



## Multifetal Reduction: A Passionless Term for a Passion-filled Issue.

### THE CASE

*Virginia Keillor calls the physician referral service run by a public hospital, State General. She is 14-weeks pregnant after successful in vitro fertilization (IVF). Three embryos were successfully implanted, but she does not want to have triplets. Since Ms. Keillor got pregnant, her father fell seriously ill and she has relocated across country to care for him.*

*She asks the referral center nurse whether State General provides abortion services; she wants to have two embryos aborted and ultimately deliver one child. Ms. Keillor lives 150 miles from the hospital. The two academic and four private hospitals that are closer do not provide this service. The nurse replies that elective abortions are done at State General, but she is not sure about “this sort of abortion” and promises to call back.*

*The nurse learns that the Obstetrics/Gynecology department does not provide these sorts of abortions (technically “multifetal reduction”) because of concerns about which embryos to select. In addition, some nurses have strong reservations about the procedure.*

*What ethical issues ought the physicians, staff, and administration of State General consider in deciding whether to provide multifetal reduction?*

### THE ANALYSIS:

## Preventive Ethics: Implanting Fewer Embryos

As with many ethical issues in health care, this is one that we create by virtue of ever-advancing medical capabilities. Two ways to assist reproduction are to implant embryos directly after IVF or stimulate ovulation with fertility drugs. The physician has direct control of the number of embryos implanted during IVF; stimulation of ovulation is less determined and unavoidably risks multiple pregnancies.

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## The NYC Diabetes Registry: Whose business is your blood sugar?

A New York City health code now mandates that patients with high blood sugar levels be entered into a citywide diabetes registry and monitored thereafter. While some praise the measure as an efficient and effective health policy, others question what role government agencies should play in controlling an individual’s health for a non-infectious disease.

Diabetes is a growing national epidemic among adults and increasingly children, costing an estimated \$174 billion per year for the 8 percent of Americans with diabetes. A similar dramatic impact is being felt in New York, with New York City alone facing \$8.3 billion per year in costs for the estimated 795,000 cases. Increasingly, public health codes are using registries to track cases and target interventions for various infectious diseases (e.g. AIDS, tuberculosis) and chronic diseases (e.g. cancer, dementia). Some argue that this method can also be used to control diabetes.

### NYC LAW:

In January 2006, New York City created a diabetes registry (NYCAR) and amended its health code to require City laboratories to send A1C test results to the City’s Department of Health and Mental Hygiene. The test measures average blood sugar level in the blood over 3 months. Results will be sent to NYCAR along with patient information (first and last

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# Bioethics *in brief*

CENTER FOR BIOETHICS AND HUMANITIES

*Bioethics in Brief* is a newsletter of the Center for Bioethics and Humanities.

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Have a question about an ethical issue? We are always happy to talk in confidence about ethical concerns. You may reach us at the Center for Bioethics and Humanities at 315-464-5404. Ethics consultations are available by calling the hospital operator (315-464-5540) and asking for the ethics consultant on call, or by contacting any of the ethics consultants at the Center (Catherine V. Caldicott MD; Robert Daly MD; James Dwyer PhD; Kathy Faber-Langendoen MD; Robert S. Olick JD, PhD; and Joel Potash MD).

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## Registry

name, address, sex, medical record number, and date of birth), and the aggregate data will be used to track

diabetes rates in the City over time. Results and alerts are sent to individual patients and their physicians so they can alter treatment plans as needed. Patients may choose to opt out of this latter notification program, but their information will still be maintained in the database.

## GOVERNMENT & YOUR HEALTH

The use of such a registry poses ethical questions about the role government agencies should play in improving individual health, as well as the effect this may have on the patient-physician relationship.

Providing patients and their physicians with patient-specific information and reminders may improve care by helping to inform doctors, encouraging patient education, and enhancing patient participation in care. Since entry into NYCAR is mandatory, it provides a more complete pool of epidemiologic data on diabetes than previously available. Use of this aggregate data can offer insight into diabetes trends, highlight specific vulnerable populations or geographic zones of concern, and help track the impact and efficacy of other public health interventions for diabetes.

