenzy of the 'flower generation' has biased mainstream medicine against their use in general and at the bedside of dying patients in particular. Physicians are not shy of the boldest and most extreme tools of biotechnology when patients' lives or limbs are at stake. However, those same doctors are reluctant to 'open the doors of perception' to the dying, particularly when the only palliation offered to them is sedation or even euthanasia.

Suppose, therefore, as recent scholarship (Smith, 2000; Rudgley, 1998; Fabrega, 1997, pp. 140-7) suggests, that the megalomaniac aura is fictitious and that dedicated research is capable of refining the use of psychoactive drugs so as to provide 'terminal elation,' which is pleasant and meaningful and non-disruptive of anything psychologically or spiritually important. In that case, I think, society should seriously consider 'terminal elation' not only as a potential solution for intractable suffering during the dying process, but also in other areas as well.

I have already argued that for those who want it, any form of 'terminal elation' is ethically superior to euthanasia, and that it is unethical to sanction euthanasia whenever 'terminal sedation' and 'terminal elation' are not viable alternatives for the patient to choose.

My re-evaluation of 'terminal elation' as a constituent of 'death plans' leads to the conclusion that it is quite possible that terminal elation would not make up a psychic or psychotic spell at all, but some sort of refined and agreeable sobriety, which will redress the assaults of disease on the mental faculties. Pharmacological refinement and clinical skills may also contribute to our ability to monitor, control and titrate mind-altering drugs and techniques.

Gordon Wasson (1986), who dedicated his life to the study of the ethnography of psychoactive mushrooms,[7] contends that one such mushroom was served to the dying Buddha in his last meal on earth.[8] If Wasson's reading of the Pali text is upheld, I wonder why the Buddha was served this special dish on the eve of his demise. E&M

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Endnotes

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† This article is dedicated to the memory of Gretchen Worden, the director of the Mutter Museum, who died suddenly when this paper was going to press, a heroine of contemporary anatomy who knew so much about the humane dimensions of the human body and its whimsical frailties. She humbly and kindly assisted whoever sought her advice. Eternity wanted her young and promising.

[1] These studies notwithstanding, Smith (1998:386) defines "terminal sedation" as the induction of general anesthesia and that the patient usually dies within a week. General anesthesia is the most extreme form of sedation and it is not induced in almost all reports about terminal sedation.

[2] Not all cases and practices of Voodoo death are euthanasia-like. The concept has been debated since its introduction by Walter Cannon (1944). See also comments on Eastwell in American Anthropologist 1985, 85:415-21.

[3] Compare Scanlon 1993, p.196.

[4] Ch. 2 of the book, 'History of Psychedelic Therapy" is also available at http://www.druglibrary.org/schaffer/lsd/dying.html

[5] Some patients consent to dangerous surgeries as part of an "all or nothing" strategy. They prefer taking the risk of immediate death for the sake of possible health to accepting life which is safe but includes suffering or disability. In such cases death is not an acceptable side effect, merely a bad outcome. Some patients may take their given situation as worse than *both* healing and death; possibly some take the risk with the conscious or unconscious intent of dying.

[6] This argument is different from the 'Epicurean dilemma' (Rosenbaum, 1986; Silverstein, 1980) because the latter focuses on the absence of a recipient to harm, and my argument focuses on the discontinuity between the pre- and post-event recipients of good and harm.

[7] He refers to psychoactive mushrooms, which are ingested for religious or shamanistic purposes, as 'entheogens.'

[8] In his analysis of the Pali text, Wasson (1986, p. 122) wonders if the then-tabooed mushroom, to which the Buddha had not been accustomed, hastened his dying. Wasson does not explore the possibility that the mushroom was served because the Buddha was dying presumably in some agony, at least in the view of his host.

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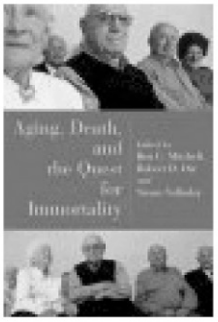

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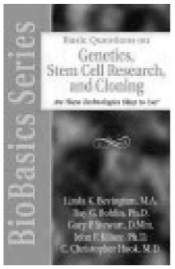

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"The Gift of Life"? A Perspective on Adult Partial Liver Donation

GREGORY W. RUTECKI, MD

If responsibility is a contingency of success, solid organ transplantation merits a revisit as medicine embarks upon a new millennium. During the last generation, the *success* of technique has catapulted the transplant enterprise from the metaphorical dark ages into a brighter era with long-term survival in the majority of graft recipients. These organs, or "gifts of life,"[1] have been conferred from the gracious source of either living or dead donors. However, technical success is not the issue for discussion here, rather *responsibility* is. Disturbing trends in regard to donor risk seem to have been ignored. It appears that the ostensible claims of excellence have been derived solely from the perspective of recipients. Why the recent changes impacting donor risk? The answer requires an abbreviated review of transplant history.

Clearly the source of transplantation's greatest dilemma has been the shortfall in organ supply. Literally, transplantation is a victim of its own success. The shortage is a reality throughout the entire spectrum of organs, but critical with single organs (heart, liver, pancreas). Until the recent past, single organ donation has utilized dead donors as its only source. This source is limited. For further consideration of single organ transplants, the liver as a scarce, non-renewable resource will serve as example. Liver donation will also engage the addition of living liver donors to a complicated mix.

In the past decade, the number of patients awaiting liver transplantation has increased from 1676 to 18,057.[2,3,4] However, during the same period, livers available for transplantation increased from 2931 to only 5293. Consistent with the disparity in supply and demand, the paucity of organs has expanded waiting time for transplantation from 65 to 795 days! The human cost of this equation is a 10% death rate per year for individuals on the waiting list. This 10% figure is an underestimate of mortality since patients who are too sick to be transplanted, and are thus removed from the list, are not included in the statistics. Yet these individuals also die as a result of the organ shortage. For patients with end stage liver failure, the wait has become tantamount to a death sentence. The future appears grim as the concurrence of more individuals with liver disease and increasing technical success further ratchet up demand for organs. The predictions resulting from the epidemic of the hepatitis C virus speak volumes about escalating future need for replacement livers. These facts of life for transplantation will continue, and as a contingent, even more donors will be required in the next decade. Or framed in another way, *new definitions for those who qualify as potential donors may become commonplace.* Will new definitions be cognizant of donor dignity as much as recipient need?

The appeals for help as warranted by the recipients' deteriorating

Ethics & Medicine, 20:3 (2004):167-178.

condition have already led to novel qualifications for donors that have, at best, dubiously expanded the donor pool. As expected, each new criterion has been driven in response to the need for livers and other single organs. The downside has been a terrible cost to donor dignity. Asystolic and anencephalic protocols have "gerrymandered" the definition of death, and all but abolished the long revered "dead donor" rule.[5,6] Also, trying to capitalize on the success of living related donation of lungs and livers in children, a complicated living adult donor liver transplantation effort has been initiated over the last decade.[7] The increase in donor numbers eventuating from this particular source has been substantial. The risks to these donors have also been disconcerting and will occupy the remaining discussion. The caution prescribed regarding donor risk throughout will be grounded in arguments from a Christian-Hippocratic perspective. The concept of donor "dignity" will assume that donors are created in the image of God. Therefore, donor dignity is valuated as a Biblical ethic.

