

## Quote to note

"This is the biggest problem we face in American health care, and it's not on the political agenda. There's no significant solution on the horizon. The country doesn't want to put up the tens of billions of dollars it would take to provide coverage for the uninsured. We have been making some progress with the small incremental reforms, but it's like shoveling sand against the tide."

—Drew E. Altman, president of the Henry J. Kaiser Family Foundation  
As reported in *The New York Times*

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## *Defending challenges to the concept of "brain death"*

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**T**he concept known colloquially as "brain death" holds that a human organism is dead if and only if all the clinical functions of the entire brain have irreversibly ceased functioning. Over the past 30 years, "brain death" has become accepted so uniformly by Western society that every state in the United States and the legislatures of many other countries have codified it into statutes of death. These statutes provide two tests of death: 1) if the patient is not on mechanical ventilation, death can be determined by the prolonged absence of circulation and ventilation; or 2) if the patient is on mechanical ventilation, death can be determined by the irreversible cessation of clinical functions of the whole brain.

"Brain death" is an unfortunate and misleading term, erroneously connoting that there are two types of death, rather than simply two methods for determining human death. But because the more precise term, "the determination of human death using a neurological criterion and tests" is cumbersome, the term "brain death" has become popularized. However, the term has led to misunderstanding and must be used and understood precisely.

When the concept of "brain death" first evolved in the 1960s, it was a prerequisite for stopping physiological support of the patient. However, now that there are accepted guidelines for stopping life-

sustaining treatment on living patients, the only act for which "brain death" remains a prerequisite is multiorgan procurement for transplantation. This fact has established a clear causal linkage between "brain death" and organ transplantation. A secondary application may be to permit physicians to terminate medical treatment over the objection of the patient's family.

Despite the widespread public acceptance of "brain death," several scholars recently have called for its abandonment on three grounds: 1) that it is an anachronism because it is no longer a necessary condition for discontinuing life-sustaining therapy; 2) that it is an incoherent concept that does not accurately represent biological death, principally because most of the patient's other organs continue to function; and 3) that multiorgan donation can be uncoupled from "brain death," permitting organ procurement from living patients who are beyond harm, with their consent or that of their proxy decision makers.<sup>1-3</sup>

Concerns about these questions are one reason the Vatican Pontifical Academy for Life has decided to re-examine the Roman Catholic doctrinal acceptance of "brain death" as human death. Because the Roman Catholic Church cannot condone killing, even in the case of an imminently dying person who has consented for organ donation, determining whether "brain

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*“Brain death” (Continued from Page 1)*

dead” patients are truly dead is of paramount ecclesiastical importance.

At first glance, the determination of death seems like a straightforward task, a purely medical diagnosis. Indeed, it was fairly simple in the era before the invention of the mechanical ventilator. At that time, all vital functions (breathing, heartbeat, brain functions) stopped within minutes of each other so it was unnecessary to consider whether a human organism was alive who had lost some but not all vital functions. But this simple matter changed forever with the advent of the mechanical ventilator. Cases then were reported of patients who had permanently lost all brain functions and breathing capacity but were kept supported by a mechanical ventilator. Were these tragic victims dead or alive?

Unfortunately, this question could not be answered solely by physicians because it was no longer clear what their examination was supposed to measure. As my colleagues, Charles M. Culver and Bernard Gert, and I pointed out 17 years ago,<sup>4</sup> and I restated in a recent article,<sup>5</sup> an optimal analysis of the concept of death should proceed in three sequential phases: 1) identifying the definition of death to make explicit the traditional meaning of the concept of death; 2) choosing a criterion of death, a measurable general standard, that shows that the definition has been fulfilled by being both necessary and sufficient conditions for death; and 3) devising tests to show that the criterion has been satisfied with no false-positive determinations. Even many scholars who disagree with our conclusions concur with this method of analysis.