Notwithstanding its positive features, there are significant ethical concerns raised by the NYC

registry. NYCAR challenges patient trust, an integral element of quality care, by inserting itself into the patient-physician relationship. Patients may have concerns about the privacy of what is shared during visits and the confidentiality of their records. NYCAR's monitoring and "prompting" of physicians and patients to alter their behaviors is paternalistic.

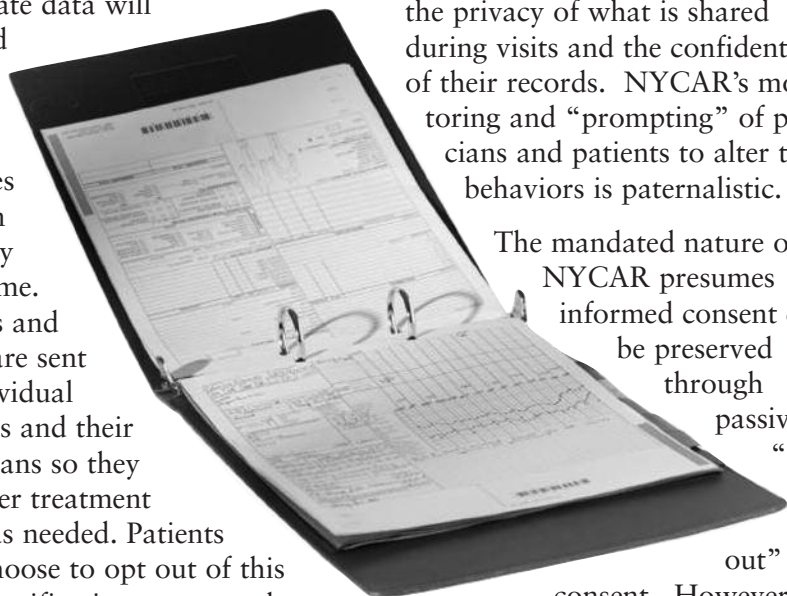
The mandated nature of NYCAR presumes informed consent can be preserved through passive, "opt out" consent. However, requiring one to opt out can create confusion and is often underutilized. This process can be so burdensome that it respects the patient's right to informed consent on paper, but not in substance.

## DISCRIMINATION

Inclusion of individual identifiers in the database, like names and medical record numbers, raise concerns about discrimination if the information falls into the hands of employers, insurance companies, or schools. For example, insurance companies might use such information to keep costs down by limiting coverage offered to people with diabetes.

## WHAT NEXT?

Beyond ethical concerns, some have argued that NYCAR might not be effective in lowering the impact of diabetes. Physicians might not alter their treatment plans as a result of receiving NYCAR's prompts, and patient education alone can have limited results. Upstate faculty member Paula Trief, PhD argued recently in the *Archives of Internal*



## Federal Mental Health Parity

An estimated one in four adults (age 18 and over) and one in five children (under 18) suffer from a diagnosable mental health disorder in any given year. Most of these individuals do not get the timely care they need, often due to inequitable insurance practices that reflect a societal stigma toward mental disorders.

A federal mental health parity bill was passed in 1996, but only extended parity (i.e., equivalence) to dollar (annual and lifetime) limits, leaving insurers free to impose other substantial restrictions on access. However, on October 3, 2008, an expanded version of federal mental health parity became law, as part of the Emergency Economic Stabilization Act of 2008 (H.R. 1424). The new law extends parity to mental health (MH) *and* substance abuse (SA) benefits (as such are defined by plans) offered by group health plans that cover 51 or more employees.

The new law requires MH/SA coverage, if offered, to be no more restrictive than medical/surgical coverage with respect to co-insurance, deductibles, co-pays, number of visits, days of coverage, and annual/lifetime dollar limits. Further, where out-of-network coverage is offered for medical or surgical care, the law requires equivalent out-of-network coverage of MH/SA, and at parity. The law exempts small employers (50 or fewer employees) and plans when actuarially-determined benefits exceed 2% in the initial year or 1% in years thereafter.

The law takes effect for renewals of group health plans one year after enactment date (for most plans = effective January 1, 2010) and for group insurance covered through collective bargaining agreements

when the next collective bargaining agreement goes into effect (not before January 1, 2009). Finally, and importantly, the bill does not preempt state laws that have more extensive parity provisions or consumer protections, but where state laws are less generous than the new federal law, federal provisions apply. Thus, many employers will now be amending their group health plans to come into compliance.

