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Quote to note

"Human embryonic stem cells might generate all or most of an animal's brain, leading to the possibility of a human mind imprisoned in an animal's body."

— *The New York Times*
April 27, 2005

Inside

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Embryo Adoption

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Couples who have used in-vitro fertilization (IVF) may choose to give their no longer needed (frozen) embryos to other couples wishing to bear and raise children. The name given to this process (based on one's frame of reference and/or ideological commitments) is embryo donation, embryo adoption, embryo rescue or human embryo transfer. This practice has been around for over 20 years[1] but has only gained widespread attention recently. Why is this?

Four reasons may account in part for the current interest in embryo adoption. First, with estimates of over 400,000 embryos currently frozen in the United States and significant numbers in other countries, the question of what to do with them has become urgent.[2] Storage is an issue in terms of space and cost as well as the "shelf-life" of frozen embryos, which will become non-viable over time. Interestingly, one option, relinquishing the embryos for research, is not chosen by significant numbers of couples for psychological and moral reasons.[3] Embryo adoption offers those couples an alternative that they may find morally more palatable than donating their embryos to research.

Second, proponents of human embryonic stem cell research (which entails the destruction of embryos) argue for the moral permissibility of stem cell research on the grounds that only "excess" embryos from reproductive medicine will be used (i.e., no new embryos will be created for research purposes). Furthermore, since frozen embryos will expire eventually, using them for stem cell research is not depriving them of a better fate. Consequently, many believe the growing interest in embryo adoption is largely politically motivated by the stem cell debate.

As evidence for this claim, some bioethicists point to the Department of Health and Human Services 2001 announcement of close to one million dollars in grants for "Public Awareness Campaigns for embryo adoption."[4] These bioethicists claim that even calling the practice embryo adoption instead of donation implies that embryos are children. Elsewhere, I have argued the error of this claim.[5] Data show that couples "considering the embryo as a child choose destruction as frequently as donation but refuse experimentation on the embryo."[6]

Third, a significant number of couples with fertility problems or hereditary disorders are seeking embryo adoption.[7] Some couples are attracted by the lower costs of embryo adoption in relation to traditional IVF. [8] For example, embryo adoption programs currently list costs of $3,600 to $10,000 per cycle, regardless of outcome and not including the expenses of pregnancy and delivery. These expenses include: the identification of a match; the cost of thawing; screening and testing of donors, embryos and possibly recipients; the hormonal preparation of the prospective mother, and the embryo transfer. Costs per cycle for IVF, using fresh embryos, range from $12,000 to $20,000, also exclusive of outcome. Costs are lower for embryo adoption, because the original couple has paid for the harvesting of gametes and fertilization of the ovums. The success rate using embryo adoption is slightly less than that of IVF using fresh embryos; however, it

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currently appears comparable to IVF with one's own frozen embryos.[9]

Finally, embryo adoption is also on average less expensive than traditional newborn adoption (for example, in the US, domestic adoption fees vary from $9,000 to more than $35,000). However, each cycle of embryo adoption, just like traditional IVF, includes a greater than 60 percent chance of failure; whereas, traditional adoption fees are paid in relation to the placement of a child. Even so, embryo adoption may appeal to people in this country who have been waiting (sometimes years) to adopt newborns and has the added advantage of prospective parental control of the prenatal environment and the chance to experience the birth of the child.[10] Embryo adoption may also afford older women, who are often not chosen by birth mothers in domestic adoptions, a chance to become mothers—a practice that raises ethical considerations in itself.

Yet despite long waiting lists for embryo adoption, it is rarely done, because people with frozen embryos are reluctant to donate. The most common reasons given are: having unknown children, the possibility of sibling marriage and legal ramifications.[11] Some studies identified willingness to donate "was associated with greater comfort about disclosing personal information, a desire to know the outcome of donation and willingness to have future contact with a child, but not with current family size."[12] Seventy-six percent of fertility clinics do not allow donors any control over who receives their embryos and further stipulate anonymous donation with no knowledge of outcome.[13]

In my view, embryo adoption is conceptually different than gamete donation, with which it is often compared. With embryo adoption, couples view the embryos as their once possible and perhaps future children. Decisions about giving the embryos to others more closely resemble adoption decisions than decisions about "donating" sperm or egg.[14] Fertility centers ought to change their policies concerning donating couples' choices to better respect the reality of this activity, to respect couples' views and finally to increase the supply of embryos available for embryo adoption. Some agencies, like Snowflakes, and clinics, like the National Embryo Donation Center, in fact, have policies that allow for greater choice of involvement for couples with embryos.

Other ethical issues raised by embryo adoption have been raised by other forms of assisted reproductive technology and by traditional infant adoption. These include: permissibility of the practice; payment for the embryos; who decides which embryos are given to which couples and on what basis; screening of donors, embryos and recipients; genetic disclosure to recipient couples; privacy and disclosure to children; anonymous record-keeping, and future relationships between genetic and rearing families.

Consensus seems to exist for one of these issues—the impermissibility of paying the donor couple for the embryo itself (though reimbursement for some specific expenses is permissible).[15] This is based on views about gift giving, solidarity and the risk of commodification of human life. The policy is consonant with other practices in medicine, such as forbidding payment for organs and for babies.

Some major religious traditions have difficulties with the permissibility of embryo adoption, even those most associated with pro-life positions. For example, controversy regarding embryo adoption exists among scholars who accept Roman Catholic official teachings. Arguments in favor of it include the appeal to rescuing innocent human lives, for embryos are viewed as persons with inherent dignity. Arguments against embryo adoption hold that condoning embryo adoption is not acceptable, because it is too closely associated with practices considered inherently immoral, such as IVF and the freezing of embryos. Reasons of this type do not seem particularly persuasive since traditional adoption is not denounced as condoning acts (i.e., extra-marital intercourse) that have, in most cases, led to the availability of children for adoption.

