Center Newsworthy Items Cont.

William Gay received the 2005 Bank of America Award for Teaching Excellence and is the UNC Charlotte nominee for the Board of Governors Award for Excellence in Teaching.

Darlyne Menscer was elected President of the North Carolina Medical Society

Mark Romanoff was elected President of the Mecklenburg County Medical Society

Rosemarie Tong, Eddy Souffrant and Dick Toenjes helped obtain a \$29,500 grant for the Center for Professional and Applied Ethics and the Philosophy Department entitled "Moral Foundations of Capitalism." The grant is supported by the Belk College of Business through BB&T. Dean Claude Lilly was the pivotal force behind this interdisciplinary collaboration.

Center for Professional and Applied Ethics University of North Carolina at Charlotte 9201 University City Boulevard Charlotte, NC 28223-0001 704/687-3542 www.uncc.edu/ethics

University of North Carolina at Charlotte is committed to equality of educational opportunity and does not discriminate against applications, students or employees based on race, color, national origin, religion, sex, age, sexual orientation or disability. Moreover we are open to people of all races and actively seek to recruit and enroll a larger number of African-American and other ethnically diverse students. Produced in May 2005, by the Center for Professional and Applied Ethics. 750 copies of this public document were produced at a cost of \$2,331 or \$3.108 per copy.



Ethics on Call

From the Editor

From the Director

Reflections on Punishment and Freedom

Bruce A. Arrigo, Ph.D.
Professor
Department of Criminal Justice



In Western societies, freedom assumes a prominent role in charting the development of cultures and civilizations. In advanced, technologically sophisticated democratic societies, freedom is cherished: it is defined as that condition which enables choice, informs reasoned judgment, and fosters independence. Conversely,

IN THIS ISSUE...

Ethics and Public Policy

Associate Editor's Note by William Brandon, Ph.D.....

Response to Mary J. Ruwart's Article "Is Death by Regulation Ethical" Ethics on Call, Fall/Winter 2004 by *Betsy J. Walsh, JD, MPH*......

Author's Response to Betsy J. Walsh Commentary by *Mary J. Ruwart, Ph.D.*.....

The Virtue of Drawing Lines

Rosemarie Tong, Ph.D.
Director Center for Professional and
Applied Ethics
Distinguished Professor for Health
Care Ethics
Department of Philosophy



At present it is possible to test pre-embryos and embryos for a wide variety of genetic diseases, (both single gene disorders and chromosomal abnormalities) at the preimplantation state (through pre-embryo biopsy) or sometime during the course of gestation (through maternal serum screening, ultrasound, chorionic villus sampling, and amniocentesis). These tests are usually offered only for serious genetic diseases such as cystic fibrosis, Duchenne muscular dystrophy, Tay-Sachs disease, hemophilia A and B, Betathalessemia, sickle-cell disease, (-1-antitrypsin deficiency, fragile X syndrome, Lesch-Nyhan syndrome, Down syndrome, and neural tube defects. Moreover, they are usually offered to prospective parents only for established medical reasons. For example, pre-implantation genetic diagnosis (PGD). is indicated when a couple has been "psychologically traumatized by repeated pregnancy loss due to genetic disorders" [1] or has had a child with a serious genetic disease previously and is at high risk for having another. Similarly, prenatal genetic testing is indicated when one or more of the following conditions is met: (1) advanced maternal age (age thirty-five and upwards); (2) a family history of genetic abnormalities; (3) membership in an at-risk ethnic group (e.g., Tay Sachs in Ashkenazi Jews. sickle-cell anemia in African-Americans and cystic fibrosis in Caucasians); (4) a family history of infants with birth defects; and/or (5) multiple miscarriages

Center for Professional and Applied Ethics at UNC Charlotte

From the Editor Cont.

EDITORIAL STAFF

ASSOCIATE EDITORS

ETHICS & PUBLIC POLICY......WILLIAM BRANDON, Ph.D. CASE REPORTJULIA BEEMAN, M.S.