Living Related Liver Donation in Adults:

What Would Hippocrates Say About Transplantation's Utilitarian Calculus?

> Standards for acceptable rates of *donor* morbidity and even mortality, must be evaluated in the context of recipient risk of dying while on the waiting list and outcome after transplantation.
>
> —J. F. Trotter[8]

In addition to his oath, Hippocrates was associated with a *corpus* containing the often-quoted maxim, primum non nocere or *first, do no harm*.[9] The living–donor liver transplantation exercise should be viewed in the context of this traditional imperative to medicine. Since Hippocrates would be as astonished as anyone to hear about the remarkable success of solid organ transplantation, the ethical questions will be posed to him in the form of a conversation. The ensuing dialogue will review the gains made by transplantation during the last generation. The success will, however, be appraised from the perspective of Hippocratism. Permit an anachronism as arguably credible. It may be concluded that someone from an earlier generation would not exhibit bias toward either remarkable technical outcomes, or for that matter, toward the disparity in valuation of recipient vis-à-vis donor dignity. Postmodern attitudes, a recent dynamic force in decision-making, have been fueled by an unbalanced sentiment towards recipients.

Dr. R. Speaks to Dr. Hippocrates[10]

> R: Dr. Hippocrates, contemporary medicine has the skill to transplant hearts and livers into literally dying patients whose native organs no longer function well enough for survival.

H: The first thing that I need to know is who donates these "living" organs. It would seem to me—as someone who took traditional medical ethics quite seriously—that if someone is born with only one heart and liver, he or she would need to keep that organ to survive.

R: Excellent question posed from the perspective of one keenly interested in ethics. You see up until very recently, patients could be declared dead either by cardiac or whole brain death criteria. Obviously the cardiac criteria go back to time immemorial—heart and lungs stop working and you've died—but brain death criteria are a twentieth century addition. Society, ethicists, and the courts have agreed that "whole brain" criteria can also be utilized to declare death. The concept of brain death was accepted readily and became entrenched over a period of approximately 20 years. The French utilized the term *coma dépassé* in 1959 to describe patients with irreversible damage to the cerebral cortex as well as the brain stem. They felt that this clinical entity was a unique form of coma. Then in 1968, the Harvard Ad Hoc Committee posited the position that patients with *coma dépassé* (cortical and brainstem death) were dead and the term *brain death* was first utilized.[11] The public accepted that definition of death and in 1970, Kansas became the first state to incorporate a statute regarding brain death as a legal definition of death. In 1981, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research defended the adoption of brain death to the Uniform Determination of Death Act.[11] That means both a cortical and brain stem death that is irreversible. This concept would not even have been discussed in earlier times for two reasons. First, the only way these patients can be sustained is either on a ventilator or by cardiac balloon pump, and I will not bore you with the details of these devices. Suffice it to say, it took exceptional technology to arrive at this criterion for death. Secondly, the definition for brain death literally came into being in order to increase the donor pool. This was the first of many times that success of technique outstripped the supply of organs and as a result led to a new definition of death. At the same time, living donors were only being utilized when they had one of two organs to donate—such as kidneys—and could therefore give one away safely.

H. Okay, but also germane to our ethical discussion, how do the recipients do after they receive these organs? We have the dignity of two human beings to consider!

R. They do very well. We are presently talking about decades of high quality survival. In fact, medicine's unparalleled success in general is the rub so to [deleted hyphens]speak! As more and more people survive longer periods of time with liver disease, more people wait to receive a transplant and there are not enough organs to meet the demand.[12] Since there is no way to significantly increase the number of brain dead donors, other sources of organs are pursued. Surgeons have even taken to considering animal organs as substitutes for human ones and these are called xenografts. And

as you might suspect, that is another ethical story altogether.

H. Can we remain true to my oath, the corpus, and traditional Hippocratism and still find more organs for those in such terrible need?

R. Well that may be the toughest question of all. The definition of death has been tampered with since the inception of whole brain death criteria, and as a result, patients with cortical, but not whole brain criteria are now being considered potential donors. But, more recently, a lesson learned from living donors in the area of kidney donation has been expanded to another organ. Back to the basics for just a moment. Since kidneys are double organs, transplantation has had a rich history of living donors in this specific venue. In fact, from a technical perspective, the first transplant of this sort was between identical twins. As you would expect, the safety of the donor *independent of the safety of the recipient* has to become paramount in any living donor endeavor.[13] As you would surmise, live donor surgery is "the only area of medicine and surgery wherein a major operation is performed on an individual for whom it is *not medically indicated*."[14] Recently, people have developed a nasty habit of skewing the great benefit accrued by recipients towards greater incurred risks for donors. This imbalance has almost become an ethical de rigeur. In fact, the quote utilized to begin this segment actually suggests incorrectly that certain liberties can be taken with the dignity of donors as a compensation for decreased recipient suffering!

To give you further perspective on the increasing importance of living donors, these donations reached a record high last year and for the first time outnumbered organ donations from the dead.[15] Over the last ten years, living solid organ donations have grown more rapidly than those from cadavers.[16] As an example of this trend, in 2001, living donors increased by 13.4% after a 16.5% increase the preceding year. In comparison, cadaver donations (far and away the majority, coming from brain dead donors)—increased by only 1.6%. Of these living donors, more than 90% donate a kidney. Since the kidney experience has been so positive, sectioning and dividing liver tissue—expecting excess or redundancy in such a large organ—has followed.

H. Go on please.

R. In the past, considering the entire transplant equation, the worst supply and demand problem occurred with liver grafts for children. This demand led to the first consideration of a living donor for a single organ (1990).[17] In theory, parents could donate a relatively small portion of their liver to their child and since kids are smaller, parents would be left with enough liver to do well. This part of the process is analogous to living related kidney transplants. The smaller transplanted graft would grow with the child and outcomes have been acceptable for *both donors and recipients*.

H. Wow, even though I prefer to dwell further on the ethical ramifications of these innovations, wouldn't it be nice if we could do the same thing for adults?

R. You conceptualize very well and have reached our next and most contentious ethical plateau! The technique of living liver donation to children had to be modified for adults and the technique has become considerably more complicated. Adults need a much bigger portion of liver for the simple reason that they are larger. The exact size of the graft—at the same time, not too small for recipients nor too big for donors—is still not completely clear. It would be best at this point to quote an experienced surgeon regarding the pitfalls of graft size in adults: "Neither the minimum transplantable hepatic mass nor the optimal mass have been accurately determined. In all likelihood, these values are dependent on both donor—and recipient—specific characteristics and could never be determined with precision."[18] Suffice it to say, the technique is demanding of a substantial volume of liver tissue, and contingently, donors have died, both recipients and donors have required re-transplantation and long-term follow up studies of donor safety are essentially nil.

H. It would seem to me that you have finally reached the point where you have violated my imperative—*first*, do no harm. If this is the case, you must declare a moratorium on the procedure. The risk to donors is prohibitive.

The End

As we exit the Hippocratic dialogue, certain fundamental issues have been brought into stark relief. Selected aspects of the conversation will be amplified for study. Continuing attention will be focused on the two most controversial issues—donor safety and informed consent.