The most reasonable definition of death is “the permanent cessation of the critical functions of the organism as a whole.” Critical functions are those that are necessary for the continued health and unity of the organism, such as breathing, functional integration, homeostasis and consciousness. The criterion that is necessary and sufficient for death by this definition is “the permanent cessation of all clinical functions of the whole brain.” Because the brain stem, hypothalamus, thalamus and cerebral hemispheres subserve the functioning of the organism as a whole, critical functions of all these areas must be lost. The tests of death are those outlined in the statute in the first paragraph of this article. The specific brain tests were enumerated

recently by the American Academy of Neurology<sup>6</sup> and comprise the quartet of utter unresponsiveness, absence of the capacity to breathe (apnea), loss of brain stem reflexes, and irreversibility.

Some proponents of “brain death” oppose a whole-brain criterion and instead favor a higher-brain criterion of death. They claim that because consciousness and cognition are the unique features of human life, only their absence, and not the absence of vegetative functions such as breathing, should be necessary for death.<sup>7</sup> I oppose such a formulation because it is a contrived redefinition of death. The higher-brain formulation would declare as dead patients in a persistent vegetative state who are considered alive in every country. It would also create the disquieting situation of burying, cremating or removing organs from individuals who remain spontaneously breathing and moving. Indeed, no jurisdiction anywhere in the world is even considering such a radical change.

Most opponents to “brain death” propose a circulation formulation in its place: the human organism is not dead until its circulation ceases irreversibly. They regard “brain dead” patients as alive, though hopelessly ill. However, circulation proponents do not necessarily insist on mandatory treatment of “brain dead” patients; they merely assert that such patients are not yet dead.<sup>2,3</sup>

Of the several arguments refuting this position, the most powerful is that the brain is the central generating, regulating and integrating organ of the body and it is responsible for the unity of the organism. The brain is the critical system of the organism without which the remaining organs may continue to function independently but cannot together comprise an organism as a whole. As the critical system of the organism, the brain can neither be transplanted nor replaced with a mechanical device. When the brain is destroyed, the entropy of the organism increases inexorably because the critical system opposing entropy and subserving the functional unity of the organism as a whole is gone forever.<sup>8</sup>

There are pragmatic reasons not to abandon the dead donor rule — the axiom of multiorgan transplantation, which requires that the multiorgan donor first must be dead. Loss of public confidence in physician death determination has followed

several highly publicized cases in which the press alleged that physicians were prematurely determining death merely to procure organs for transplantation.

One proposed solution is to use non-heart-beating organ donors. For example, the “Pittsburgh” protocol allows dying patients or their surrogate decision makers to authorize organ donation immediately after life-sustaining treatment has been removed and the heart has stopped beating for a few minutes. However, I question whether non-heart beating donors are truly dead at the moment of donation because their hearts potentially could be restarted before all brain function had been lost.

Some have suggested that instead of struggling to agree upon a uniform definition of death, organ removal could be permitted in certain situations as a form of justified killing. Irrespective of the moral issues, procuring organs from people who are not yet dead constitutes poor public policy. Public confidence in death determination is precarious and can be shaken easily. As a conceptual issue and a matter of public policy, continuing to use the concept of “brain death” as the basis of human death determination, particularly to qualify as a donor for multiorgan procurement, remains both coherent conceptually and prudent pragmatically. □

<sup>1</sup> Truog RD. Is it time to abandon brain death? *Hastings Cent Rep* 1997;27(1):29–37.

<sup>2</sup> Taylor RM. Re-examining the definition and criterion of death. *Semin Neurol* 1997;17:265–270.

<sup>3</sup> Shewmon DA. Recovery from ‘brain death’: a neurologist’s apologia. *Linacre Q* 1997;64(1):30–96.

<sup>4</sup> Bernat JL, Culver CM, Gert B. On the definition and criterion of death. *Ann Intern Med* 1981;94:389–94.

<sup>5</sup> Bernat JL. A defense of the whole-brain concept of death. *Hastings Cent Rep* 1998;28(2):14–23.

<sup>6</sup> American Academy of Neurology Quality Standards Subcommittee. Practice parameters for determining brain death in adults (summary statement). *Neurology* 1995;45:1012–1014.

<sup>7</sup> Veatch RM. The impending collapse of the whole-brain definition of death. *Hastings Cent Rep* 1993;23(4):18–24.

<sup>8</sup> Korein J. Ontogenesis of the brain in the human organism: definitions of life and death of the human being and person. *Adv Bioethics* 1997;2:1–74.