Locally, this new federal legislation will extend the reach of New York's mental health parity law (Timothy's Law, effective January 1, 2007) — specifically provisions related to large (51+ employees) employers — in the following ways:

- Self-insured plans, Healthy NY, Child Health Plus, and Family Health Plus, which had been exempt from Timothy's Law, are now covered under the federal provisions;
- Mental health coverage goes beyond the specific, and limited, list of biologically-based diagnoses (defined as schizophrenia, major depression, bipolar disorder, delusional disorders, panic disorder, OCD, anorexia, and bulimia) previously covered at parity for large employers;
- Caps on inpatient/outpatient days are not allowed, if there are no equivalent caps in medical or surgical care; and
- Substance abuse benefits are included.

This legislation is a step in the right direction in its recognition that mental health and substance abuse are health problems like any other, and inequitable access to treatment is not acceptable.

—Amy T. Campbell



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## **MFR**

The American Society for Reproductive Medicine's guidelines do not strictly limit the number of embryos transferred with IVF; the Society suggests transferring one to five embryos, based on patient age and other prognostic factors. If physicians transfer only one or two embryos, patients may need more repeat attempts at IVF in order to successfully have a child (driving up costs and exposing patients to greater risks). Data from the Centers for Disease Control (2003) indicates that 56 percent of IVF cycles involved transfer of three or more embryos. In many Nordic countries, transferring only one embryo is the standard of care (and insurance coverage is not an issue, given governmental financing of IVF).

If one considers abortion to be morally problematic, one can reduce the demand for it in fertility clinics by strictly limiting the number of embryos transferred to one or two. Some find this to be a reasonable exercise of the physician's moral prerogative; others argue that the physician ought to transfer as many embryos as a patient wants, as long as the patient gives fully

informed consent, as the moral issues of subsequent consideration of multifetal reduction are uniquely hers to consider. Requests for multifetal reduction would decrease if physicians implanted fewer embryos, but they would not totally disappear, given the risk of multiple pregnancies when using fertility drugs to stimulate ovulation.

## **Do you need a good reason?**

US law treats the decision to have an abortion as a private decision between a woman and her physician. Early in pregnancy, there are few legal restrictions about under what circumstances a pregnancy may be aborted, given the pregnant woman's consent.

People often find some reasons for an abortion to be more compelling than others. If the fetus was conceived through rape, even those who generally oppose abortion may favor an exception. Some may find abortion more morally acceptable in the setting of anticipated severe physical deformity; others will not. Some find overwhelming social circumstances of the mother (responsibility for other children with inadequate support from family) compelling. Carrying



multiple fetuses has a higher risk of prematurity and medical complication than carrying one. But even if a woman has a seemingly trivial reason for seeking an abortion (e.g., she doesn't want morning sickness to interfere with a long-planned vacation), our society has been unwilling to put legislators or review panels in the position of approving or disapproving requests for abortion services.

Similarly, most hospitals do not make a policy judgment as to more and less ethically legitimate reasons for abortion, leaving this to the patient and physician. Little is known about the extent to which physicians who provide abortions do so based on whether they find the woman's reason to be ethically persuasive. Given this ethical and legal climate, it is not immediately clear why a decision to abort the two "extra" embryos — so Ms. Keillor can devote her parental energies to the one remaining child — is something the hospital should restrict further.

Some may be concerned that multifetal reduction presents a greater ethical quandary for the physician, because it puts her in the position of selecting which fetus will die and which will live. The choice of which fetuses to abort is sometimes made randomly (which arguably decreases the weight of this ethical concern). In other cases, specific embryos might be selected based on risk of genetic abnormality (ranging from near-certain devastating illness, to slight predispositions to various chronic diseases) or personal characteristics (such as gender). Some will raise issue about "eugenics" or a devaluation of those with disabilities if this is allowed, concerns already apparent as the numbers of children born with Trisomy 21 declines, as fetuses with this condition are more often aborted. Thus, this is not a concern unique to multifetal reduction, and our society has shown little energy for restricting abortions on this basis apart from the setting of IVF.