Scrutiny requires that a few moments be dedicated to technique itself. Although the issue at hand is an ethical one, technique in this area *is* a significant portion of the ethical dilemma. Since technique was originally developed in children, that is where to begin. In reality, the adult surgery *evolved* directly from the pediatric model. In fact, one may reach the conclusion that the analogy with evolution may be accurate up to and including random mutations.

Pediatric living donor liver transplantation may account for as many as 50% or more of all pediatric liver transplants today![19] In fact, a single registry from Essen, Germany, presently contains more than 1,500 pediatric liver recipients from living donors.[20] But attempts to extrapolate the success of the pediatric enterprise to adults has not met with uniform success. The old adage that children are not little adults, or for that matter, that adults are not big children, has been the insurmountable obstacle. In children, the adult donor gives the lateral segment of the left hepatic lobe. This graft fulfills two important requirements. First, it is sizeable enough to function and later "grow

with" the child. Secondly, it leaves the donor with enough residual liver tissue to do well. Unfortunately, the graft size from the left lateral segment is too small for adult recipients. As a result, four anatomic grafts have been utilized for adult transplantation.[21] Presently, the most common graft appropriated is the donor's right lobe which accounts for approximately 60% of the donor's liver volume.[22] Complications related to such a sizeable procedure are significant and include biliary problems, bleeding, as well as arterial and venous thromboses. But more disconcerting, the "estimated" (the word choice here will be justified later) *ideal* graft size has been associated with liver failure in donors.

In a recent editorial in the *New England Journal of Medicine* addressing partial liver donation, the author expressed concern from the perspective of donor safety.[23] He said, "At present, there have been seven reported deaths among donors in the United States who have participated in all types of partial-liver donation. The incidence of death among right lobe donors is probably 1% or more – far higher than for kidney donation, which has a mortality rate of 0.03% and a low rate of serious complications. In two known cases, donors of a right hepatic lobe had to undergo liver transplantation themselves because they were left with insufficient liver volume." In the editorial, the author alludes to a death that was reported in the *New York Times*. A 57-year-old man donated a lobe of his liver to his physician-brother. The donor died three days after surgery from aspiration pneumonia. The articles in the newspaper were less about the ethics of donation—although that is the issue at hand—but more about care for transplant patients in general. However, since the care rendered is also an ethical issue, it is germane. The New York State Health Commissioner discovered that the inexperienced first year resident caring for said patient was responsible for 34 transplant patients![24] In this specific transplant situation, both donor and recipient are seriously ill postoperatively. The resident told state investigators that she was "overwhelmed" by the census and the conclusion was drawn that the donor received " woefully inadequate care." Although the donor who died is an extreme example of this living donor model gone wrong, a number of other issues came to light serendipitously. On further review, eighteen program deficiencies were uncovered, meaning that more than a single donor was jeopardized. The surgeon who performed the procedure did not even see the dying patient after surgery! The problems uncovered in the investigation ultimately led to a six-month suspension of the program in question.

Another adult living donor attested to the inadequacy of Informed Consent. For the sake of simplicity, the recurrent ethical themes encountered in this transplantation context will repeatedly return to the seminal issues of donor safety and inadequacies in consent. Regarding consent, Gregory Pence, a bioethicist at the University of Alabama at Birmingham, said of living liver donation: "this [the donation] is a major assault to your body, and really bad things can happen."[25] One donor, Laurie Post, donated a portion of her liver to a cousin and was admitted to the hospital six times afterwards.[26] The really bad things that could happen, did happen. If she had been informed of the potential complications, then the readmissions would have been expected. She, however, felt that the surgeon exerted a "not so subtle pressure," rather than implementing genuine informed consent. Her quote concerning her experience was informative: "I'm not sorry I did it, I'm sorry I wasn't better informed."[27]

Although referencing anecdotal newspaper stories may seem to be muckraking, please permit some latitude in this area. The regulation of transplantation ethics has often begun in the public sector. When the Cleveland Clinic reviewed an asystolic donor protocol nearly a decade ago, it was the negative press that halted further consideration.[28] Organ banks and transplant surgeons depend on the public's goodwill for success. Nothing can be worse for donation than a perception of organ cannibalism. The amount of ill will garnered from the recent negative press may continue to have repercussions.

You may ask, how did this enterprise get in such a mess in the first place? Does it take media sensationalism to bring attention to bioethical problems? The most profitable way to review this ethical "odyssey" will be to dissect the fundamental questions. The "early days" of a technique in constant competition with ethics must be revisited. At some point, one must also ask how carefully the shift from a pediatric model was made to adults. Only then may we proceed to the question of a yellow or red light for the adult procedure.

If Living Adult Liver Transplantation Applied for Approval Today,

What Should the Institutional Review Board Say?

> Research involving *healthy people* is a particular focus of concern because it often has no direct therapeutic potential. Many argue that such research requires a higher standard for minimizing risks than research involving people who are sick and who may die from their underlying disease.
>
> —Robert Steinbrook[29]

Until now, questions raised during the transition from child to adult living transplantation were at best superficially engaged. In-depth study necessitates wrestling with optimum graft size (in respect to both donors and recipients), immediate and longer-term graft function, as well as donor-recipient morbidity and mortality. The most profitable manner in which to pursue these queries would be to place the endeavor into the category of *experimental* treatment. Indeed, at some point in time nearly one decade ago, living adult liver transplantation was a therapeutic experiment. Before medicine knew that the procedure was safe, it could not be considered anything more or less. There is considerable controversy in the area of human experimentation anyway, and as a result, many bioethical guideposts are available by which to navigate the issue.[30,31]

In this regard, the group at the University of Chicago has been intimately involved with living donor liver transplantation from the perspectives of technique as well as ethics.[32] Furthermore, the experience has involved both pediatric and adult programs. The University of Chicago approach in preparation for technique is a model to be carefully imitated. The first pediatric operation (1991) was preceded by a grueling evaluation called "research ethics consultation."[33]

The actual process included raising ethical issues occasioned by innovative therapy and then presenting those issues to a diverse audience for intense analysis. All this must occur *before* any protocol is submitted to the Institutional Review Board for approval. The discussions at the University of Chicago lasted one year and were open to the entire University community. The first transplants were performed in children only after the completion of the "process" and IRB approval. More recently, the same group received approval to extend the process to adults. As of April 2001 and the writing of this manuscript, no further adult transplants have been performed. Apparently, careful consideration given to the obstacles encountered in transition from kids to adults halted the procedure. The title of the editorial from the same group in this context was, "Transplantation of liver grafts from living donors into adults—too much, too soon."[34] All therapeutic innovations should follow a similar process for approval, followed then by a guarantee of the ongoing monitoring of donor and recipient safety. With the recent proliferation of adult living donor transplant programs, coupled with a continuing paucity of follow-up data, it appears that neither of these essential criteria have been consistently complied. At this juncture, even ten years later, it is still impossible to characterize this procedure as anything but experimental.