A second type of argument against embryo adoption from Catholic scholars is that the ends do not justify the means. It is wrong for a woman to intentionally become pregnant with a child that is not the fruit of marital intercourse. Just as surrogacy and the use of donor gametes is impermissible, so is embryo adoption, despite the seemingly "good" intentions in this case. This set of arguments is currently at the heart of the debate among Catholic scholars. [16]

A separate set of ethical issues arises once embryo adoption successfully has been accomplished. I will discuss just one of these here—parental privacy. With embryo adoption, no one, including the child, will know that a baby born into a family is not genetically related to that family, unless the couple chooses to share that information. I hold that children's best interests are served by knowing about their origins as early as possible. Counter-arguments about the privacy of the couples, the liberty of parents to decide for children and the privacy of the genetic parents are weaker claims. Moreover, secrets of this magnitude, if discovered, are usually very damaging to the parent-child relationship and will be more difficult to keep as genetic testing becomes more comprehensive and routine.[17] The obligation of parents to inform their children about the use of embryo adoption is founded on philosophical views about the rights of individuals and the obligations of the parents. It is also based, in part, on outcome data from the literature on traditional adoption concerning disclosure to children. Telling those other than their children entails different considerations, including that of the children's privacy. Centers and agencies offering embryo adoption should counsel, if not require, couples to agree to disclose the use of embryo adoption to their future children. □

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Ask the ethicist:

When is resuscitation not medically indicated?

Question: A 64-year-old Portuguese-speaking woman was admitted for dehydration, exhaustion and delirium. She had undergone surgery, chemotherapy and radiotherapy for colon cancer but had developed rapidly progressing metastatic liver disease. On her last oncology visit a decision was made to stop further chemotherapy and enlist hospice for end-of-life care.

She had immigrated to the United States 20 years ago. She had worked in the domestic service of a local hotel, lived alone, never married and had no children, siblings or other family living in the United States. Her English was poor.

Her neighbors knew she was feeling poorly, so they checked on her and found her unconscious on the floor. She was taken to the ER by ambulance. There were no signs of trauma but she was somnolent, dehydrated and jaundiced.

Despite hydration, she remained somnolent, unable to speak and developed irregular breathing. Physicians caring for her did not know her wishes regarding resuscitation, and there was no record of a health care proxy. They contacted her oncologist, who confirmed the advanced stage of her metastatic disease and the lack of any treatment, but he did not know her wishes regarding end-of-life care. She was clearly dying, but her medical team was unsure about what to do when she stopped breathing. An ethics consultation was requested.

Response: The most striking aspect of this consultation was the genuine uncertainty about what to do on the part of her caretakers. They felt obligated to resuscitate her even though they knew it was medically inappropriate. She was dying from a disease for which there was no further treatment, and resuscitation would be traumatic and not accomplish any worthwhile goal.

Resuscitation seems different from all other medical treatments, because it usually requires an order *not* to do it. In this case, for instance, there was no requirement to order no further chemotherapy even though that decision had been made. Her caregivers had the impression that in the absence of a DNR order, they were obligated to perform cardiopulmonary resuscitation (CPR), yet clearly the best medical care was to ensure a comfortable and peaceful death.

The caregivers' genuine uncertainty reflects progress in making patient-centered care and shared decision-making a reality.[1] Physicians and nurses a few decades ago would not have been puzzled about what to do: even though CPR was available, it was simply not performed in this situation. There was no need to inquire about a patient's preference or seek a surrogate's substituted judgment. Sometimes this plan was indicated by writing an order for a "slow code" or to "Page House Officer in the Case of Cardiopulmonary Arrest." This course of action is no longer acceptable.[2]

An ethics consultation can accomplish four goals in this situation. First, the consultant can review and help confirm the validity of the supposed facts: untreatable, advanced metastatic cancer, no prior discussion of resuscitation preference and no surrogate. This goal was accomplished by assuring that the oncology team had been contacted and verified the underlying facts.

Second, the consultant can review the options and goals of treatment. This patient was clearly dying and in this circumstance with advanced cancer, resuscitation is virtually certain to fail and hence is futile. The outcomes of resuscitation for the past year at this hospital recently had been reviewed. The overall survival to discharge was 50 percent, but there were major differences depending on the patient's condition and location in the hospital. More than 80 percent of cardiac surgical patients survived to discharge, but none of the 10 patients resuscitated on the oncology service survived. These differences are consistent with other reports and confirm the futility of CPR for this patient.[3]

Third, the ethics consultant can review with caregivers the hospital policy on resuscitation. The hospital's policy required discussion before writing a DNR order but did not require resuscitation simply because a DNR order was lacking. Thus there was no medical, legal or hospital policy requirement to resuscitate her. A consensus statement by experts in CPR further clarifies this situation; they agreed resuscitation should be performed unless one of three circumstances exists: the person is already dead, there is a DNR order or resuscitation is not medically indicated.[4] Our patient clearly falls in this last category.

A fourth goal of the ethics consultant is to bring this case to the attention of the ethics committee or body responsible for writing hospital policies, because revising the policy would help clarify what to do in these circumstances in the future. The policy was changed to explicitly state that when resuscitation is not medically indicated and it is impossible to discuss preferences with the patient or a surrogate, then resuscitation does not have to be performed. This makes it clear that resuscitation is similar to other medical interventions, but at the same time makes it important to discuss whenever possible.

This consultation also illustrated the need to discuss end-of-life care preferences with patients when they have decisional capacity. Some oncologists and physicians make these discussions routinely, while others find it difficult either because it takes away hope or takes too much time. In this case it was even more complicated because of the language barrier (interpreters are helpful, but the discussion is still difficult because of all the implicit meanings) and the presumed lack of a surrogate. Some have urged naming it an order to "Allow Natural Death" (AND) rather than DNR in these circumstances to avoid the negative connotation of giving up hope.[5] Enlisting the aid of trained nurses, social workers or others may help physicians accomplish this important goal.

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Outcome: The patient expired comfortably, approximately one hour after the consultation was called, in the presence of caregivers and the ethics consultant. No code was called. □

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The legal column:

Maternal infanticide and the insanity defense

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In June 2001, the public was riveted by the news that Andrea Yates had drowned her five children in the bathtub of her Houston, Texas, home.[1–4] Mrs. Yates, an exemplary nurse and mother, was an honor student, a jogger and a champion swimmer. She also had a history of mood swings. Andrea Yates was persistently pregnant or lactating from 1994 to 2001 and spiraled down into mental illness with the birth of each child. Mood states of high energy and a hyper-religious focus on Satan switched to worsening depression, psychosis, suicide attempts and four psychiatric hospitalizations in the years preceding the tragedy of the Yates children.[5–6]

Mrs. Yates's fluctuating affect and disorganized, labile clinical picture lend support to the contemporary theory that women with postpartum psychosis have an underlying bipolar disorder diathesis.[7]

In the weeks before the tragedy, Mrs. Yates claimed she was directed by Satan to kill her children to save them from the fires of hell. Both the state and the defense agreed that she was floridly psychotic at the time of the crime.