Ask the ethicist:

## A lesbian couple who both want a biologic link to their offspring

**Q**uestion: Two professional women have been in a stable lesbian relationship for five years and want to have children. Neither woman has a fertility problem. Ordinarily, pregnancy would be achieved with donated sperm and insemination could be performed at home or with a simple office procedure — intrauterine insemination. In this case, however, both women want a biologic link to their offspring similar to that of heterosexual couples.

Their plan is for the oldest, who is 36, to have one of her eggs retrieved and fertilized with donor sperm by *in vitro* fertilization (IVF) to produce an embryo that would be implanted in her 35-year-old partner who would become the gestational mother. When ready for their second child, they would switch roles and the younger woman's egg would be fertilized and implanted in the other woman.

The fertility team is concerned about using the complex medical technology of donor egg and IVF with the attendant costs and risks of ovarian stimulation, anesthesia and a slightly higher chance of premature birth when there are no medical reasons for IVF. How would you advise the fertility team?

**R**esponse: Assisted reproductive technologies (ARTs) were originally developed to assist infertile married couples to have children. As their use has spread, and social practices regarding marriage and sexuality have gradually changed, a new question has emerged: Should lesbian and gay couples also be able to use assisted reproductive technologies? If the answer is “Yes,” a follow-up question surfaces: To which of the ARTs should lesbian couples have access?

Three main arguments can be given in answer to the first question concerning any use of ARTs by lesbian couples. One is that this would violate the basic goals of medicine — to heal the sick and disabled. Neither woman in this case has a physical malfunction that renders her sick or disabled; both are fertile. It could therefore be argued that to provide each with artificial

insemination by donor (AID) and egg donation would be to misuse medicine.<sup>1</sup>

Second, some maintain that giving lesbian couples access to the ARTs would be harmful to the resulting children.<sup>2</sup> These children, they hold, will have difficulty developing gender identity and sex-role behaviors. Critics further contend that they will not only have more adjustment difficulties than children born to heterosexual parents, but will be rejected and stigmatized by their peers. Some courts have denied custody of children to lesbian couples on such grounds.

Third, some would argue that giving lesbian couples access to the ARTs would have detrimental social effects, for it would weaken and ultimately destroy the role of the family in protecting basic social values. To this, others would add that such practices would lead to the objectification of children as manufactured products, the impoverishment of the meaning of procreation, and the perpetuation of degrading views of women.<sup>1</sup>

Yet the opposite answer to the initial question can also be given. Medicine is appropriately used, some argue, not only to heal those who are ill or disabled, but also to promote their well-being. Thus, we provide plastic surgery to those who are disfigured, but not sick or disabled. Similarly, some would hold, medicine is appropriately used to support the well-being of lesbian couples who desire to have children.

Further, there is some evidence that the welfare of children is not jeopardized by being brought up in a lesbian household.<sup>1,2</sup> Studies suggest that the sexual orientation of parents does not determine that of their children and that the development of children of lesbians is comparable to that of children raised in non-lesbian households.

Finally, those who would provide lesbian couples with access to the ARTs maintain that individuals should be allowed to reproduce in ways of their own choice, whether or not they are married. While a constitutional right to reproduce noncoitally, if one exists, would apply only to married couples, lesbians can also have “valid interests” in having children.<sup>3</sup> Cases

are beginning to appear in which lesbian couples have sued clinics for discrimination on the basis of marital status or sexual orientation because they have refused them AID.<sup>2,4</sup> It is not clear, however, whether any of these suits will prove successful.

As a society, we are moving toward a greater acceptance of lesbian couples and an increased willingness to use the ARTs to assist them to have children. Indeed, the American Medical Association has stated that “it is not unethical to provide artificial insemination as a reproductive option” for lesbians.<sup>5</sup> Yet some caregivers disagree and believe they should be exempt as a matter of conscience from treating lesbian women with the ARTs.

Is it right for caregivers who are not opposed to providing the ARTs to lesbian couples to offer egg donation to these two women? Each is (presumably) unwilling to engage in sexual intercourse with men and can therefore be said to have what amounts to an inability to have children coitally. Egg donation, however, is not medically necessary to achieve pregnancy in their case. Indeed, there is good reason not to add this procedure to the repertoire of treatments for these women, for it bears greater medical risks than AID to them and to the resulting children. Moreover, it has a relatively low chance of success, especially in women of their age. Much as physicians are not required to provide computerized tomography (CT) scans or brain surgery to patients who suffer from simple headaches, physicians are not required to provide egg donation to women who can conceive in a simpler and safer way.