Section three of the Nuremberg Code enumerates several responsibilities in the context of experimentation. "The experiment should be designed and based on the results of animal studies…". But in direct opposition to this rule, the living liver procedure in adults has proceeded in a relative vacuum. For instance, one of the reasons that the exact transplantable liver mass in human adults that is *safe* for both *donor and recipient* is unclear is that the question hasn't been unequivocally answered. This fact is true whether we ask about either animal or human studies! The following is a quotation from the head of a leading surgical team concerning graft size in adults:[35] "In animal experiments, it was demonstrated that *10%* of viable liver mass was adequate for spontaneous recovery after major hepatectomy [only one reference provided!]. In human situations, many patients survived major hepatectomy of large tumors because the contralateral lobe had undergone hypertrophy before the operation…Stone estimated that removal of 70% of the total volume of the liver was well tolerated by patients with a *normal liver*…Recently (it was) shown that individuals with normal liver function could tolerate resection of up to 60% (of their liver)…the present data *albeit limited* indicated that residual liver volume that is 27% of the total...is the lowest limit that can support survival, *provided that the liver itself* (donor) *is not fatty.*" Now therein were numbers whose pregnant content cannot be ignored. In essence, the choice representing residual donor liver is tantamount to choosing between life or death for the donor! Which is it then: 10%, 30%, or 40%? How do we know for sure? Should every donor be biopsied to preclude occult liver disease? Actually, the author of that paper then proceeds to choose 30% residual donor liver as acceptable so that there might be a little cushion between 27 and 30%! That number was chosen arbitrarily without scientific mandate. How does one exactly measure a 3% difference in size anyway? Is this a variation on "a pound of flesh"?

Other aspects of the Nuremberg code that have been ignored in the context of adult living liver transplantation include: the caveat that no experiment should be so conducted where there is an a priori reason to believe

that death or disabling injury might occur; that adequate facilities should be provided to protect the experimental subject against even remote possibilities of injury, disability, or death; and finally, that during the course of the experiment, the investigator must be prepared to terminate if the experiment is likely to result in injury or death.[36] At one time there were a priori reasons to suspect at least injury to the donor since the lack of preliminary experiments did not define a safe residual liver volume. The New York donor death alluded to earlier has spoken to the adequate facilities issue. Finally, the question of a moratorium because of injury or death is surely a viable one and merits national and international discussion.

In addition to the Nuremberg Code, a Consensus statement on the live organ donor has also identified lapses in the present system.[37] Discrepancies between many liver transplant programs and the Consensus include absence of short- and long-term disability data (such as medical uncertainties up to and including whether the donor can even obtain health insurance in the future) as well as the nagging issues surrounding informed consent for transplantation. The issues swirling around consent are so critical that they warrant discussion.

More Than Just Ethical Leftovers:

What Has Living Liver Donation Done to Informed Consent?

The informed consent discussion can be subsumed under two subheadings, namely, misrepresentation concerning what is really known about technical outcomes and coercion of donors. How can a donor's consent be genuinely *informed* when critical information is unavailable? Is the absence of adequate animal studies, the contingent,[comma inserted if both adjectives equal and separate] experimental nature of the procedure (particularly related to ideal graft size), the prohibitive morbidity-mortality statistics from centers on a learning curve (experienced by every new program),[38,39] the lack of a common registry or of safety oversight committees, the under-reporting of bad outcomes,[40] lack of consistency throughout many disparate protocols,[41] or the absence of long-term data factored into consent discussions? Is consent obtained by individuals who don't profit from an increase in procedures or an increase in publications? Or do the surgeons get to present selected data prior to surgery? Is recipient success the major focus of discussion?

Genuine informed consent is the sine qua non of a yellow light to living donor liver transplantation. The permission will necessitate regulation including the empowerment to close programs that do not comply with guidelines. The Nuremberg caveat that "the *voluntary consent* of the human subject is *absolutely essential*" is fundamental and non-negotiable. In fact, the Belmont Report,[42] a later addition (1978) to the Nuremberg rules, provides more explicit guidance in this regard. The timing of the Belmont Report was related to the proliferation of IRBs and an increasing number of research protocols with human subjects. In retrospect, the report appears to have been prophetic. Three specifics to the Report are: 1) that the subject is adequately informed of the risks of the research

study; 2) that the study (itself) is designed to maximize the chance that consent by research subjects will be voluntary, without coercive influence; 3) that the informed consent be documented by having the subject sign a document that explains the essential elements. At this juncture, it appears that consent in the living adult liver arena has a long way to go to fulfill either the Nuremberg or Belmont criteria. Until it does, serious injury to donors will continue.

"To The Least of These": Does the Gift of Life Get a Yellow Light?

Back to the press for one final moment. An article in the *Chicago Tribune* entitled, "Priest gives parishioner gift of life," is a prime example of sharing with the least of these. The story resulted from living related liver donor transplantation and therefore is timely.[43] A Latino male dying of sclerosing cholangitis with advanced liver failure had an estimated six months to live. Transplantation was the only option consistent with survival, but the wait was typically prohibitive. Although the patient's brother offered to donate, the patient's parish priest stopped him saying, "I can't let you do it, you are the father of four, I'll do it." And he did, with successful outcomes, thus far at least, for both recipient and donor.

Despite the necessity of negatively critiquing aspects of live donor liver transplants, transplantation remains one venue wherein the gift of life transcends ordinary giving and is supererogatory. The preceding list of deontologic "thou shalt nots!" should in no way detract from the love exemplified in the giving of an organ. Regulation of the technique by ethical standards is essential, but when accomplished for *donors and recipients* equally, should still permit a degree of risk voluntarily assumed. When questions confronting living donor transplantation are rectified ("rectified" meaning that all protocols meet the high standards required by the sanctity of human life), there may be no other place as appropriate to share life than from a Christian worldview perspective.

In sum, the author suggests an immediate red light for certain programs. Registries established to safeguard donor safety are a welcome addition. Programs like the one sanctioned and discussed earlier require an immediate stoppage with monitored follow-up by strict guidelines after reopening. But it may be that a yellow light should be permitted for other programs based on their positive results, carefully regulated informed consent, and careful attention to safety for both recipients and donors. The establishment of new programs should be halted until agreed-upon safeguards and universal regulations are in place. Oversight committees should become operative and empowered to close programs for safety reasons—related to donor or recipient. Informed consent has to be unequivocally designed to be genuine, and administered by individuals completely outside the influence of the transplant team. Because of the impossibility of obtaining truly informed consent in emergency situations, emergency transplants should also be halted.

The ethics surrounding living adult donor liver transplantation are in tension between the virtuous donor and the deontology inhabiting unacceptable donor risk. It may be that discussion of transplantation's future, especially as

it relates to living donor dignity and recipient need, should further evaluate supererogatory acts (donation that is risky) in the context of a Christian worldview. What are the boundaries to neighbor love in an arena of obligation to the sanctity of life? When a donation can save a life, how much donor risk can be ethically assumed? The gift of life fits well into the Christian tradition. Can a lesson be learned for the future of transplantation, however? Never again can technique proceed in an ethical vacuum! Only then will Hegel's adage that "the one thing man learns from history is that man does not learn from history" be disproven and protect transplantation's recently tarnished image. E&M

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Book Reviews

Ethics in Community-Based Elder Care

Martha B. Holstein and Phyllis B. Mitzen

New York: Springer Publishing Company, 2001

ISBN 0-8261-2297-3, 336 PP., HARDCOVER, $48.95

"Caring for older people outside of institutions is the largest growing sector of the U.S. health care industry"—and thus it is necessary to examine the myriad issues that arise when examining community-based care for seniors. As the population of seniors continues to rise in the U.S., so do the options for long-term care. *Ethics in Community-Based Elder Care* discusses trends that show an increase in the number of seniors who are opting to remain in their communities for as long as possible. With this move towards non-institutional long-term care for seniors come the numerable problems that they, along with their caregivers, will encounter.