DIVISIONAL SUPPORT

transgression is regarded as an artifact of one's freedom gone awry or of making "bad" choices. Punishment (e.g., surveillance, sanctions, confinement, torture, execution), then, is the mechanism by which people and their behavior are socially controlled. But in consumer-driven capitalistic societies, is freedom necessarily the condition that liberates us? Moreover, are choices presumed to be inappropriate, deviant, dangerous, and criminal - that result in punishment, necessarily a function of unrestrained freedom? In short, might "bad" choices signify the limits (rather than the excesses) of freedom? And, if so, might the culture of control be the least humane and insightful response for those who draw our attention to freedom's shortcomings?

The relationship between punishment and freedom was provocatively considered in Erich Fromm's now classic text, Escape from freedom (1994). Originally released in 1941, Fromm argued that the desire for success, accumulation, and consumption in capitalistic and democratic societies like the United States comforted (and anesthetized) people so much so that they willing obeyed (tyrannical) authority, willing practiced "automaton conformity." What Fromm realized was that the potent elixir of market-savvy freedom - conspicuously consumed by a mostly unreflective public - denied them their human capacity for creative and authentic self-expression. Thus, escaping (really

transcending) the allure and trappings of "negative" freedom was paramount to reclaiming the generative potential within us all and the sustainability of a society built on such an altruistic, well-intended value.

The problem of freedom as specified by Fromm raises a host of interesting ethical dilemmas in relation to our urge to punish, particularly when the popular view insists on "harsh" penalties or "get tough on crime" responses. Interestingly, following Fromm, what makes such criminal justice solutions problematic is that those who promote retributivist ends are themselves the unwitting products (indeed, commodities) of a culture where independence, autonomy, self-determination, liberty, and choice-making are mere illusions. In the information superhighway of competitive, consumer driven capitalism, what is taken to be de facto freedom is mostly manufactured by sensationalized images, me dia sound bites, and feel-good political slogans. Mobilized on behalf of the "reality" construction efforts of the state, the stylized message disseminated is that our precious "freedom" is certainly worth defending and certainly worth dying for. Moreover, we are told that, although regrettable, when others are punished (e.g., monitored, imprisoned, executed) such control is necessary because serious and persistent transgressors defile or undermine the rights and freedoms of others. But is our freedom categorically our own? Are transgressions really symptomatic of unrestrained freedom? I do not think such two-dimensional responses (yes or no) adequately capture the profoundly vexing ethical dilemma at hand.

Freedom emancipates and constrains, makes possible and forecloses, confirms and contests the humanity of us all. As such, punishment for wayward conduct may be entirely uncalled for, especially when the root of such deviance or criminality is traceable to the recognition that the presumption of freedom's very existence is itself ungrounded. Transgression, then, may very well signify one's desire to reclaim a sense of true personhood and authentic place amidst a culture that invents counterfeit representations of identity, fellow-

Barnhardt Seminar Cont.

The case for review, discussion, and solution by the Barnhardt Lecture Series attendees entailed a public relations ethical dilemma and, in pertinent part, included the following information:

On Monday, June 18, 2001, CBS News promoted its "Eye on America" Series claiming it had new evidence of wrongdoing in California's energy market. The "Eye on America" was focused on Duke Energy. Three former Duke employees were filmed claiming knowledge that Duke had withheld electrical power during a time of crisis, helping to create the shortage and price spike in 2000. The CBS story aired on Thursday, June 21.

Ms. Bowman screened the CBS News clip, and then asked the Seminar participants the following question: "As Duke Energy's Chief Communications Officer, what would be the right course of action in this situation?"

Participants devised a variety of answers, including press releases, news conferences, ad campaigns stressing Duke's core values, detailed responses to each specific charge, and so forth. All Seminar participants were sensitive to the problems Duke would cause if it publicly blamed California political leaders or state regulatory agencies for the energy crisis in which Duke was ensnarled along with other energy providers.

Duke's response was essentially to rely on the facts of the matter in the belief that the company would prevail. It prepared a fact sheet and released this to the media. Moreover, it opened its books to newspapers, particularly the Los Angeles Times and the Charlotte Observer. These data confirmed that Duke's generating decisions were directed by the California Independent System Operator and not by Duke to manipulate supplies.

Postscript:

In March of 2003 the Federal Energy Regulatory Agency (FERC) found that California electricity consumers were due a refund of over \$3 billion, not the \$9 billion sought by the state of California.

FERC found no evidence that any of the five big generators, including Duke, had withheld any material amounts of available power during the blackouts.

FERC found that seven Enron subsidiaries and five other companies manipulated natural gas and electricity prices.