Should an infertility specialist decide to accede to this couple's desire for egg donation, he or she should consider developing procedures designed to give them a full picture of the risks and benefits and to protect the welfare of any resulting children. The National Advisory Board on Ethics in Reproduction recommends that physicians who provide egg donation to lesbian women (whom it presumes are infertile in such instances) should carry out their usual screening procedures for donors and for recipients beforehand, and should

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## *The legal column:*

# *Confidentiality in the age of the electronic medical record*

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All states have statutes in place specifically designed to regulate and protect the confidentiality of medical records. Most states require specific legal authorization for the release of certain records, such as those concerning HIV testing<sup>1</sup> and treatment, psychiatric and psychological conditions, children's medical treatment<sup>2</sup>, child abuse<sup>3</sup>, sexually transmitted diseases and substance abuse.

Institutions and health-care providers have methods in place to protect the confidentiality of records. However, with the increasing use of the electronic medical record, new and potentially serious opportunities exist for breaches of confidentiality and consequently, exposure to litigation. In this article, we explore ways to protect the privacy and confidentiality of the electronic record in light of the potential legal ramifications that can flow from its breach. In this age of widespread computer usage, new or expanded systems are too often implemented in the interest of improving care before thought was given to the ability of the computer system to protect the information. The challenge is to maintain a reasonable balance between the patient's confidentiality rights and the needs of clinicians and others to access patient information for legitimate purposes of treatment, follow-up, billing and other functions.

The ability of an electronic medical record system to audit access to the system should be as important as any other consideration. Although the paper record does not allow such auditing, physical reality makes unauthorized access to the paper record less likely. An electronic medical record, however, allows individuals access from the relative privacy of their own office or home. Crucial elements of an effective auditing process include 1) consistent use of auditing technology, 2) notification of staff verbally, in writing and on screen of the presence of such a system, 3) signed confidentiality statements, 4) the empowerment of staff to speak up when they see behavior which puts patient confidentiality at risk, regard-

less of their place in any perceived or actual institutional hierarchy, and 5) action, including termination of employment when inappropriate access or disclosure is found.

Access to the electronic medical record should be determined by a particular individual's job description and "need to know." Because system capabilities expand over time and individual job responsibilities change, it is prudent to periodically audit the type of access given to each employee. Passwords to authorize functions are essential and should be changed with reasonable frequency. Employees should be instructed that passwords are not to be revealed to anyone. If an office or home computer needs to be left unattended after logging on to a limited-access computer function, a screen saver with a password should be used. Organizations and physician offices must have protocols, and employees with home computers must be educated about erasing hard drives when computers are discarded, sold or given away.

Violation of confidentiality statutes create absolute liability with civil penalties. Therefore, it may be advisable to create restricted access to certain types of medical records, such as records containing psychiatric or HIV/AIDS information, or the records of certain individuals such as employees, physicians, employees' family members or subjects of media scrutiny. Barriers, or "firewalls," can prevent access to certain types of information and should be used when possible. However, there is no electronic barrier to prevent an employee with access to the electronic medical record from wrongly looking up the record of a family member, celebrity, another employee or a neighbor. Therefore, education of employees is essential. They need to understand that they are authorized to access patient information only on a job-related need-to-know basis and that confidentiality is breached whenever an unauthorized individual accesses a patient's medical record.

Policies and procedures should also make clear that ancillary systems — such as those used for appointments, pharmacy, central processing, laboratory and billing — contain patient information which is equally subject to protection from unauthorized release. This includes well-intentioned access or release of any information.