The book is a compilation of articles written by more than 30 contributors, providing many different perspectives on topics related to community-based elder care. The contributors attempt to give direction based on their collective experiences, united by the common goal of establishing ethically based services that will help the elderly and their caregivers make educated, sound, ethical decisions while maintaining healthy morale. The editors proudly claim they took no liberties in removing any one author's personal views, so that the book provides a range of views on how value conflicts and ethical dilemmas are to be handled.

Comprised of five sections, the book introduces the topic, provides background to the ethical problems being faced by the industry, covers specifics regarding the organizations including both the providers of care and their receivers, treats the practice of ethics, and lastly, explores the policy involved in practicing ethics in community-based elder care.

The first section, written by the editors, outlines the problems that need to be addressed and a variety of aspects of community-based health care needs for seniors. They maintain that many of the ethical issues being discussed throughout the book are a result of the efforts of workers to help their clients spend the last years of their lives in a manner that is both dignified and allows them to maintain a level of self-respect. To accomplish this, the editors establish a case-based narrative approach to exploring ethical patient care from a perspective of both the giver and receiver of care.

The second section provides a detailed and necessary history of issues that have emerged in the field of bioethics and long-term care of the elderly. The first author, Brian F. Hofland, briefly outlines various methods of helping seniors and their caregivers deal with the ethical situations that develop in community-based care, specifically in the home. The main problem identified is that of maintaining the client's sense of dignity and privacy; one solution offered is to train all those involved in care giving on proper ethical behavior. Martha B. Holstein establishes the value of home-based as opposed to institutionally based care. She argues that seniors who remain in the home environment are able to maintain their sense of self-respect and self-worth. This is often absent once they are removed from the privacy of their own homes and the comfort and memories attached to their possessions. Mark Waymack discusses what is identified as the four phases of care: Caring About (individuals), Caring For, Care Giving, and Care Receiving. Included in this section is a set of questions that will allow workers to make caring judgments related to providing ethically based care. Joan C. Tronto evaluates the old framework under which long-term care was provided, and surmises that the previously established ethics are no longer sufficient for the current dilemmas faced today.

The third section examines organizations, care providers, and care receivers. The first author, David B. McCurdy, discusses the challenge of creating an ethical organization. He writes that all organizations need to operate in such a manner that is ethically sound. He suggests incorporating the help of outside panels whose sole purpose is to assist organizations during their initial phases of establishment to operate ethically. These groups would offer a framework for assessing dilemmas and making sound decisions, provide support, and establish accountability. Using such groups is suggested for both profit and non-profit organizations. Phyllis Mitzen discusses the issues that are faced by non-profits as they fill a unique role in the community. For them it is especially important to establish ethical practices that are consistent with their mission and embody the values of the organization. Two authors, Robyn L. Golden and Sallie Sonneborn, discuss the biases that should be taken into consideration when attempting to provide ethical care. Narratives in this chapter provide vivid examples of how, pushed by biases, workers will cross established professional boundaries, though they believe they act toward the client's benefit. The key point is that "values shape moral perceptions and judgments, which in turn, influence the treatment of the client." For this reason it becomes clear that practitioners need to be aware of their own biases and attempt to evaluate the biases from the client's point of view in order to remain within the ethical boundaries established by each organization. Robyn I. Stone and Yoshiko Yamada focus on the frontline workers and the ethical challenges they face. Though they have little power to change a poor situation the client may be in, they often feel a strong sense of responsibility. They often find themselves in poor work environments and working for low wages relative to the demands placed upon them. The authors discussed the increased number of paraprofessionals who are providing care, and the increased number of family caregivers in community-based care. With this increase of untrained workers come many dilemmas, and with these new encounters there is a great need for establishing ethical codes that can be introduced and taught to such workers. One of the main ideas to be conveyed for the benefit of frontline workers is the importance of practicing everyday ethics to provide the best level of care for the elders in the community. Nan G. O'Connor writes a very informative narrative about her experience as a social worker-turned-care-receiver due to her physical condition. Her story validates the need for ethical codes to be enforced by frontline workers, and gives a graphic picture of the experience of those who are unable to change the position they find themselves in when they have to depend upon others to have their basic needs met. The concluding chapter of this section, written by Hilde and James Lindemann Nelson, describes how some long-term home care often takes place in an environment that is comprised of more than one generation. It is this multi-generational experience that the authors contend becomes a cross-cultural experience. Here, the best remedy for the distinctive dilemmas encountered is an environment that encourages fluid movement between the cultures, communication, and respect for the differing perspectives that are joined under one roof.

The fourth section in the book deals with practices involved in ethical care. The first chapter, written by David Fireman, Sharon Dornberg-Lee, and Lisa Moss, presents the results of forums conducted by the Council for Jewish Elderly. The forums produced a risk assessment chart to assist field workers provide ethical care in a manner that upholds the client's dignity while also solving the dilemmas they face. Pat Stacy Cohen outlines the many benefits of adult day care and introduces a few of the ethical dilemmas that are faced by the caregivers, families, and day care workers. The day care scenario presents a unique quandary for the workers, since they are often required to make ethical decisions without being able to fully assess the client's situation. Daniel Kuhn evaluates the home care environment and the cases in which home care might not be the best for the client, specifically in cases involving Alzheimer's disease. The author establishes that these situations are especially difficult because current social services and policies are insufficient to even meet the basic needs of Alzheimer's clients and their families. Stephen Ellingson and Jon D. Fuller offer a look at the terms of a "good death," often no more than an ideal that places strenuous demands upon caregivers and medical practitioners. Often, "the end" experience does not meet the expectations of the one who is dying. The argument is made that the notion of a "good death" is held with disregard

for the consequences that will be entailed for anyone else other than the one who is dying. The authors contend that often the "good death" experience ends up not being all that it was anticipated to be anyway, suggesting that this is not an ethically sound practice, as there is no one who consistently benefits from the practice. Gail McClelland, summarizes the ethical concerns identified by case managers in a monthly forum. These forums allow case mangers to discuss important issues and share narratives that have spurred discussions within the department of aging, and have helped in sharing services provided to the elder population in the community. In practices of home- and community-based services (HCBS), the "do no harm" statement has been one that has shaped the services provided to consumers. In light of this, the emphasis is that there needs to be a close evaluation of what "no harm" looks like, relative to the risks that need to be taken. Of high importance in HCBS are the legal risk agreements that must be a part of the arrangements made with the clients and their families. Without such arrangements there is a risk of things going wrong, as well as doing considerable harm to the HCBS organizations. The final two chapters sketch the difficult practices associated with prejudices and the cross-cultural geriatric ethics. When encountering dilemmas such as the ones presented in the narratives in these chapters, the authors contend that the main goal is to maintain respect for the beliefs and views held by the elders. Often, common ground can be reached with a little extra work, if respectful treatment is to be a priority.