In July of 2004 Duke announced an agreement to settle many of the outstanding legal and regulatory issues associated with the energy crisis. Duke agreed to provide \$208 million in cash and credits to various parties.

In September of 2005 Duke Energy announced that it planned to sell or divest all of its generating plants outside of the Midwest, including its California portfolio.

Center Newsworthy Items

Ann Burlein received a Pew Grant tot be the Senior Visiting Research Scholar at the Center for Religion and Media at NYU to be part of the working group "Bodies, Beliefs, and Bioethics" from Fall 2005 through May 2006.

William Gay and Eddy Souffrant, Co-Prinicpal Investiagors, received a two-year \$25,000 Implementation Grant from the Council of Graduate Schools for the Department of Philosophy's proposed M.A. in Ethics and Applied Philosophy.





COMMENTARY CONT.

sion makers themselves; regulators, however, can harm millions without adverse consequences to themselves. What infallible person will regulate the regulators?

The ethical question has nothing to do with the effectiveness of the marketplace versus bureaucracy. When we cannot agree on what is best, who should finally decide? Should it be the individual who suffers the consequences of the decision or the regulator (or commentator) who is covered by the cloak of sovereign immunity?

The AIDS patients answered that question when they hired black-market chemists to synthesize potential new therapies that were tied up in FDA-mandated testing for years. By the time the pharmaceutical firms, including the one I worked for, finally got FDA permission to test the effectiveness of these new drugs in people, virtually every AIDS patient in the country had already received them.iv

People clearly want the freedom to choose. Is it ethical to take that freedom from them---and risk their very lives---based on blind faith in regulation?

1 Upton Sinclair, The Jungle, The Uncensored Original Edition (Tucson, AZ: Sharp Press, 2003).

1 Roosevelt to William Allen White, July 31, 1906 in E.E. Morison and J.M. Blum, eds, The Letters of Theodore Roosevelt, 8 vols. (Cambridge: Harvard University Press, 1951-54), V, p. 340. Quoted in Lawrence W. Reed, "Of Meat and Myth," The Freeman, November 1994. Available on the web from the Mackinac Center for Public Policy, http://www.mackinac.org/print.asp?ID=4084).

1 Mary J. Ruwart, Healing Our World: The Other Piece of the Puzzle (Kalamazoo, MI: SunStar Press, 1992). Available at http://www.ruwart.com/Healing/

1 Jonathan Kwitny, Acceptable Risks (New York: Poseidon Press, 1992).

16th Annual Barnhardt Seminar

Richard Toenjes, Ph.D. Department of Philosophy

The 16th Annual UNC Charlotte Barnhardt Seminar on Ethics and the World of Business was held on September 29, 2005, in the SAC Salons. The Seminar has been supported since 1989 by grants from the family of William H. Barnhardt. This year, additional funding was provided by the BB&T Foundation, allowing the Seminar's organizers to expand the attendance to 12 groups of 8, or nearly 100 persons. Ms. Roberta Bowman, Vice President of External Relations for Duke Energy, was the guest speaker. The case she presented and which was discussed by the conference attendees (many of them from Charlotte's largest banks and business establishments in the region), included important background material.

The California energy crisis of 2000 was a time when state customers suffered blackouts, huge spikes in the price of electricity, and the California Independent System Operator (ISO, the state distribution agency) declared 36 Stage-Two alerts (meaning state operating reserves dipped below 5%). On June 14, 2000, temperatures in the San Francisco area reached 103 degrees, causing the state to order rolling blackouts.

The months that followed saw numerous political, legal, and public relations upheavals. Then Governor Gray Davis was accused of failure to prevent or take prompt action in the crisis, opinions that lead to his removal from office. By November 2000, Duke Energy was named one of 16 defendants in a class-action lawsuit filed against electric generators and energy traders doing business in California.



From the Editor Cont.

ship, and community. Thus, much like Fromm, the challenge is to transcend the present social and political climate of imitation and illusion. In other words, the call is to probe the boundaries of how freedom and punishment are inextricably wedded to one another, particularly on matters of consumerism, democracy, capitalism, and ethics. How we do this is not so easily discernible. However, this is a challenge that awaits us all. In the final analysis, the nature of our freedom may very well be what fails to genuinely liberate us. Thus, punishing those whose transgressions aptly demonstrate this, may do nothing more than confirm our worst fears, fostering a society in which obedience to authority and automaton conformity prevail. Such conditions render humans mere functionaries of the state and docile bodies of abject utility.