A new and potentially serious problem may arise with the use of e-mail. Litigation is now being brought in a number of jurisdictions which will determine whether the use of e-mail represents a private communication with an expectation of privacy. Although this area of law is only beginning to surface, there are precedential cases which hold that cell phone or home portable phone usage does not create the same expectation of privacy that a conventional telephone does. The distinction is that these phones are considered radio transmitters with no expectation of privacy while conversations on a conventional telephone are expected to be private. There are serious concerns that e-mail may not constitute a private communication with an expectation of confidentiality. Many patients today desire to communicate with their physician via electronic mail; many do not understand the lack of privacy on the internet. From the perspective of protecting confidentiality, e-mail communication is risky. It is not wise to assume that the patient who initiates this electronic mail communication is knowingly assuming the risk of loss of confidentiality. Policy and procedure statements, discussion with the patient and a thoughtfully prepared consent form for electronic mail communication are advisable before patient information is transmitted by e-mail. The possibility of encryption should be explored. In any event, e-mail communications should not be used for communication of sensitive or specially protected information.

Breach of confidentiality can lead to litigation in civil court or to prosecution in criminal court. A patient or appropriate

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*Ethics and literature:*

## *The Mortal Presidency*

By Robert E. Gilbert

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Confronting our own mortality may jeopardize our ability to function effectively, psychologically if not physically. Arguably, those in positions of power are more susceptible, in part due to age-related infirmity and vocational pressure. Of particular concern are the potential sequelae of executive incapacity, the sphere of influence of a person in a position of power extending far past that of the average citizen. Where does the interface lie between an individual's right to privacy regarding matters of health and that same individual's obligation to those that he or she governs, if and when poor health jeopardizes their performance?

In *The Mortal Presidency*, Robert Gilbert provides us with insight into the personal and familial illness of six 20th century U.S. presidents, the consequences of which may have influenced and directed world events. He reminds us that our presidents are not invincible, eight having died while in office. Even if spared physical infirmities, many have borne the psychological wounds inflicted by the loss of children or other loved ones.

With Calvin Coolidge, the author chronicles the life of a governor, a vice-president and for a brief period, a first term president who possesses, in Gilbert's eye, energy, vision, integrity and significant political skill. His generally perceived legacy, however, is that of one of our least effective presidents, shaped by a second term of little accomplishment. Gilbert holds little doubt that Coolidge's uninterested and withdrawn behavior of 1924–28 was a direct result of the unexpected death of his son in 1924 from an infected foot wound inflicted while playing tennis on the White House lawn.

Franklin Roosevelt nearly died at birth, was sickly as an infant, and contracted poliomyelitis at age 39. Gilbert believes that Roosevelt's liberal politics — in particular, his advocacy for the physically impaired — were in part cultivated by the profound effect of his own poor health. In

his later years, Roosevelt suffered from hypertension and congestive heart failure. He was said to experience periods of inattention and confusion. He eventually died from a cerebral hemorrhage. Much has been discussed about Roosevelt's poor health and any competitive disadvantage it may have placed him in during his meeting with Churchill and Stalin in Yalta in 1945. In this case, Gilbert believes it was Stalin's mendacity rather than Roosevelt's blunted negotiating skills that led to the subsequent U.S. disadvantage in Eastern Europe.

Dwight David Eisenhower, despite his robust image as the Supreme Commander of the Allied Forces, would ultimately be afflicted by numerous illnesses including malaria, tuberculosis, Crohn's disease, a series of heart attacks, and a stroke with resulting aphasia. Paradoxically, it was Eisenhower's heart attack of 1955 that in part drove him to seek a second term of office. Originally intending to serve one term only, the boredom of his prolonged convalescence and a well developed sense of duty propelled him into the race of 1956. Conversely, Eisenhower's health may have adversely affected the candidacy of Richard Nixon, limiting his involvement in Nixon's campaign. This may well have affected the outcome of the closest election result in America's presidential history.

Though now well chronicled, John F. Kennedy's numerous illnesses, including chronic back pain and Addison's disease, were shrouded during his political life. Provocatively, Gilbert speculates that Kennedy might have survived his assassination were it not for his bad back, his back brace holding him upright for the second fatal shot instead allowing him to slump from the first bullet that he might have otherwise survived.

Lyndon Johnson's long personal and family history of illness may have made him sympathetic to the needs of the infirm, leading to his support of many legislative initiatives that benefited health care, most

notably Medicare. Unlike Eisenhower, Johnson chose to forego a second term in office for reasons that included the recognition of his own poor health.