The fifth and final section presents chapters related to the policies in the ethically based community care of elders. Larry Polivka discusses the systems that are currently in place, the level of awareness that has been raised, and the gap that remains between where the current policies are and where the increases need to be made. The main proposal is that policies need to be reevaluated and changed with a move towards a system that functions much the like the system currently supporting people with developmental disabilities. In a system such as the one Polivka proposes, the focus would have to be ethically based, featuring a commitment to "quality of life values." In doing so, many of the ethical dilemmas faced in the current system would no longer be encountered. C. Jean Blaser addresses the policies regarding paying family members as caregivers with the basic premise that while family-based care can be good, it can also be and more frequently is a bad scenario. Blaser argues that family-based care exploits family values, promotes cases of abuse, and costs more in the end. Blaser instead suggests the need for more community-based home care providers, which will provide the much-needed care for the elderly while creating jobs that would bolster today's economy. In the next chapter, Lori Simon-Rusinowirz, Kevin Mahoney, and A.E. Benjamin argue the exact policy Blaser looks to discount. They propose that families should be able provide care and receive payment for their efforts. They present research that evaluated family-based care against care provided by agencies or outside individuals, and showed that care provided by paid family members is preferred by clients. They claim that a policy for paid family-based care can be a good option when the policy requires that care is monitored and that there is accountability for the caregivers. June L. Noel closes the book with a look at creating policy in ethics within state agencies in Florida, and the reality that elder care is now in a new era. This is an era that calls for guidelines that move beyond the traditional policies that have been previously practiced. Florida has thus embarked on an "ethics initiative." Careful examination revealed that the state's established policies were "fraught with value issues." This essay uncovers the validity of state-based policies, also examining the problems encountered with such statewide policies, and the importance of public dialogue in examining policies in community-based care.

Overall this book provides an excellent context for examining the ethics in community-based elder care. The contributors provided compelling narratives and enlightening perspectives which would be beneficial for anyone involved community-based care. The writing will be accessible to readers, who can easily benefit from the arguments presented.

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The Physician's Covenant: Images of the Healer in Medical Ethics, 2nd edition

William F. May

Louisville, Kentucky: Westminster John Knox Press, 2000

ISBN 0664222749, 249 PP., PAPERBACK, $19.95

William F. May is professor of ethics and founding director of the Cary M. McGuire Center for Ethics and Public Responsibility at Southern Methodist University in Dallas, Texas. The second edition of his book *The Physician's Covenant* is directed toward accomplishing a paradigm shift in the medical profession as well as the entire health care industry. To that end, he makes excellent use of five metaphors describing physicians, and extends the idea of covenant to include far more than the physician-patient relationship.

The author looks sequentially at the physician as parent, fighter, and technician, and finds all three images wanting. May rightly points out the pitfalls of paternalism in the medical model, stating that such a model "keenly experiences the absence of divine providence and substitutes a providence of its own" (p.54). The physician as fighter is aptly described by May, and he presents plausible evidence for the genesis of this view so prevalent in medicine today. The contrasting of the two contenders, suffering and the fear of death, as the *summum malum* provides rich imagery as well as enriched understanding of who we are as a people. His differentiation between "maximal care" and "optimal care" is most helpful (pp. 73-8). Although May does not dismiss the importance of technical skill for physicians, he disagrees with the process, stating, "The cumulative impact of the training filters out the personal, not merely the patient as person but the physician as person" (p. 103). These three metaphors of physicians as "types" are summarily discounted by the author.

While I understand his reasoning, and concur with many of his conclusions, as a physician and patient I have witnessed both the excesses and the need for some aspects of paternalism in medicine. May recognizes the importance of some paternalistic values in medicine, but his defense of them pales in comparison to his opposition of the same. He argues eloquently against the concept of physician-as-fighter in terms of end-of-life issues. I am confused by his statement that there is "after all, a time to live and a time to die, and a right to die well" (p. 72). The writer of Ecclesiastes would have no difficulty with the first premise, nor do I. With the second—"a right to die well"—I see a difficulty. Although the author may be speaking of the inappropriateness of certain procedures at the end of life, this is not clear. A right entails responsibility: if there is such a right to die well, then someone, presumably someone in the realm of medicine, has the responsibility to ensure that such a right is fulfilled. This seems at least a small step toward euthanasia, but the author does not elaborate. May rejects caring "in the form of killing" on the basis that such does not fulfill the obligation to care for patients (p. 80), but leaves open the "rare exception to the prohibition against euthanasia" (p. 87). He also writes that he would hope on the battlefield that he "would have the courage to cross the boundary and kill the [horribly maimed] sufferer with mercy" (pp. 86-7). I have not been on a battlefield, but I have seen many people approach death, and a number of them die. Yet I have not seen an instance where it seemed appropriate for me to wield the final stroke that would result in one's death.

The metaphors May considers appropriate for physicians are covenanter and teacher. He writes, "A covenantal ethic positions human givers in the context of a primordial act of receiving a gift not wholly deserved, which they can only assume gratefully" (p. 114). The ensuing description of physician as bound by a covenant to be not only healer but also teacher, is elegant work indeed. By his words, May challenges the reader to rethink—and redefine—his or her definition of physician as well as "healthcare" in general. May is an ethicist, not an economist. How his proposal would function in a world where both physicians and patients

are not only fallen, but act that way on a regular basis, is unclear. The idea of covenant is not new, but is less and less understood by most people. Those who have a Jewish or Christian faith tradition are more likely to understand the concepts presented by May. A reader of any tradition will be challenged.

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BIOTECHNOLOGY UPDATE

The Stem Cell Debate Gets Hotter—and What We Need to Do About It

NIGEL M. DE S. CAMERON, PHD

Nancy Reagan's recent intervention in the debate over federal funding of destructive embryo stem-cell research has given fresh heart to those pressure groups, celebrities and biotech enthusiasts who are seeking to overturn President Bush's careful policy compromise—which he announced to the nation in his first televised broadcast as President, on August 9, 2001.

It is plain that the administration is not going to change its policy. What we need to understand is that there is so much *mis*understanding abroad that it is proving very difficult for honest people to come to honest conclusions. The press is now focusing on the alleged fact that "conservatives" in the religious community are changing their view. Perhaps some are. Many have never thought seriously about this matter, and are anxious about sick relatives and the need to cure diseases. It's never been more important for those of us who *have* thought long and hard about these issues to get the word out and clarify the thinking of the nation.

Here are some of the very common misunderstandings; some of them deliberately—shamelessly—purveyed by the press and advocates of destructive embryo research.

The Bush administration has banned stem cell research

There is no federal law banning stem cell research of any kind. There has long been a ban—imposed by Congress—on federal funding of destructive embryo research. This ban was enforced by the Clinton administration. President Bush's decision of August 2001 was in fact a liberalization of that ban—and it was denounced by some conservative groups as a result! The Bush decision *permitted* funding of embryo stem cell research. The permission extended to cell-lines cultured from embryos that had already been destroyed, so that there would be no encouragement to destroy further embryos—but the basic research could be funded. And, of course, there is no restriction at all on "adult" stem cell research.

Cures are right around the corner if only the administration changes its mind

One of the cruelest myths ever put out in the press is this one. Whatever has been said, the implication is clear: aunts and uncles and parents who are now sick could be cured; perhaps even President Reagan could have been saved; all that stands in the way is this funding ban.