Mrs. Yates was charged with capital murder with a possible penalty of death. After only three and one-half hours, the jury returned a guilty verdict. The prosecution sought the death penalty; the jury elected a prison sentence for life.[3]

The United Kingdom and 29 other European countries have laws that make infanticide a less severe crime with mandated sentences of probation and psychiatric treatment for mentally ill women who are found guilty. In contrast, in the United States, a woman convicted of infanticide may face a long prison sentence or even the death penalty. And yet, the prevalence of infanticide in countries where treatment is mandated is no different than that in countries where punishment is mandated.[8] If the purpose of punishment is deterrence, then it is not working.

In Texas, the M'Naghten Test, or the "right and wrong test," is used to determine the legal state of insanity.[9] Derived from a landmark 1843 English case, it focuses on the cognitive aspects of behavior.

The M'Naghton formulation has inherent problems. The role of the expert psychiatric witness is to opine whether the mentally ill defendant "knew right from wrong" at the time of the crime. Cognitive capacity during most psychotic states remains unclear. The contemporary literature is filled with ongoing clinical research that queries the effect of psychoses on executive function, memory, cognitive capacity and attention. In fact, Wisner's group, using objective neuropsychiatric testing, demonstrated cognitive impairment in women with childbearing-associated psychosis compared to those with non-childbearing psychosis.[10–11] This places into question the appropriateness of using a law based on cognition.

In light of 21st century neuroscience, it is questionable that a 160-year-old legal case can be applied for accurate determination of the state of insanity. Yet, we in psychiatry continue fruitless attempts to adapt our contemporary scientific knowledge to antiquated legislation. We endeavor to fit our current "square peg" into the obsolete "round hole" of the law.[1]

Andrea Yates pled innocent by reason of insanity to capital murder. But the prosecution's expert asserted that she knew right from wrong at the time of the killings, because she knew Satan, who urged her to drown her children, only encourages evil.[5]

Such psychiatric testimony made the difference between this case and that of another mother who killed her children in Tyler, Texas.[12] In 2002, Deanna Laney killed two of her children and tried to kill a third by bashing them with rocks because, she said, God ordered it. Andrea Yates and Deanna Laney both were loving mothers whose severe mental illness led them to kill their children. While Andrea Yates was found not legally insane, guilty of murder and sentenced to life imprisonment, Deanna Laney was acquitted by reason of insanity and remanded to a psychiatric facility.

The outcome and the difference in the expert testimony suggest that we can distinguish right from wrong based on the nature of the perceived authority directing one's actions. Defendants with mental illness who face the criminal justice system have the right to a defense based on scientific fact, not whether God or Satan is a more appropriate moral authority. Such a defense is essential for equal representation under the law.[1]

The fact that the insanity defense is nonexistent in some states and extremely limited in others speaks to our society's disregard for equal protection under the law for persons with mental illness.[1] Until persons with mental illness are afforded the same legal and moral dignity given to other illnesses, the course will remain unchanged. □

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Abu Ghraib and Guantanamo: medical professionalism, dual loyalty and human rights

This article was adapted from the transcript of a forum presented by the Harvard Medical School, Division of Medical Ethics, in March 2005. The forum was moderated by Mildred Z. Solomon, EdD, Associate Clinical Professor of Social Medicine, Medical Ethics and Anaesthesia, who is Director of Clinical Research for the Division of Medical Ethics and Director of the HMS Fellowship in Medical Ethics. Panelists included Steven Miles, MD, Professor of Medicine at the Center for Bioethics at the University of Minnesota Medical School; Leonard Rubenstein, JD, Executive Director of Physicians for Human Rights; and Robert Jay Lifton, MD, Lecturer in Psychiatry, Harvard Medical School/Cambridge Health Alliance and Distinguished Professor Emeritus of Psychiatry and Psychology, City University of New York.

Mildred Solomon: In May 2004, photographs taken at the Abu Ghraib Prison revealed shameful abuses of prisoners and tarnished the image of the United States worldwide. Subsequently, it became apparent that military medical personnel had been complicit with these behaviors. Although these revelations are deeply disturbing, they are not unique events. Medical professionals often find themselves in circumstances of "dual loyalty," where they must choose between responsibility for individuals in need of care and demands placed upon them by the state or another entity.

With Abu Ghraib and Guantanamo as case examples, this forum explores the problem of "dual loyalty" and its implications for medical professionalism and human rights. Our panelists will address three questions: How were military medical professionals involved at Abu Ghraib and Guantanamo? What guidelines currently exist to guide health care professionals when they are in situations of dual loyalty? What makes it difficult for individual physicians and health care providers to abide by such guidelines?

Steven Miles: The information I am going to share with you is based on approximately 14,000 pages of government documents, including Congressional testimony and military investigations which became public, thanks to a Freedom of Information lawsuit filed by the American Civil Liberties Union and other organizations. These reports and investigations show how military medical professionals acted in ways that are prohibited by the Geneva Conventions and violated medical codes of professional conduct.[1–2]

The Geneva Conventions prohibit violence to life and person, murder, mutilation, cruel treatment and torture, outrages upon personal dignity, humiliation and degrading treatment at any time and any place. Coercion may not be used to secure any information. Prisoners of war who refuse to answer may not be threatened, insulted or exposed to any unpleasant or disadvantageous treatment of any kind.[3–4]

The "counter-resistance" techniques employed by the guards at Abu Ghraib and Guantanamo included the use of dogs, nudity, stress positions, exposure to heat and cold, and isolation. These coercive techniques are all disallowed by Geneva. The guards' behavior may be directly traced to the policies of senior US officials. The founding Presidential Directive says, "As a matter of policy, the United States Armed Forces shall continue to treat detainees humanely and, to the extent appropriate and consistent with military necessity, in a manner consistent with the principles of Geneva."[5] The operative phrase here is "to the extent appropriate and consistent with military necessity," which creates the loophole the Administration was seeking. The Secretary of Defense essentially took this language, and it flowed down the chain of command to guide behavior at Guantanamo and then in Iraq and presumably in Afghanistan.