Ronald Reagan enjoyed a period of significant popularity as our president, much of which can be linked to his survival of the assassination attempt early in his first term of office. Not only did this heroic image serve him well with the electorate, it provided him with the support in Congress necessary to ratify an aggressive and successful legislative agenda. Reagan's leadership style has been characterized as one of delegation of responsibility, at times to a fault. One cannot help but wonder how much of his reliance on others was a product of his incipient dementia, of which there were many indications prior to his retirement in 1988 — notably his vagueness during his first debate with Walter Mondale in 1984.

A recurrent theme of the book is the tendency for presidential infirmity to be minimized or covered up. Although this behavior would frequently appear to be politically motivated and promoted by advisors or family members, denial of disease may exist as pervasively in presidents as it does in anyone else. It is difficult however, to justify the withholding of information regarding presidential infirmity, if and when it compromises presidential function and national well-being. Despite our heritage of individual rights, the nation's welfare should not be jeopardized by the health and political welfare of one individual, even a president. Of particular irony is that Coolidge, a president whom Gilbert feels was rendered dysfunctional by depression during his second term, was a strong advocate of the belief that the public good supersedes that of any individual or group of individuals. During his tenure as the governor of Massachusetts, he was quoted as saying, "there is no right to strike against the public safety by anybody, anywhere, anytime." □

## Dialogue:

# Cloning Human Beings

*The following letter was written in response to both the article "Cloning Human Beings" by Dan W. Brock and to Ruth Macklin's response (Lahey Clinic Medical Ethics Newsletter, Fall 1997 and Winter 1998 respectively).*

**T**he debate on human cloning has brought to the surface a glaring deficiency of bioethics. It has few if any good methods for dealing with new and novel technologies. By that I mean those technologies where there seem to be no relevant historical precedents and where the potential benefits and harms are speculative only, not yet available for empirical testing. How might we best try to assess such technologies, and what counts as a good or bad argument for ethics and for public policy?

Macklin and Brock, for instance, both want "clear and persuasive" arguments to support a ban on cloning and "empirical evidence" of "demonstrable harms." But how could there be wholly persuasive arguments in a domain new to human history and experience? Their invocation of reproductive rights as the premise for such arguments does, as an earlier critic noted, beg the issue of whether or not that is the appropriate — much less only — starting point for argumentation.

Nor is it reasonable to insist on "empirical evidence" of benefit or harm when the scientific outcomes are still in the future and wholly speculative in nature. Such evidence could become available only when human cloning was a reality; and then it could take years or decades after that to determine whether it had been a wise move to allow the research to go forward in the first place.

Our common problem, in any case, is to know how to make a judgment now about whether the research should go forward when no such evidence is available. Brock and Macklin have not, to use their own standards, demonstrated in some universally compelling, rational way that their acceptance of human cloning under some circumstances makes good sense. They have only shown that they like

their reasons better than those of cloning opponents. Their reasons turn on their embrace of reproductive rights — surely contested terrain. Even if there is widespread acceptance of reproductive rights as a general category of rights, there is surely no agreement whatever that these rights entail a parental right to choose cloning as a means of reproduction. An independent case must be made for that entailment. The possibility of a relief of infertility is hardly sufficient for that purpose.

In their seeming inability to understand why anyone could feel repugnance at the prospect of human cloning, Macklin and Brock overlook or minimize why there was that reaction. Such cloning is perceived as a threat to individuality, a trait accorded a high status in western societies. Threats to it, even remote threats, are taken seriously, as well they should be. If we have learned anything from 20th century history, it is that dangers to individuality usually come disguised at first as progress and liberation. While sometimes excessive, even as well-meant an idea as school uniforms for children usually sets off a fierce community debate. We prize difference in people and take to the ramparts when it is threatened.

The key issue here is not, as Brock implies, genetic determinism or genetic identity but the preservation of individuality — by no means the same as genetic identity. Even so-called "identical" twins are not wholly identical genetically; that is well known. More to the point here is the issue of parents trying to use children for parental ends, procreating them with traits chosen by the parents for the purposes of the parents, not the welfare of the children. We happily accept twins when they are born, but no parents I have heard of go out of their way to procreate twins, or turn to assisted reproduction specialists to procreate twins.