From the Director Cont.

The present state of affairs is unlikely to remain the same for much longer, however. As genetic tests become available for mild genetic diseases and susceptibilities to genetic disease as well as for a greater number of serious genetic diseases, and as the public becomes increasingly aware of the existence and availability of such tests, prospective parents may demand as much in the way of tests for their future children as their wallets can afford. Some of these prospective parents will want the information to prepare for life with a child that may be born with significant physical and mental disabilities. But others will want the information for the purposes of discarding their pre-embryo or aborting their embryo. Indeed, there is considerable evidence that a high percentage of prospective parents already choose to eliminate embryos with Down syndrome, for example [2]. There is also increasing evidence that a significant percentage of prospective parents would consider aborting their embryo if it had only a slight genetic disease, a susceptibility to a genetic disease, or a characteristic that did not mesh with one of their preferences (for example, a preference for a male as opposed to a female child). In one study, researchers surveyed a sample of prospective parents about what type of genetic risks would lead them to terminate a pregnancy. They discovered that one percent of the surveyed couples would terminate a pregnancy if the fetus was not the sex they wanted; six percent would abort a fetus susceptible to Alzheimer's disease; and eleven percent would abort a fetus susceptible to obesity [3].

Studies such as the one above have triggered heated debates about procreating "less-than-normal" children. Advocates of procreating only "normal" children claim that it is emotionally and economically draining to bring children with disabilities into the world, especially if they have a serious genetic disease or disorder. Furthermore, they argue that it is not in the best interests of such children themselves to be forced to live a difficult life that could have been avoided if only their parents had acted responsibly.

Critics of the "normal" children only argument claim that it reinforces the view of those who long for a society in which only perfect or nearly perfect people are tolerated. They point out, as does lawyer Lori B. Andrews, that the concept of "normality" is a moving target. She claims that as genetic testing becomes available for a greater number of genetic characteristics (most of them non-medical), our understanding of what is normal and what counts as a life worth living will be continually "upgraded" [4]. She cites approvingly the views of Michael S. Lagan, a vice president of the National Organization for Rare Disorders, who has commented that "Eventually there will be discrimination against those who look 'different' because their genes were not altered. The absence of ethical restraints means crooked noses and teeth, acne or baldness, will become the mark of Cain a century from now" [5]. Like others who wish to slow the march towards genetic perfectionism, Andrews and Lagan are particularly concerned that pro-



From the Director Cont.

spective parents will increasingly feel they have not simply a right to test their embryo for genetic disorders and diseases, mild as well as serious, but a duty to do so with a view towards aborting their embryo if it proves less than completely "normal."

The current consensus of clinicians is that it is wrong to pressure women to abort "less than normal" embryos. As they see it, couples in general and women in particular must decide whether, in their particular case, they should or should not bring into the world a child with a serious genetic condition. However, clinicians are not presently of one mind with respect to advising prospective parents who wish to abort their embryo merely because it is affected by a slight genetic disease (e.g., myopia), a susceptibility to a genetic disease (e.g., cancer), or a non-disease related genetic characteristic (e.g., sex). Some clinicians believe that it is up to prospective parents to decide what they consider a "normal" child; but others insist that judgments about "normalcy" belong to the public as a whole.

One way to prevent prospective parents from terminating pregnancies of embryos who are not affected by serious genetic diseases and defects would be to withhold from prospective parents information about their fetus's slight genetic diseases, genetic susceptibilities, and generally non-health related characteristics (e.g., sex) [6]. But the medical justification for this policy is not altogether clear, unless test results for such genetic characteristics are highly inaccurate, difficult to interpret because of the way in which environmental factors influence one's genetic health, and/or very costly. Thus, an increasing number of clinicians who value autonomy over paternalism believe that absent such considerations, they have neither a right nor a duty to withhold from prospective parents any of the information they discover about their embryo's genetic condition. Not only do they reason, as mentioned above, that it is up to prospective parents to decide what kind of child they are ready, willing, and able to raise, they also reason that if a woman decides to exercise her right to have an abortion, it does not matter to the law whether she does