The Geneva Conventions also say that the detaining authority has to provide adequate medical care and sanitation services for detainees and must maintain adequate records. The Army Inspector General's own investigation[6–7] found that authorities at detention centers throughout Iraq failed to insure proper treatment of persons with disabilities, injuries and illnesses. Food was poor, and in some instances debasing, including for example, the provision of jambalaya to Islamic prisoners. There were no monthly health inspections, no weights were measured to assess whether diets were adequate. There were no TB screenings, even though active cases were discovered. In Iraq and Afghanistan, the military often failed to create internment cards, which are medical records that both protect detainees' health and serve as a method of accountability in subsequent investigations of abuse. Families were not notified of the fact that a loved one was incarcerated. Families were not told if their loved one had been transferred to another medical facility, nor, if someone died, what had happened to the remains.

Department of Defense policy also actively involved medical personnel in designing and supervising coercive interrogations. Secretary of Defense Rumsfeld and Abu Ghraib policy called for medical clearance of wounded or medically burdened detainees prior to interrogation and medical supervision of coercive "diet manipulations" and "sleep management." In addition, clinicians who were treating prisoners shared medical information about the detainee with military intelligence, so that presumably physically coercive interrogations could be tailored to that individuals' psychosocial and medical assessment. Such complicity violates principles established in numerous medical ethics codes and international treaties.[8–10]

When injuries were noted, physicians often failed to investigate or report their true cause. Sometimes physicians and nurses failed to sign their notes, so that when criminal investigators went back to evaluate a torture-related injury, they were not able to identify the clinician who had seen the patient.

Physicians collaborated in completing and releasing false, delayed and misleading death certificates. Death certificates fail to give detainee identification numbers, city locations, the institution where death occurred or the deceased's age. Major findings and circumstances of death are missing from many death certificates. The autopsy records and photographs are classified. Next of kin are not

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listed, although such data are easily obtainable upon admission. Failure to note next of kin was part of a system of not notifying families that loved ones had died. The dates and signatures of many death certificates suggest that they were prepared as a batch for a military press conference rather than as part of an orderly forensic investigation.

Finally, there was wholesale failure to report injuries due to torture. Even though these abuses did not become public until mid-2004, they had been going on since 2002. They were well known to human rights organizations, yet I cannot find a single report by any military medical professional protesting these events, prior to the mid-2004 public controversy.

Leonard Rubenstein: The problems raised for military physicians at Abu Ghraib and elsewhere concern the problem of dual loyalty. Dual loyalty means that there is a role conflict between a physician's obligations to the patient and an obligation to some third party, usually the state. The third party could be an employer, a health plan or some other entity. Clinicians sometimes experience this conflict when managed care organizations restrict the kind of care they can offer. Problems of dual loyalty are especially vexing when it is the state making the demand for adherence to its objectives and providing external pressure to accomplish them.

Dual loyalty is not always prohibited or a violation of ethical obligations. Under certain circumstances, it can serve a legitimate social purpose. That's the problem with dual loyalty: It's not simple. In the case of a patient who threatens to harm a third party or where the clinician suspects a patient is engaging in child abuse, the obligation to report supersedes the obligation of confidentiality. Why? Because there is a strong social interest in protecting innocent people from harm, even if it results in harm, even incarceration, to the patient. In these instances, there's a clear and legitimate social interest that overrides a physician's loyalty to his or her patient.

The problem is not that dual loyalty exists. The problem is that legitimate and illegitimate social interests are not distinguished from one another in any cohesive, rigorous or consistent way.

The most serious dual loyalty conflicts are ones that lead to violations of human rights and involve health professional complicity in those violations. So the bright line is this: If the social purpose involves using the medical role to further a violation of someone's human rights, the physician should not yield to the state's interests.

There are many kinds of inappropriate conduct where the health professional becomes an instrument or facilitor of a violation of the human rights of an individual in one's care, and physicians often find themselves in these situations. I will describe four.

Pressure to compromise one's medical judgment. In Turkey, in Mexico and in many other parts of the world, doctors who examine detainees are under very severe pressure from authorities not to record medical evidence of torture in the medical record. So they don't do it; they just leave it out.

Imposition of medical procedures to serve state interests. Sometimes, and this is more common than you might think, medical procedures are imposed on people solely to serve state or social interest, not patient interest. For example, health professionals have become involved in imposing punishments. In Iraq, under Saddam, physicians amputed the ears of political prisoners; in the United States, physicians have performed lethal injections. Elsewhere, physicians perform forced sterilizations or engage in "virginity examinations."

Lower quality of care. Sometimes, a segment of the population consistently and systematically receives lower quality of care than that available to other groups within the same society. In apartheid-era South Africa, blacks were explicitly given less care than whites, and physicians participated in those lower standards of care, adopted and abided by them.

Formal and informal gag rules. Medical professionals are sometimes prohibited by law, or hindered by culture or the pressures of the social setting, from providing necessary information, essential for supporting a person's health. The most common example is the denial of information to women about reproductive health. In other cases, physicians are asked not to report injuries or not to document the cause of injuries.

All four of these dual loyalty circumstances involve *violations of human rights*, and that is why they are unacceptable.

Part of the problem in trying to sort out where social interests are legitimate—and thus can result in a compromise of loyalty to the patient—and when they are not derives from the traditional ethical framework that has been used to guide the professional behavior of physicians and other health care providers. Typically, clinicians are taught to balance four competing principles (beneficence, non-maleficence, autonomy and justice) in order to figure out how best to handle the ethical dilemmas they face. Yet, these four principles rarely consider conflicts with the state or potential human rights violations.

There are also process concerns with the traditional approach. Consider the situation of health professionals being asked to advise interrogators about a person's medical condition for the purpose of interrogation. These interrogations aim, presumably, to stop terrorism. Even putting aside the question of whether a health professional should ever aid a particular interrogation, how is a clinician supposed to have the competence to know whether the information needed is so important as to warrant a breach of confidentiality?