If the cloned children share no other trait than simply looking like the parents (give or take minor variations), then that child's individuality will be compromised. Is it too hard to imagine that a

child might not choose to look like a parent, even if most of his other traits are different?

Analogously, don't most of us already feel repugnance at parents who excessively try to shape children to live out parental wishes, whether to follow in a parent's professional footsteps, to be pushed into professional tennis or soccer camps at an early age, or pressured academically for years in school in order eventually to gain admission to an elite college? If most of us tend not to like or approve of such conduct, why should we be expected to embrace human cloning, which raises the stakes many orders of magnitude? Arguments based on reproductive rights, it should be noted, are parent-centered and not child-centered. There is considerable interest these days in the welfare of children. Is there any evidence that what future children need is a right to be cloned, or that a world lacking in cloned children would somehow be a less worthy world?

As it happens I do not support a ban on cloning. I don't think it could be enforced. I will be satisfied if the federal government does not provide grant money for that purpose, and if most scientists, together with Ian Wilmut [who cloned the sheep Dolly], continue to feel repugnance at the idea (however badly they may articulate their reasons). As for Macklin and Brock, fine and conscientious philosophers, I would hope that they might cast a broader imaginative net as they continue to think about this problem.

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## Professors Brock and Macklin respond

**D**an Callahan takes both bioethics and us to task for having “few if any good methods for dealing with new and novel technologies.” In particular, we are chastised for wanting “clear and persuasive arguments” and “empirical evidence” of “demonstrable harms” to support a ban on cloning. He then argues that this is an impossible standard to impose on radically new technologies. He is correct, of course, that we cannot show “demonstrated” harms from an as yet undeveloped and unused technology. But this is not to say we cannot impose reasonable standards on the speculations many opponents of new technologies offer about disasters the technology will bring.

There are two aspects to reasonable standards for claims about prospective harms. One concerns a showing about the probability or likelihood that the harms will occur, the other a showing that the feared effects would indeed be serious harms. Even in the absence of experience with the new technology, we can assess the likelihood of causal relationships between the technology and the feared harm, in part by reviewing experience with similar kinds of technologies in the past. For example, in the area of new reproductive technologies we can look to experience with artificial insemination to judge the likelihood of posited harms from a related technology like oocyte, or egg, donation.

However, even if people can come to agree about the probability of such posited harms, they may still disagree about the magnitude of harm. In the case of a new technology like human cloning, it is reasonable to demand of opponents that they identify tangible and serious harms of the sort generally required to support a prohibition of research on or use of the new technology. The language of repugnance, used by Leon Kass<sup>1</sup> and apparently endorsed by Callahan, makes clear that they find human cloning deeply offensive, but it does nothing to identify the harms, much less to establish that those harms are of sufficient magnitude to support a public prohibition of human cloning. In a free society, the bur-

den of proof should be on those who wish to prohibit behavior, and mere offense to some people typically is not, nor should it be, sufficient to meet that burden.

What does Callahan offer as good reasons why human cloning should not take place? He argues that cloning would be a threat to individuality, on which our society places very high value. He takes this rather vague notion of individuality to be different from genetic identity and to be threatened even if a child should look like its father. But this is problematic at best. Even with genetic identity, phenotypic expression would be different, as would the personal history, relationships and choices of the two individuals, and all of these would be the basis for distinct individuality. In Callahan’s own example of a child cloned from the adult cells of its parent, the child would at most look like the parent looked two or more decades ago; the two would not look the same contemporaneously. Why would this seriously threaten individuality when the individuality of contemporaneous identical twins is not threatened by their looking alike? Why would it threaten individuality any more than that of a child conceived in the normal way who closely resembles a parent? This is an example of the kind of argument we were criticizing — the harm is neither sufficiently probable nor substantial to ground a legal prohibition of cloning.

But Callahan adds a second reason why cloning is repugnant: It represents the use of the child by the parents for their own ends, excessively trying to shape their children to live out parental wishes. We share Callahan’s disapproval of extreme forms of such parental behavior, but there are at least two reasons to be skeptical about the import of this disapproval for public policy about cloning.