so because her healthy fetus is male rather than female, or because she and her husband do not have the means to rear a child, or because her fetus has tested positive for Tay-Sachs disease. Finally, some clinicians stress that if they prevent prospective parents from learning everything there is to know about the genetic status of their child, prospective parents will simply turn to technicians outside of the health care realm for this information. Better, they say, for prospective parents to be properly counseled and advised by trained health care providers who can guide them to wise reproductive decisions than to leave them to the vagaries of self-administered, in-the-privacy-of-your-own-home genetic tests, the results of which are sent to a distant lab which, in turn, sends prospective parents a printout of their fetus's complete genetic status.

Although I agree that if clinicians draw lines about the kinds of genetic tests they offer, some unscrupulous technicians may arise to take advantage of prospective parents, I still think that clinicians should continue to valiantly steer between the Scylla of patient autonomy run wild on the one hand, and the Charbydis of clinical paternalism grown arrogant on the other. Medicine is not simply a set of techniques and tools that may, willy-nilly, be used to attain whatever ends people have and clinicians are far more than mere technicians who simply have a bag of skills to sell to the highest bidder. It would be a colossal shame if in the name of preventing prospective parents from turning to an ir responsible and amoral technician-entrepreneur class that may or may not arise, clinicians found themselves no better than their rivals. Better to continue the hard work of line drawing, and all the human disagreemen and tension that entails, than to destroy the hard wor and long sustained internal morality of medicine and with it one's own ideals.

References

1. American Society for Reproductive Medicine. Fact Sheet: Preimplantation genetic diagnosis. December 1996. Available at: http://www.asrm.org/Patients/FactSheets/PGD-Fact.pdf. Accessed March 5,

ETHICS AND PUBLIC POLICY CONT.

riculum in a medical school does not supply the intense knowledge in chemistry required for these type of decisions absent studies such as the ones conducted by the current FDA process. Third, Dr. Ruwart's opinion assumes that physicians will have opportunities to research and fully assess pharmaceutical choices for their patients. With reimbursement for services stagnant or decreasing, physicians are under pressure to increase their patient throughput. Adding this investigatory burden to a physician's responsibilities will dramatically increase the time pressures involved in treating patients. For example, what doctor would have time to read the massive number of studies it would take to obtain the knowledge contained in the FDA mandated labels? Finally, Dr. Ruwart presupposes that physicians will be inclined to take up this responsibility. In an era of perceived litigiousness, it is highly unlikely that physicians would assume the burden of assessing the safety and efficacy of drugs not regulated by the FDA or some similar body. One can only imagine the jury verdict with the first bad outcome.

This leaves Government regulation, the option our Congress chose in 1906. Congress could have left the regulation to the states under the Constitutional Police Powers. The Police Powers vest in the states the right to pass laws protecting the health safety and welfare of their respective citizens. By centralizing regulation in the federal government, Congress saved pharmaceutical manufacturers considerable costs. Imagine if each of the fifty states enforced its own drug safety scheme: the compliance costs would be astronomical. Instead, the centralized US system has been described as the "gold standard" around the world. However, what would be the impact of deregulating pharmaceuticals?

First, we could return to the era of loss of life from unsafe, adulterated, or ineffective products. Even with the FDA's rigorous screenings, we still have deaths due to unforeseen complications. In the past two years we have seen two widely marketed and distributed products pulled from the market for further study: certain SSRIs in adolescents and Cox-2 inhibitors. While the

case of Thomas Navarro is compelling, the families of teens who committed suicide while on Prozac and active adults who died of heart attacks while on Vioxx believe their loved ones could have been saved if more time had been devoted to the study of those medications. Second, the public's trust in our pharmaceutical and medical communities would be jeopardized. Most consumers rely on the FDA "seal of approval" as an assurance that a particular drug is safe and effective. Ask your average consumer if he or she would prefer to buy drugs manufactured in the US or another nation, controlling for cost differences. What do you expect that answer to be? If we decimate our FDA, the answer might be quite different.