We can resolve these problems through a human rights framework, based on international humanitarian law, as articulated in the Geneva Conventions, as well as on human rights law. We take it as a given that physicians and other health personnel should not be instruments of human rights violations. Moreover, in cases where human rights may be at stake, clinicians should not attempt to evaluate the strength of the social purpose or try to balance competing obligations, as one would in a clinical case. The default position should be loyalty to the patient. Clinicians have neither the information nor the competence to assess the legitimacy or relative weight of the state's demands. Only a competent standard-setting body, which can also take into account the human rights at stake, should authorize a departure from loyalty to the patient.

Ethical requirements alone, moreover, won't assure that health professionals avoid complicity in human rights violations. We need to build mechanisms that protect clinicians from the pressures the state places on them.

The International Dual Loyalty Working Group, jointly convened by Physicians for Human Rights and the University of Cape Town in South Africa, developed both general guidelines and ones tailored to five particularly vexing areas: prisons, the military, refugees, forensic evaluations and the workplace.[11]

The guidelines call for training health care professionals in human rights and for developing the skills necessary for recognizing situations of dual loyalty. Instead of asking the individual clinician to make his or her own assessment as to whether state inter-

ests should supercede loyalty to the patient, there should be a standard-setting authority competent to define human rights obligations. Any deviations of loyalty to the patient should also be disclosed.

The proposed military guidelines start with the premise that a military doctor is a doctor first. Military physicians should follow civilian medical ethics, including confidentiality, and shouldn't participate in torture or cruel, inhuman or degrading treatment. Violations must be reported.

To support health professionals in these situations, we recommend appeals mechanisms and protective mechanisms for clinicians who speak up against abuse.

It's not that health care professionals can never play any role in advising military personnel about the process of interrogation. Some methods of interrogations do not violate human rights or result in harm to the person. For example, psychologists could contribute to the design of non-coercive techniques to encourage cooperation. But even in that role, the question is who decides. The Working Group's position is that these decisions should not be left to individual clinicians nor should the command authority make them. There should be a special military ethics commission, which is an independent third party that can develop the necessary competence for assessing the competing demands and determine the human rights at stake.

It is not easy. We need clarity about the roles and responsibilities of people in different positions; we need reporting relationships that deny command authority to interrogators, custodians and base commanders; we need an independent source of authority for ethical guidance, and we need protection of independent professional judgment. That way we can avoid medical complicity.

Mildred Solomon: Our next speaker is best known for his work on Nazi medicine.[12] However, we did not invite Professor Lifton because the actions of US military physicians are in any way equivalent to the actions of Nazi physicians. None of us, including Dr. Lifton, believe that to be the case. Rather, Professor Lifton's research on the very extremity of Nazi doctors' violations can help shed light on less extreme violations, which are nonetheless troubling.

Robert Jay Lifton: As physicians, we are heirs to shamans and witch doctors, and we still carry about us something of an aura of magic, omnipotence and power over life and death. We can be seen as gatekeepers to the other side, so to speak, and that can create a temptation on the part of demagogic groups to utilize this magic or omnipotence. It can also create a temptation within ourselves to be so used.

There is plenty of evidence of a perverse tradition of medical misbehavior. We see this in physicians serving as torturers in Chile, Soviet psychiatrists incarcerating political dissidents in mental hospitals and idealistic American physicians involved in cultic behavior, including mass killing by The People's Temple in Guyana. This perverse tradition, the reversal from healer to killer, is also evident in the roles that physicians played in the fanatical Japanese cult Aum Shinrikyo, which released sarin gas into the Tokyo subways in 1995. And physicians associated with the CIA were involved in harmful, sometimes fatal experiments, with drugs and mind control. Physicians are capable of these things, often for ostensibly patriotic or spiritual or idealistic reasons.

They may come to this misbehavior because they find themselves in what I have called atrocity-producing situations.[13] An atrocity-producing situation is one in which ordinary people become capable of committing atrocities. These situations are structured militarily and psychologically to evoke that kind of behavior in people socialized to those groups. In Vietnam, atrocity-producing situations were created first by military policies, such as "free-fire zones," where soldiers were encouraged to fire at anything, and "body counts" as a means of gauging success; and then by soldiers' experience of angry grief in response to buddies killed. In Iraq, the military environment is different from that of Vietnam, but there are certain parallels. There is a counter-insurgency war on alien terrain with considerable hostility from much of the population, which is non-white, and the enemy is difficult to find or track down. The situation is highly dangerous. There is also an exaggerated focus on interrogation in order to uncover the enemy or perhaps other secrets, including hidden weapons that haven't been found.

At Abu Ghraib these conditions created a three-tiered dynamic. At the lowest tier are the foot soldiers, the MPs and civilian contractors who did the dirty work and whom you see in the photographs. At the next tier are the intelligence personnel and officers who organized and conducted the interrogations, and the medics, doctors and nurses who became involved. At the third and highest tier are the war planners, who created the policies and who were ultimately responsible for the events.

The group pressure can be overwhelming and extremely difficult to resist, and the very presence of physicians or psychologists tends to legitimate such situations. Physician involvement brings the trappings and symbolic power of medicine to a criminal event, making it easier for people to accept.

There also is the special matter of being a military doctor. Years ago, when I was an Air Force physician assigned to Japan and Korea, I had to decide whether or not men I examined were sick enough to be sent to the rear for psychiatric treatment and sent home eventually, or whether they should be required to go back to duty. I could feel the conflict between my medical self, which felt a given man needed more treatment, and my military self, which felt the pressures of command to keep people at duty.

I had another experience in working with Vietnam veterans in the early 1970s, when they expressed considerable antagonism toward chaplains and "shrinks," as they put it. They explained that they would often find themselves feeling extreme anxiety and revulsion in connection with the atrocity-producing situation of the Vietnam War. They would seek out either a chaplain or a psychiatrist, only to discover that he or his assistant would try to help them to be strong enough to return to duty. The vets felt that the very people who, by virtue of their professional commitments, should be providing spiritual or psychological support, were actually serving to undermine their own resistance to bad behavior. The authority figures were sabotaging what these soldiers saw as finest in their own sensibilities.

A person in an atrocity-producing situation is responsible for what he or she does, but one also wants to look at the psychological and historical conditions that are conducive to violations of this kind. The Nazis "nazified" German medicine through an explicit process they called *Gleichschaltung*, or "regearing" of the profession. First physicians-in-training were socialized to medicine, a profound transformation in itself; then the Nazis socialized these physicians to the military and ultimately to the death camps.