## Institutional Values

Ms. Keillor's request should prompt State General to reflect on its institutional values and mission. Some private institutions have clearly articulated religious values that preclude offering selective fetal reduction. Because State General is a public hospital, some might argue that it has a particular responsibility to provide medical services that other institutions will not. However, this hardly provides an accurate moral compass. For example, many hospitals might refuse on

ethical grounds to provide medical treatment to stunt the growth of disabled children, in order to make it easier for their parents to continue to care for them as the children age (as was done, with great controversy, in the "Ashley case" at the University of Washington). The fact that other hospitals are unwilling to provide this medical procedure does not mean that State General must, as if every conceivable medical treatment must be available somewhere.

A procedure like this requires several health care professionals; a willing physician is only part of this team, which also includes sonographers and nurses. While physicians often determine what procedures they will offer, they have no greater moral authority than the nurse or sonographer, and a hospital ought to consider the viewpoints of all personnel involved in this procedure.

## Individual Conscience

Most hospitals have policies allowing staff to choose not to participate in certain procedures based on deeply held moral or religious objections, at least in some circumstances. The hospital's decision about whether to provide multifetal reduction is unlikely to happen precipitously, and the request for the procedure does not constitute a medical emergency, allowing time for staff to think through and register their objections. Staff should not invoke their right of non-participation lightly. If they are willing to assist with some abortions but not others, they should be required to explain and defend their reasons for seeing one type of abortion as different from another.

## Summing Up

Multifetal reduction may be wrenching for health care professionals because they are put in the position of determining which fetuses live and which die. Some may find it hard to be sympathetic to a prospective mother who wants exactly one additional child and is unwilling to provide for (or adopt out) the others.

Any abortion is the termination of a fetal life. If State General is willing to provide abortions generally without evaluating the merits of the pregnant woman's reasons, it will have a difficult time constructing an ethical argument as to why it ought not provide multifetal reduction.

—Kathy Faber-Langendoen

## Physicians and Pharmaceutical Companies: A Questionable Relationship

Congress continues its inquiry into the relationship between physicians and drug companies who pay them consulting fees. Sen. Charles Grassley (Iowa) has been leading the investigation, and he recently published some disturbing findings. Although academic medical centers have strict federal rules to follow about regulating and reporting the income any faculty researcher receives from a drug company, Grassley's committee has discovered many examples where the guidelines have not been followed.

In October '08, the New York Times reported that several well-known physician-researchers have broken both their universities' and federal rules for reporting income earned from drug companies who were providing drugs and/or devices for their research projects. Dr. Charles B. Nemeroff of Emory University signed a letter in 2004 promising Emory administrators that he would be complying with federal rules and earn less than \$10,000 from GlaxoSmithKline. That company was providing the

drugs for a National Institute of Mental Health grant worth \$3.9 million to the university. Dr. Nemeroff was the chief investigator for the grant; he repeatedly assured the university that he was within the federal guidelines for his consulting fees. However, Sen. Grassley's committee can show that Dr. Nemeroff earned \$170,000 that year from GSK. From 2000-2007, he earned more than \$2.8 million from drug makers.

Other cases are equally shocking. Dr. Melissa P. DelBello of the University of Cincinnati told her university that she was earning about \$100,000 from eight different drug makers between 2005-2007, but the facts show she earned \$238,000 from just one of those drug makers, AstraZeneca, alone. Harvard child psychiatrist Dr. Joseph Biederman and a colleague Dr. Timothy E. Wilens reported earnings of "several hundred thousand dollars apiece" in consulting fees from 2000-2007 when the actual figure was \$1.6 million each.

Sen. Grassley says that so far the committee has talked to 20 physicians and their research institutions and has found problems everywhere. The National Institutes of Health (NIH) expects each institution to adhere to NIH rules to eliminate conflicts of interest among grantees. In turn, universities have relied upon

researchers to report their earnings honestly and ethically. In the current climate of Wall Street's collapse, it would seem that once again asking people to police themselves is not the best way to ensure compliance or ethical behavior. Since schools share in the benefits of the fame and money such relationships between physician-researchers and drug companies can bring, it may even seem naïve to suggest that schools act as overseers.