It does not take a lot of intelligence to see the many fallacies here. Even the more honest advocates of embryo stem cell research have admitted that "cures" are a long, long way off. This is patently clear to those who have followed the animal experiments, which have so far yielded very little evidence of "cures" and many problems. But the proof lies in the market place. If the hype were to be believed, and a whole new world of cures were on our doorstep, there would be massive investment from venture capitalists and major Pharma corporations and start-up IPOs, pouring into embryo stem cell work—the new gold rush. Economics is an interesting study: the market places values on information, summing up all that there is out there and coming to conclusions that lead to prices, assessments of risk, and to investments. The markets have spoken: the best-informed people around, the biotech investors, have taken a walk. And, of course, that is why there is such pressure for public money.

Adult stem cells are second best

I gave an invited presentation at the vast Experimental Biology conference in Washington, DC, a few weeks ago. I was surveying the ethical pros and cons of stem cell research, and alongside me were three other speakers: my friend Professor David Prentice, an adult stem cell expert, who summed up the state of the science in both adult and embryo research areas; and two famed experts, one working in each field. The embryo research expert talked about basic research. The adult stem cell expert (who was not against embryo work in principle) talked about patients with what had been thought to be incurable diseases going home from hospital cured. (If you want to read some of the latest research info, go to stemcellresearch.org—and tell your friends, pastor, physician, neighbors, local newspaper, congressman, kids, sick relatives, state representatives, mailman—tell them all to go there and read the *facts*.)

They only want to use the "spare" embryos that will die anyway

Tell that to the marines! The entire celebrity-led, emotionally-driven case for using embryos for research has been built on the idea that it will result in one-on-one medications, using embryo-derived tissue to regenerate and replace tissue cells that have gone bad. This is what has been deceitfully called "therapeutic cloning," and involves the mass-production of embryos by the hundreds of millions—and the production of an identical twin for each patient so that the twin embryo can be destroyed to produce the "cure." This idea is horrific, and the horror is by no means confined to pro-lifers!

In fact, "therapeutic cloning" has already been banned by law in many countries. The Germans, who know a thing or two about where science can go wrong, banned it back in 1990. Australia banned it last year. The latest was Canada, where the ban was finalized in April of this year. The French are next in line: we expect their law to be voted through later in June. The US is among many countries supporting Costa Rica in an attempt to get an international convention banning cloning through the UN. Among the big democracies, only the UK is in favor of "therapeutic cloning," and the UK has been in the pro-embryo-research lead for 25 years. Here in the US, the Brownback-Landrieu

bill to ban cloning is languishing in the Senate. But remember, its equivalent (Weldon-Stupak) has twice passed the House with a huge bipartisan majority.

So the "spare embryo" argument is a red herring. In any case, these embryos should be adopted and given a chance of life. And we should stop freezing embryos. To be stored in deep-frozen vats is not a proper use of God's gift of life.

So what can we do?

We need to get these arguments and the facts behind them into our local media and our local politicians' mailbags and offices. We need to get them out through the churches. One of the greatest debates of our generation—some would say, *the* greatest—is the struggle for human dignity in the face of these amazing, and potentially terrible, new technologies. Pro-life Christians need to be in the forefront, and that means all of us!

Use those special websites: cloninginformation.org,
and stemcellresearch.org.

Use the *Playing God?* Sunday School materials—in which Chuck Colson and I explain these debates—with your church or home group or just your friends.

Look for the new book, *Human Dignity in the Biotech Century*, which Chuck and I have edited and which brings together some of the best brains to make our case (InterVarsity Press, July).

And, whatever your politics, support President Bush's stem cell funding policy.

The Language of Cloning: How the Terminology Affects the Politics

AMY MICHELLE DEBAETS, MA

With the recent passing of former U.S. President Ronald Reagan after a long battle with Alzheimer's disease, his wife Nancy Reagan joined an unusual coalition of Republicans and Democrats, such has Orrin Hatch and Diane Feinstein, in calling for expanded federal funding for human embryonic stem cell research, including research into cloning human embryos for use and destruction in research. The language used was that of cures, with the implication that not using increased tax dollars to pursue this avenue of research would directly and surely result in the deaths of sick patients.

That call was opposed by another bipartisan coalition, including President Bush, who claimed that the limited federal funding for medical research should not include expanding already existing funding for embryonic stem cell research, but that the amount available now is sufficient, and that allows funding to be directed toward other important areas of research, including therapies that utilize stem cells from patients' own bodies, drug therapies, and other innovative, non-destructive techniques. This debate will continue in the

months and years to come, as traditional partisan alliances morph and the demand for all types of publicly funded medical research grows.

Proponents of expanding the current federal funding for embryo research, including human cloning, speak of "therapeutic cloning," "somatic cell nuclear transfer" (SCNT), and "unfertilized blastocysts." But for whom is "therapeutic cloning" actually therapeutic? What does the process involve? And is an "unfertilized blastocyst" really anything other than a human clone?

All human cloning, as with animal cloning, is done by the process of somatic cell nuclear transfer. This is nothing more than the process by which the nuclear DNA from a normal, adult body cell is taken and injected into an egg cell which has been enucleated (had its nucleus removed). The newly formed zygote (single-celled embryo) is then given a small electrical shock in order to begin the process of cell division, just as any other embryo would undergo. In fact, it is then indistinguishable from any other embryo. There are no genetic or other markers to indicate, "This is a clone." This cloned embryo is what proponents of cloning research choose to call an "unfertilized blastocyst." This is really nothing more than semantic dissembling to give people the idea that the cloned human embryo is somehow other than human, something that can simply be created and destroyed at will for any purpose without any moral issue. The term itself is scientifically incorrect, as the cell's nuclear DNA was originally the result of a fertilization process, and the cloned embryo must grow to become a blastocyst (14-celled embryo), just as all embryos pass through the blastocyst stage.

Once this cloned embryo has grown and divided for approximately 10 days, it can have its stem cells harvested, a process which inherently involves the destruction of the embryo. This is what is known as "therapeutic cloning." The process required to gain access to these stem cells, however, is anything but therapeutic for those involved. Cloning is a notoriously inefficient process, with hundreds of attempts required to develop a single, healthy clone. For this, hundreds of eggs are needed, and they must be harvested from women's bodies. In order for a woman to donate her eggs for this kind of research, she must take the dangerous drug Lupron to stimulate her ovaries to mature many eggs at once, then she must undergo surgery to remove the eggs. All of this is done with no medical benefit whatsoever to her. The cloned embryos are created using these eggs, the vast majority of which do not survive, and those that do almost always have significant health problems that are not initially identifiable.

What should be made of the call for the federal funding of human cloning? Its proponents would use dissembling language to dehumanize the clones so that the public is unaware that they are seeking to use taxpayer money to create thousands of human clones solely for the purpose of destruction in research. All people of conscience want to provide cures for those who suffer with debilitating illnesses, but using the bodies of women as egg factories and creating human clones simply to destroy them is not the way to accomplish that end. There are other very promising avenues of research, including research using adult stem cells, that should receive heightened attention and public funding instead.