Once the physician is in one of these extreme, isolated, atrocity-producing environments, other mechanisms help to complete the transformation from healer to killer. One mechanism is something I call doubling, or the formation of what is func-

***Abu Ghraib** — continued on page 8*

Abu Ghraib — continued from page 7

tionally a second self. Nazi doctors involved themselves in Auschwitz in the killing process from 9 to 5, five or six days a week, and then would go home to Germany over the weekends and be ordinary fathers and husbands. The self can do that; it can split off in that way. Doubling is a form of dissociation, which can be a way of adapting to evil or destructive behavior.

In fact, one of the defenses for doctors being involved with interrogators has been that they were not functioning as doctors therapeutically. This stance is an invitation to doubling. It's wrong, of course, because they were physicians and that is why they were asked to do this specialized work. Other forms of dissociation include psychic numbing and a diminished capacity to feel. There can be a lot of dissociation, numbing and doubling, in environments like Abu Ghraib.

Discussion

Question: One might argue that there was a moral impulse behind the military's desire to involve medical personnel. Such reasoning would rely on a principle of harm reduction, arguing that the presence or involvement of physicians might make these situations less bad. Perhaps the panelists have been making a professional integrity argument, saying physicians' hands shouldn't get dirty. Yet, there might be a consequentialist argument that the presence of physicians reduces the harm to detainees.

Leonard Rubenstein: The argument has been made frequently that the physician can ameliorate the harm to an individual during interrogation. One way, people suppose, is that the clinician's very presence may act as a constraint. Another is by saying "Stop, you're going too far." However, the track record is quite different, because the flip side is that the health care professional's presence legitimates the use of coercion and encourages the interrogator to go as far as possible. For that reason, most ethical authorities have condemned all forms of medical participation in coercive interrogation.

Mildred Solomon: There is also evidence that coercive and degrading treatment yields exceedingly unreliable data. The way to unnerve a detainee is to surprise them with the humanity of the detaining authorities. This creates cognitive dissonance and calls into question the belief structures that many detainees hold with respect to the United States. Developing alignment over time is likely to yield better information than torture or abuse.

Question: We've talked a lot about the importance of individuals resisting inappropriate behavior. What about medical societies and professional organizations?

Steven Miles: When organized medicine acts as part of a global community, the result can be very effective. For example, a South African medical society had not signed the Tokyo accord and did not have a position on professional sanctions against physicians who participated in torture. They were a sister society of the American College of Physicians, and when they came to the annual ACOP meeting in California, they were challenged. As a result, they immediately endorsed the Tokyo convention and then proceeded to "out" the physicians who were collaborating with the security police in concealing torture.

Leonard Rubenstein: Professional societies are important, but individual doctors acting as part of a social movement can be very effective as well. For example, politicians really listen to physicians, and we like to bring members of the medical community to meetings with members of Congress. We are planning to mobilize people, and we hope physicians will play a leadership role in this campaign.[14]

Question: I am interested in dual loyalty outside the military context in more every day circumstances, when physicians are pressured to do things by their employers or simply by dint of exhaustion and overwork. I often see clinicians acting as though they are numb to the suffering around them.

Robert Jay Lifton: Selective professional numbing is sometimes necessary. A surgeon can't afford to experience the full emotions of a family member. There is always a struggle that we have as physicians between feeling and not feeling. Often, unfortunately, we allow ourselves to go too far toward numbing or not feeling. We can be blinded by the fact that we identify ourselves as healers. We are healers, and we should identify ourselves this way, but it doesn't mean that everything we do has a healing effect. We have to look at the institutions we are serving. We have to ask: What is the nature of the project of which we are a part? □

[1]Miles, S. Abu Ghraib: Its legacy for military medicine. *Lancet.* 2004; 364:725–29.

[2]See American Civil Liberties Union website: www.aclu.org.

[3]Geneva Convention relative to the Treatment of Prisoners of War (also known as the Third Geneva Convention). http://www.hri.ca/uninfo/treaties/92.shtml.

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[10]See American Civil Liberties Union website: www.aclu.org

[11]International Dual Loyalty Group. Op cit., 2002

[12]Lifton, RJ. *The Nazi Doctors: Medical Killing and the Psychology of Genocide.* New York: Basic Books, 1986.

[13]Lifton, RJ. Doctors and torture. *New England Journal of Medicine.* 2004; 351(5):415–16.

[14]See Physicians for Human Rights website: www.phrusa.org

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Ethics and the humanities:

"Foolsbus" in American Spectacles and Other Cultivated Illusions

Stories by Deborah Shai
(New Haven Press, 1993)

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Caring for a severely disabled family member, whether physically or mentally compromised, can be, as the cliché goes, a full-time job. One's identity as spouse, child or parent may be subsumed by the role of caregiver. Thorny but inevitable questions—ethical and practical—arise: How to meet the daily challenges and stresses and manage the guilt provoked by fantasies of alternatives—nursing homes, institutions or even death? Not least, is there any hope of tapping into the unspoken wishes and motives of the severely disabled?

Deborah Shai's 112-page novella "Foolsbus," in *American Spectacles and Other Cultivated Illusions*, portrays one caregiver's experience in confronting these questions. The story takes place over a day in the life of Arthur Cormorant, a divorced literature professor, who lives with his fifteen-year old mentally retarded son Mark, and Mark's younger sister. Cormorant awakens during the night, looks in on Mark and is overcome with a desire to kill him, followed, just as suddenly, by a surge of love. Unable to bear these conflicting feelings, he descends to his basement printing press to rewrite his reality. But "Cormorant barely reads the words he's written":

> "It's the print that counts… The words and spaces on the page [are a] design that creates order and tempers a painful reality… with a press you can create something that never existed. Or annihilate something that did."

Cormorant is awakened a second time by a strange laugh that grows louder and louder. Then the stench hits him. Mark has rubbed excrement everywhere, in his ears, on his face, in his pubic hair and, to Cormorant's horror, he is eating it.