Sen. Grassley is sponsoring a bipartisan bill called the Physician Payments Sunshine Act which will require a public registry of all payments over \$500 made to physicians by drug and device companies. The bill is expected to be debated by Congress next year. Eli Lilly & Company announced in late September that they would begin posting an online database in 2009 to record all payments made to doctors for speaking and consulting services. Merck & Company soon followed with a similar plan for 2009. Dr. Paul S. Applebaum, a professor of law, medicine, and psychiatry at Columbia welcomes these developments: "Any physician who believes that disclosure is likely to be embarrassing should not be accepting the money in the first place."

—Deirdre Neilen

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## Registry

*Medicine* that a better approach would be to help people make truly informed decisions about their care, set realistic health goals, and develop the strategies to meet those goals.

While Trief does not consider NYCAR as adequately meeting these goals, she suggests that the registry could be improved by switching to an “opt-in” approach to inclusion, and by entering only de-identified data (e.g., zip codes, race/ethnicity, sex — but not name, medical record number or specific address).

Both options would preserve the registry as a means for policy-makers and epidemiologists to study diabetes in the population. The former option, however, would take the patient’s right to informed consent more seriously by limiting the number of people who are entered into the database unknowingly or unwillingly, while the latter would restore trust to the patient-physician relationship by ensuring that personal medical information could not be used against them by outside agencies.

It is a laudable goal to control diabetes, and a registry can be an effective means to reach this goal. Yet, the use of the means to an end is also important, and the ethical complexities of such a system should be critically questioned.

— Andrea Asprelli and Amy T. Campbell

# University Hospital’s HealthLink On Air

## Upstate’s Radio Show Focuses on Ethics

The HealthLink on Air radio show, which has aired on Sundays from 9 to 10 a.m. on WSYR since June 2006, introduced a monthly feature in December entitled “What Would YOU Do?: Difficult Decisions in Health Care.” Gregory Eastwood MD, president of Upstate for 14 years and now a professor in the Department of Bioethics and Humanities, shares the microphone with HealthLink’s weekly host, Trisha Torrey, as well as with guests who are conversant on the dilemma of the month.

Prior to the program’s launch, the HealthLink staff and Dr. Eastwood sought community input during a special program held at Upstate’s OASIS/HealthLink Learning Center at ShoppingTown in mid-November. Topics of interest ranged from genetics, personalized medicine, and complementary medicine to medical mistakes, access to care, experimental drugs and procedures, organ donation, and many more.

The inaugural program aired on December 7 and addressed dilemmas faced at the end of life. Upstate Geriatrician Sharon Brangman was Dr. Eastwood’s guest.

The January program, tentatively titled “My Doctor: Friend or Foe?,” will consider the physician-patient relationship when wrestling with ethical issues, while the February show will consider genetics and personalized medicine. Darwin’s February birthday is the catalyst.

For information on the HLOA radio show, visit <http://www.healthlinkonair.org>. You can find archives of past shows, background on guests and the show’s host, and extensive resources for the topics presented.



Trisha Torrey



Gregory Eastwood MD

From Upstate's latest issue of *The Healing Muse* published by the Center for Bioethics and Humanities. These pieces speak to the ongoing and dynamic relationship between medicine and ethics.

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## I Hope My Nurses Remember Playing Records

— Anya Silver

I hope my nurses remember playing records,  
the way we'd slide from paper slip each disc,  
holding it still between our flattened palms,  
easing it gently (A side, B side, back and belly)  
down to the table. The wrist raised,  
needle suspended, the pause to gauge  
the proper place. It was important to wait,  
to sink the point — don't slip! — into its groove.  
*Big stick*, the nurses say, before the needle  
enters muscle, or drains the opened vein.  
Sweet ease, funk, crescendo, *oh*. Dancing  
late night in a darkened rec room. Furrowed,  
ruttled, scratched in love and worn from use —  
I hope my nurses remember playing records.

Anya Silver is a survivor of inflammatory breast cancer; she teaches at Mercer University in Macon, GA, and her first book of poetry, *The Ninety-Third Name of God*, is forthcoming from LSU Press.

You can order copies of *The Healing Muse* for \$10 each by calling 315-464-5404 or by going to the website: [www.thehealingmuse.org](http://www.thehealingmuse.org). Or you can purchase a copy at the HealthLink/OASIS site in ShoppingTown Mall (lower level).



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