First, if human cloning becomes possible, many uses of it would not involve these undesirable parental behaviors or attitudes. If a couple used cloning to avoid the risk of transmitting a genetic disease, or to have a biologically related child in the face of their own infertility, no such objectionable motivation would be involved.

Second, we believe that in general, public policy and the state should not be

in the business of evaluating people’s motivations in reproduction and child-rearing. To do so could invite widespread abuse and be deeply invasive of both reproductive choices and family privacy. Public policy and the law appropriately intervene only when such motivations and attitudes result in behavior seriously harmful to the child, and it is worth noting that we impose a relatively high threshold of parental autonomy before intervening in other behaviors of the sort Callahan cites.

Finally, we are surprised at Callahan’s conclusion that despite what he takes to be very strong reasons against human cloning, he does not support a ban on it because he believes it could not be enforced. Surely, a federal ban on human cloning would substantially reduce its use if and when it became possible to do it. It would not eliminate it entirely, and it could certainly go on in countries that choose not to ban it, but why should this be a reason not to support prohibition if cloning is as wrong as Callahan apparently believes? We believe our difference with cloning opponents like Callahan comes not from having failed to cast our imaginative net broadly enough, as he suggests, but from being unpersuaded by what we find in the imaginative nets of cloning’s opponents. □

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<sup>1</sup> Kass LR. The wisdom of repugnance. *The New Republic* 1997;216(22):17–26.

*Ask the ethicist (Continued from Page 3)*

also have qualified counselors discuss with them special considerations that may arise.<sup>2</sup> These could include what support system they have, what they will tell the children about their origins, and who would have custody of the resulting children should the couple separate.

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**O**utcome: The fertility team decided the risks were significant and did not honor the women's request for the use of assisted reproductive technologies. The women then chose artificial insemination. □

<sup>1</sup> Cohen, CB. Reproductive technologies: ethical issues. In, Reich W T (ed): *The Encyclopedia of Bioethics*. New York: Macmillan, 1997;4:2233-40.

<sup>2</sup> National Advisory Board on Ethics in Reproduction (NABER). Report and recommendations on oocyte donation. In, Cohen CB (ed): *New Ways of Making Babies*. Bloomington, IN: Indiana University Press, 1996:67-9.

<sup>3</sup> Robertson JA. *Children of Choice: Freedom and the New Reproductive Technologies*. Princeton, NJ: Princeton University Press, 1994:36.

<sup>4</sup> New York State Task Force on Life and the Law. *Assisted Reproductive Technologies: Analysis and Recommendations for Public Policy*. New York, NY: New York State Task Force on Life and the Law, 1998:183-7.

<sup>5</sup> American Medical Association, Council on Ethical and Judicial Affairs, Artificial insemination by an anonymous donor. *Current Opinions*, 2.05.

*The legal column (Continued from Page 4)*

surrogate can bring a civil action against the organization and the individual responsible. The Commonwealth can prosecute an individual<sup>4</sup> under a Massachusetts law that authorizes imprisonment for not more than 30 days and a fine of not more than \$1,000 for knowingly accessing a computer system without authorization, or failing to terminate access after realizing the access is not authorized. For a health-care institution, health-care provider or any employee of a health-care facility, the loss of trust and integrity which accompanies a breach of confidentiality is also a grievous penalty regardless of any civil or criminal penalty.

The realities of the electronic medical record present a multi-faceted challenge. The choice and development of hardware and software which allows effective record-keeping and access for direct and indirect care and support function, while allowing barriers and password restriction, is vital. Protection of patient confidentiality depends upon staff understanding their legal and ethical responsibilities, as well as upon excellent electronic systems and the vigilance of management and peers. □

<sup>1</sup> Massachusetts General Laws Chapter 111 Section 70F

<sup>2</sup> Massachusetts General Laws Chapter 112 Section 12F

<sup>3</sup> Massachusetts General Laws Chapter 19 C Section 5

<sup>4</sup> Massachusetts General Laws Chapter 266, Section 120F

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# Medical Ethics

The *Lahey Clinic Medical Ethics Newsletter* encourages reader participation. We welcome comments for our "Dialogue" column and invite submission of ethical dilemmas for "Ask the ethicist." Send correspondence and requests for complimentary subscriptions to David Steinberg, MD.

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