Cormorant copes by detaching himself from the scene, mechanically cleaning his son and the room. There is no acknowledgment of the accident, no kiss, no calming words, just scrubbing. Later, in a metaphorical scrubbing, he again goes "underground, to breathe ink, to revise what happened" into a story about a boy who can only whistle and because the sound of the whistle is pure, he is saved by God. But this time, the "beautiful story" fails to transform reality. Cormorant realizes that he's turned to his press "to keep himself sane" in the face of caring for Mark. Any true liberation depends on his son's death.

A telephone call from Mark's school principal the next morning brings news of a seizure. Mark is in the hospital. Cormorant is convinced "with a leaden relief" that this is the end. Blinking back tears of joy, he produces two versions of Mark's tombstone and selects the seemingly more acceptable one: "Only Son, /the yearning of my heart/to the end of my days." He discards the one that is truthful:

> "Gift of injured love, love's injured gift, I couldn't return you/And I couldn't discard you/The ache, /the shame, /the anger, /the guilt, /the love/I feel for you/will burden me/forever."

In Chekhov's story "Heartache," the driver of a horse-drawn carriage searches futilely for a listener with whom to share his dreadful tale of the sudden death of his son. Ultimately, he settles for his horse. In a similar compulsion toward catharsis, Cormorant recounts the story of the excrement to a parade of people—among them, a bartender, Cormorant's officemate, a blind man in a drugstore, a girl blaring loud music in her car. The reactions range from anger to disbelief to indifference to laughter.

At the hospital, Cormorant wanders into a medical museum, where the curator shows off a series of deformed fetuses floating in glass jars. Most of these "monsters" were strangled or smothered at birth, the old man tells him, adding, "If you'd had a little boy like that, wouldn't you do it?" Cormorant, who just hours before wished for the death of his own "deformed" son, is sickened by the thought. It dawns on him that people who look or act different are still human beings.

Later, Cormorant observes Mark newly bathed in a white hospital gown and senses "a current of intimacy" between Mark and his nurse that locks him out. For the first time, he sees his son as a male with sexual desires. Cormorant views Mark not as a creature whose behavior he can artificially revise into some form he can endure, but as separate and human.

A hospital social worker furthers Cormorant's evolution. Through her, he sees that Mark is not, as he puts it to her, "a barely human idiot," but someone trying to say something, even through a repellent act. It hits Cormorant that Mark's strange habits, utterances and outbursts are an effort to communicate, and later, in a lovely moment of insight, he sees the world from Mark's perspective:

> "Puzzled by this world of little boxes, boxes on wheels and fixed boxes…the changing chorus of voices…the voices in the home box, big lady voice that went away, nice voice, old man voice, always there voice, scratchy and deep, often kind, sometimes angry (but don't know why)…"

It seems unimaginably difficult for a caregiver to step outside of the mundane "meaningless things"—the dressing, eating, toileting and cleaning that sum up one's relationship with a severely disabled person—and to conceive of that person as something other than that which only needs, takes and consumes. If we, like Cormorant, can learn to recognize the humanness of those we care for, we will have taken an enormous stride toward both easing our burden and improving their lives. □

Dialogue:

Are human gene banks worth it?

In **"Human Gene Banks"** (*Lahey Clinic Medical Ethics*, Winter 2005), Dr. Garrath Williams raises a fundamental question about recent efforts to build general population human DNA banks for research: Is the money needed to develop these resources worth it? Looking at a broad sample of efforts around the world suggests that the answer is a resounding "no."

There have been numerous efforts to develop population-based DNA and data banks. In addition to those discussed by Dr. Williams in Iceland and the UK, projects were announced in Tonga, Sweden, Latvia, Singapore, Estonia and Sardinia, and several have been started in the United States.[1] Most of these efforts combine public or quasi-public (e.g., nonprofit hospital) resources with commercial interests. In the US, numerous firms are in the business of procuring and storing human biosamples for research, including but by no means limited to Ardais, GeneLink, First Genetic Trust, GenomicsCollaborative, DNA Sciences, Integrated Laboratory Services, Zoion Diagnostics, Novagen, the National Disease Research Interchange and Phylogeny. With the exceptions of the MRC/Wellcome project in the UK and the Marshfield Clinic's Personalized Medicine Research Project (MPRP), the population efforts have been driven by commercial firms.

In most cases, these efforts have failed relatively early due to financial and political problems. A look at some examples of what has worked and not worked so far supports Dr. Williams's contention that the best route to take for genetics research is smaller, narrowly focused repositories. Two successful efforts at building and operating a repository include that in Umeå, Sweden, and Marshfield's PMRP. Uman Genomics is a company established to commercialize an existing tissue bank and related medical records held by the Medical Biobank of Umeå. The bank was created as part of a large population study of cardiovascular disease and diabetes, and is owned and operated by Umeå University and Västerbotten County Council.[2] The company has exclusive commercial rights to the bank, which includes blood and plasma from more than 100,000 individuals and counting.

The second success is the Marshfield Clinic's PMRP. This effort is focused on the prospective collection of DNA, with broad consent, from people in the Clinic's mid-Wisconsin catchment area. The PMRP was funded by state and federal grants.[3] Since its start in 2002, more than 20,000 individuals have agreed to participate.

In contrast, two efforts to build or operate a repository that failed may be compared and contrasted to the above. First is that of Framingham Genomics, a company started to commercialize the extremely rich research data (including blood samples) on people in the 57-year-old Framingham Heart Study. This large epidemiological study has collected information over time on two generations of residents of Framingham, Massachusetts, encompassing over 10,000 individuals.[4] The study, funded by the NIH's National Heart, Lung, and Blood Institute (NHLBI), has a DNA repository including over 5,000 of the subjects. Framingham Genomics banked on securing exclusive commercial access to the project's resources and data; the project was abandoned when the NHLBI refused to grant such broad rights, suggesting such exclusivity conflicted with their public mission.

Consent is generally seen as an ethical imperative for the compilation of human DNA and medical data banks.