Author's Response to the Commentary on "Death by Regulation"

Mary J. Ruwart, Ph.D. Adjunct Associate Professor, Biology

Rather than addressing the ethical concerns of my article, the commentary simply gives a history of FDA regulation. The commentary offers no rebuttal to the compelling evidence that the 1962 regulations resulted in a medical Holocaust. Indeed, the only citation is Sinclair's novel The Jungle.i After employing a commission to investigate Sinclair's claims, President Theodore Roosevelt wrote: "I have an utter contempt for him. He is hysterical, unbalanced, and untruthful. Three-fourths of the things he said were absolute false-hoods. For some of the remainder there was only a basis of truth."ii

The commentary correctly contends that the marketplace is imperfect. Regulation is imperfect too; indeed, the preponderance of the evidence suggests that it is frequently, if not always, a cure worse than the disease.iii The commentary correctly contends that some people will make poor choices for themselves, without much concern that some regulators will make poor choices for the entire country. Poor choices made by individuals primarily harm the deci-



ETHICS AND PUBLIC POLICY CONT.

tion of any good. The Act was initially intended to address only food safety in response to the publication of The Jungle. However, legislators broadened the bill to include pharmaceuticals as well.

With respect to drugs, the initial intent of the legislation was to regulate products that were misbranded and adulterated. Early attempts to regulate efficacy were held by the Supreme Court to be beyond the scope of the statute. In response, Congress passed The 1938 Food, Drug, and Cosmetic Act. This Act clearly empowered the FDA to regulate the efficacy of pharmaceuticals as well. Since that time, the Act has been amended a number of times. Significantly, the FDA has developed an Accelerated Development option that can "fast track" certain drugs through the process at a higher speed.

Should we be here? If not, where should we be?

Assuming that there should be some type of regulation over drug development, manufacturing and marketing, it remains to be determined who should be the regulator? There are three options. They include industry self-regulation, free market practices, and government regulation.

The first alternative is industry self-regulation. Prior to the passage of the Food and Drug Act drug makers were left largely to their own devices. The result was a heady brew of false claims, impure products, and consumer confusion. Law students nowadays read cases from the turn of the last century that describe such products as a "carbolic smoke ball" that was "guaranteed to prevent influenza." Today we refer to unsavory and untrustworthy individuals as "snake oil salesmen," a derisive term that recalls the hordes of itinerant salesmen peddling their wares in the late 1800s and early 1900s.

Prior to the Food and Drug Act, industry self-regulation failed to protect either the safety of the public or the

integrity of the pharmaceutical business. Even in the modern era, Congress has chosen to leave regulation of the enormous incentives provided by pharmaceutical companies to physicians to industry self-regulation. The result is the admirable PharmaCode. While its platitudes are reasonable and ethically sound, there are no legal penalties associated with violations of the Code. Therefore, manufacturers who choose to adhere to the tenants of the PharmaCode are disadvantaged in competition with less ethical peers. For example, who receives a greater opportunity to educate a physician about a new drug for epilepsy: the pharmaceutical representative who takes the physician to the Ritz-Carlton in Palm Springs for an all-expenses paid weekend or his competitor who is squeezed into five minutes of the doctor's overbooked calendar while she eats a hurried lunch at her desk? At the turn of this century, as in the last, pharmaceutical industry self-regulation is not proving effective.

The next option is free-market regulation. However, unlike a consumer's ability to assess household appliances, few patients feel adequately equipped to make pharmaceutical choices. As Dr. Ruwart suggests, it would be ideal if patients consulted collaboratively with their physicians to fully assess the risks and benefits of a particular pharmaceutical regimen. However, many impediments exist to transforming this utopian suggestion into a reality.

First, Dr. Ruwart's position assumes that all Americans have access to a physician familiar with their respective health statuses and histories to the extent necessary to make such important decisions. More than forty-two million Americans do not have insurance. Therefore, they lack reliable access to primary care physicians who could provide them with continuity of care. Second, Dr. Ruwart's outlook presupposes that all physicians are capable of providing such expert advice. The array of pharmaceuticals available on the market is mind-boggling to a pharmaceutical specialist, much less a practicing physician. The typical cur-



 \equiv UNC CHARLOTTE \equiv

From the Editor Cont.

2003.

- 2. Mahowald MB. Genes, Women, Equality. NY: Oxford UP. 2000; 144.
- 3. Strong C. Ethics in Reproductive and Perinatal Medicine. New Haven: Yale UP. 1997; 138.
- 4. Andrews LB. The Clone Age: Adventures in the

New World of Reproductive Technology. NY: Henry Holt and Co. 1999; 162.