BIOTECHNOLOGY NEWS

Major Therapeutic Advances Using Adult Stem Cells

Researchers at the University of Florida recently had great success in treating diabetes in mice by using stem cells derived from bone marrow to produce insulin. Other scientists used bone marrow–derived stem cells to destroy ovarian cancer in mice. A new source of stem cells that avoids the controversies involved in embryonic stem cell research has been found—the pulp from children's baby teeth. Those who are looking into this source say that these stem cells have all of the capabilities of embryonic stem cells, are not rejected by the children's bodies, and do not involve destroying embryos. Dental pulp is also being cited as the most promising source of stem cells to successfully treat Parkinson's disease, as those cells actively aid in nerve cell survival. Another unusual source of stem cells, human fat tissue, has been shown to be able to regrow bone tissue that has been damaged in human adults and children. Patients with spinal cord injuries can now have hope that they might regain sensation by taking advantage of therapies using stem cells derived from their noses, as the Rehabilitation Institute of Michigan opens a new center. The first federally approved clinical trial using bone marrow-derived stem cells to treat patients with heart failure has begun as well, with positive results so far. Stem cells derived from the patient's own body are also being used to treat lupus by boosting the immune system. The regenerative properties of adult stem cells are well documented, and many of their benefits are described in a recent Tulane University article.

http://wwwnapa.ufl.edu/2004news/stemcelldiabetes.htm

http://www.nature.com/cgi-taf/DynaPage.taf?file=/labinvest/journal/v84/n5/abs/3700074a.html

http://msnbc.msn.com/id/4630527/

http://news.bbc.co.uk/2/hi/health/2967355.stm

http://www.nature.com/cgi-taf/Dynapage.taf?file=/nbt/journal/v22/n5/abs/nbt958.html

http://www.freep.com/news/health/spine13_20040413.htm

http://www.genomenewsnetwork.org/articles/2004/04/16/stem_cell_trial.php

http://www.nature.com/nsu/040426/040426-3.html

http://www.eurekalert.org/pub_releases/2004-05/uom-dpc050404.php

http://www.publicopinionononline.com/news/stories/20040521/localnews/473677.html

http://www2.tulane.edu/article_news_details.cfm?ArticleID=5155

Ohio Funding Adult Stem Cell Research

The state of Ohio has begun to fund medical research using adult stem cells, including a major research facility at Case Western Reserve University. Ohio has provided nearly $20 million from the biotechnology fund created using

money from the state's tobacco settlement to start The Center for Stem Cell and Regenerative Medicine, which will utilize only those stem cells taken from non-embryonic sources, including those derived from bone marrow, blood, and umbilical cord blood.

http://www.cwru.edu/pubs/cnews/2003/6-19/stemcell.htm

Stem Cell Wars: New Articles Available Online

A new article in *Insight* highlights the promise of adult stem cells and dispels some of the myths and the hype regarding human embryonic stem cell research. Another article in the *National Review* looks at the politics behind embryonic stem cell research and the realities of the speculative nature of the research. A third article by William Saletan discusses the politics of cloning language and the problems inherent in denying that the human embryo (cloned or otherwise) is anything at all, much less a person with moral standing.

http://www.insightmag.com/news/2004/05/16/National/The-Stem.Cell.CoverUp-682587.shtml

http://www.nationalreview.com/comment/cohen200405251335.asp

http://slate.msn.com/id/2076199

Embryonic Stem Cells an Unlikely Treatment for Alzheimer's

Contrary to the claims of Nancy Reagan and other proponents of human embryonic stem cell research, stem cells derived from human embryos are not likely to lead to treatments for Alzheimer's disease. Even researchers who support embryonic stem cell research acknowledge that the potential for such therapies has been blown out of proportion in the public mind in recent months and weeks, based largely on political support from public figures such as Nancy Reagan and actor Christopher Reeve. Alternatively, new research studies using genetically modified skin cells are proving promising in slowing the progression of the disease.

http://www.washingtonpost.com/wp-dyn/articles/A29561-2004Jun9.html

http://www.nature.com/nsu/040426/040426-7.html

Cells Can Reverse Course, Become Stem Cells Again

Researchers at Johns Hopkins University who are working with fruit flies have found a way to reverse the course of differentiation in order to make specialized cells revert back to a stem cell stage.

http://www.eurekalert.org/pub_releases/2004-05/jhmi-sct051804.php

President's Council Report on Assisted Reproduction

A new report from the President's Council on Bioethics is now available online. The report, titled "Reproduction and Responsibility: The Regulation of New Biotechnologies," considers various assisted reproductive technologies including emerging genetic engineering options, and proposes regulations for the currently unregulated industry.

http://www.bioethics.gov

Mice With 2 Genetic Mothers, No Father

The first mammals to be created using genetic material from two females and no males has been born. These mice were developed using altered genetic material from an oocyte that was made to mimic the contribution of sperm in the reproductive process. The procedure was difficult to accomplish and resulted in large numbers of dead and deformed mice before any were born healthy. The mice did not result from a cloning technique, as they are genetically unique, but any similar experimentation with human beings would be subject to the same ethical problem as cloning. Other researchers have discovered that males do contribute their unique RNA as well as DNA to the process of reproduction, which may aid in explaining why the mouse experiments experienced such a high failure rate.

http://www.iht.com/articles/516218.html

http://www.washingtonpost.com/wp-dyn/articles/A32121-2004Apr21.html

http://www.theaustralian.news.com.au/common/story_page/0,5744,9349294%5E30417,00.html

http://www.nature.com/nsu/040419/040419-8.html

http://www.biomedcentral.com/news/20040513/01/

Holocaust Museum Exhibit on Nazi Medicine

A new exhibit on the medical research and eugenic experiments conducted by Nazi doctors is now on display at the United States Holocaust Memorial Museum. The exhibit is a potent reminder of the dangers of unethical research and the devaluation of human beings. It will be on display until October 2005. (Caution: the USHMM site contains graphic depictions which are inappropriate for young children.)

http://www.washingtonpost.com/wp-dyn/articles/A32933-2004Apr21.html

http://www.ushmm.org/museum/exhibit/online/deadlymedicine/

Protein Could Be Key to Alzheimer's

Researchers at Northwestern University have isolated a protein that they think may hold the key to understanding Alzheimer's disease. The proteins, called ADDLs, have the capacity to bind together and destroy neurons. Mouse studies

have shown that their neurons functioned normally once ADDLs were removed. This may be indicative of the trajectory of future therapies for Alzheimer's, which would not relate at all to stem cell therapy.

http://www.scientificamerican.com/print_version.cfm?articleID=00083B38-9C12-1084-983483414B7F0000

UK Legal Loophole on Human-Animal Hybrids Exposed

A loophole in the UK 1990 Human Fertilisation and Embryology Act that might allow for the unlicensed creation of human-animal hybrids has been exposed, and authorities within the HFEA are seeking to close it by identifying specifically what types of research are regulated under the Act.

http://www.biomedcentral.com/news/20040602/02

Arab Nations Propose Comprehensive Ban on Human Cloning

Nations across the Arab region are expected to agree to a treaty that will ban all human cloning, including cloning for research. Islamic scholars have recently debated whether or not cloning of any type should be considered ethical, and a consensus has recently formed that cloning should be banned. This action will likely have a significant effect on upcoming discussions regarding a comprehensive cloning ban within the United Nations, as Arab states had been hesitant to support such a ban when the issue came up last fall; most chose to abstain from the vote that failed by a very narrow margin.

http://www.scidev.net/news/index.cfm?fuseaction=readnews&itemid=1421&language=1


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