Second is the population effort by Iceland's deCODE Genetics. deCODE proposed legislation allowing the compilation of the population's medical record data (going back some 15 years, plus comprehensive prospective collection) into a centralized Health Sector Database (HSD). An exclusive license was granted to deCODE allowing the company to build and operate the HSD, and, critically, to link the HSD with an extremely complete genealogy on the Icelandic population and with a proprietary dataset of genetic markers (this last developed with consent from subjects). This combined database, called the Genealogy Genotype Phenotype Resource (GGPR) could be used for research. The HSD has not been built, and it is not clear that it will be. Independent of its efforts to conceptualize the GGPR, deCODE has performed smaller studies targeted on a range of specific diseases. They have developed rich databases and networks of clinicians that enable them to do gene discovery as well as other types of research, now even including clinical trials. For example, deCODE's genetic studies identified a gene, defects in which put patients at high risk of heart attacks. Knowing the mechanism of disease, they identified and licensed a drug candidate from Bayer, and are now running a clinical trial in Iceland on the drug.[5] Given the success of their smaller, disease-focused research, the estimated $100 million it would have cost them to develop a computerized medical record system, install it in clinics and hospitals across the country, and pay for the past abstraction of medical records is not likely worth it.[6]

These four projects, perhaps exemplary of the kinds of human DNA banking activities that have been pursued, suggest several things. First, consent is generally seen as an ethical imperative for the compilation of human DNA and medical data banks. deCODE, which proceeded with a waiver of consent but an opportunity to opt out (totally or by individual doctor visit), is the lone exception to this. Even for some retrospective efforts (using tissues collected in years past), researchers have ensured that the scope of past consent would encompass the types of things proposed in the future, and, if not, required a new consent from subjects for new uses that exceed those disclosed in the original informed consents.

Of course, consent can be problematic, because it adds to the cost of research, it can impute biases if some people are more or less likely to participate (for example, in Iceland, it was reported that psychiatric patients were more likely to opt out; in other cases, women are more likely to opt out of having their medical records included in research), and it can result in low participation rates. Nonetheless, consent is the best way to show respect for persons and their rights to privacy and to choose whether and in what ways they will participate in research.

Second, privacy is universally acknowledged as requiring protection, particularly for research involving human genetics. Methods of protecting privacy range from anonymization (stripping all links and identifying information), use of firewalls to prevent subject identification, data smoothing to help mask identities and data (or linking code) encryption. In Europe, researchers are required to use Data Protection authorities, which are governmental boards that ensure adequate protections are in place for use of many different types of private information.

Third, commercial pressures and intellectual property ownership issues can determine whether a project succeeds or not. Firms that have been highly involved in official gene banking efforts often demand exclusive commercial rights to the resources (the DNA banks and related databases) developed at their expense. Exclusivity is exclusionary, and it cuts against the grain for public institutions and for academic or clinical researchers to agree to such conditions. The exclusivity demanded by Framingham Genomics was a deal breaker, and the exclusivity granted to deCODE was a sore point for many critics.

As suggested by the numerous efforts described here, many believe there is money in human genes, but few efforts have succeeded thus far in developing generalized population-based research human gene banks. Patents on human genes, while arguably necessary to foster downstream research on therapies, are far removed in technology and time from a profitable product. Thus, the investments have largely proved thus far to be commercially too risky and may only proceed if development costs are supported by public or foundation grants, as seen with both Uman Genomics and the Marshfield Clinic. This does not imply that no commercial entities are or will be successful, but it is too soon to predict whether firms—such as Ardais[7]—will be around for the long haul.

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Editor's note: Dr. Merz received research support from deCODE Genetics and serves on the Ethics and Security Advisory Board for the Marshfield PMRP. The opinions expressed here are his own.

[1]Merz JF. On the intersection of privacy, consent, commerce and genetics research. In: Knoppers BM, ed., *Populations and Genetics: Legal Socio-Ethical Perspectives.* New York: Kluwer Legal Int'l, 2003.

[2]http://www.umangenomics.com/.

[3]http://www.mfldclin.edu/pmrp/.

[4]http://www.framingham.com/heart/.

[5]http://www.decode.com/.

[6]Merz JF, McGee GE, Sankar P. "Iceland Inc."? on the ethics of commercial population genomics. *Soc. Sci. Med.* 2004;58:1201–1209.

[7]http://www.ardais.com/

It is too soon to know how important a role commercial activity will play in developing even these smaller scale gene banks and in delivering the oft-made promises of beneficial products and technologies.

Response: Professor Merz's reply usefully widens our discussion of genetic banking to smaller, disease-specific collections. As he argues, these are much more practicable and more likely to bring about results than the much hyped national collections. It is too soon to know how important a role commercial activity will play in developing even these smaller scale gene banks and in delivering the oft-made promises of beneficial products and technologies. His examples suggest that the projects most likely to succeed rest on large-scale public investment.

Professor Merz rightly highlights the difficult question of how, and on what terms, such resources should be commercialized. A great deal will hinge on the particular nature and circumstances of the bank. While Merz asks how likely is it that commercial investment will make the research possible, my emphasis was upon how far public and charitable resources *ought* to be given over to such research.

Ruth Chadwick has recently stressed an interesting disjunction raised by the promised applications of genetics to health.[1] A rhetoric of personalized medicine promises drugs tailored to a person's genetic make-up and dietary and lifestyle advice to enhance the sphere of personal choice. Genetic science heralds, then, a greater *individualization* of health. At the same time, such technologies can only be developed by large, collective endeavors that rely on extensive support from public bodies.

It is a testament to our sense of health as an individual rather than a social matter, that we are happy to nurse the prospect of individualized benefits, so marginal compared to those that might be gained from addressing, say, the "toxic food environment" facing our children (to take just one example). Of course, these are not exclusive alternatives: We can surely stress the collective as well as the individual aspect. And one important way to do both, I believe, is to continue pressing the question of our priorities for publicly funded research. □

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Embryo Adoption *continued from page 2*

[10]Robertson, 1995; Lee, Yap, 2003.

[11]Burton PJ, Sanders K. Patient attitudes to donation of embryos for research in Western Australia. *Med J Aust.* 2004;180(11):559–561.

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[13]Kingsberg, et al. 2003.

[14]Brakman, 2004.

[15]The American Society for Reproductive Medicine. Guidelines for cryopreserved embryo donation. *Fertil Steril.* 2004;82(supplement 1):S16–S17.

[16]For more, see *Natl Cathol Bioeth Q,* Spring 2005 issue.

[17]McGee G, Brakman S-V, Gurmankin A. Debate: disclosure to children conceived with donor gametes. *Hum Reprod.* 2001;16(10):2033–6.

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