- 5. Andrews, 147.
- 6. Sex is a medical criterion when an X-linked recessive condition such as hemophilia is present.

Faculty Associate Highlight

Some Reflections on Ethics and Higher Education

Nancy Gutierrez, Ph.D. Dean, College of Arts & Science

(This essay is an abridged version of a taped conversation between Dean Nancy Gutierrez and Bruce Arrigo, Editor of the Newsletter, Ethics On Call. The purpose of the interview was to explore with the Dean her thoughts on the challenges higher education confronts (especially in the Arts & Sciences) on matters of ethical decision making and moral accountability. The interview focused on some of the Dean's past experiences, present concerns and future reflections.)

Bruce Arrigo (BA): Good morning Dean and thank you for agreeing to meet with me as the editor of Ethics on Call.

Dean Gutierrez (DG): Good morning and it is my pleasure.

BA: I would like to get your impression on ethics and higher education. The questions are designed to be reflective for the audience and to encourage them to think about the challenges we confront as administrators, educators, and students in the field. Let me begin by asking you about your background and your professional and work-related experiences.

DG: I came to UNCC after being a faculty member and administrator for 20 years at the Arizona State Univer-

sity (ASU). Prior to that, I was a full-time instructor at the University of Cincinnati in the English Department and then an assistant professor for four yours at the University of Texas in San Antonio. I received my Ph.D. from the University of Chicago in Renaissance Literature. I've taught the range of courses in Renaissance Literature as well as freshman composition, which all English teachers have to cut their teeth on, along with general education courses. I've taught everything from the classics to Norman Mailer and Joan Didion. My experiences as an administrator at ASU consisted of being associate chair and chair of the English department, then Associate Dean for Personnel in the College of Arts and Sciences, and then Vice Provost for Academic Affairs at the University level.

BA: I'm wondering if you might comment on particular challenges that you've confronted over the course of your career; challenges that have emerged with respect to ethics. For example, there might be different types of trends or kinds of ethical dilemmas that as a faculty member or administrator you've witnessed over the years.

DG: I will talk about one week in February in 1996 when I was Chair of the English Dept. These are two specific experiences that I had as Chair, and both of them create or demonstrate certain ethical issues.

The first example concerns the events surrounding a teaching assistant's decision to use hate speech material, directed against African Americans, in her fresh-



Faculty Associate Highlight Cont.

man composition class as an example of the abuse of rhetoric. Since the focus of the class was to look at the misuse of language and come to terms with how language could be more appropriately used, she believed that the students would be able to handle this kind of offensive language. Also, she had been with the students for the entire fall semester and for several weeks into the spring semester, so she and the students had developed a strong and supportive professional relationship. However, she miscalculated the emotional distress that some of the students might feel when confronted with such ugly language. One African American student took the material to her Resident Assistan who took it to the Provost's Office. A series of conversations were held about the chilly climate issues on the campus, particularly for minority students-with the particular student, with other students, with faculty members and staff. The Provost's Office decided to schedule an open forum to discuss the issue, expect ing 30-50 people. Over 300 people showed up. The audience was very angry, and there were several death threats directed towards the university president and the TA. At one point, the Director of Composition resigned because he felt he had not provided the proper advice to the teaching assistant. In retrospect, I realize that the TA's miscalculation did demonstrate that our program needed to be more in touch with the first-year instructors on staff. While the TA had the best of intentions, she presented the material badly. There was no documentation about the source of the hate speech. nor did the TA collect the material afterwards. She ultimately did not make the student in question feel comfortable. The TA herself took several years longer to finish her Master's degree, and ultimately decided not to pursue a doctorate. The incident itself led to a very good thing-the creation of an Intergroup Relations Center-but clearly there was also emotional scarring for a number of those involved.

BA: It seems to me that the ethical dilemma there was the extent to which one in an educational environment has the obligation to express hate speech material for a pedagogical purpose knowing full well the inflamma-

tory nature of that material. We don't want students and teachers to feel a sense of outrage but we want students to understand the importance of how this speech can be inappropriately used.

DG: The other issue is how we should present this material to a group of 18-year olds, many of whom are sheltered and who come from many different experiences, backgrounds, and forms of educational preparation. This level of diversity in the classroom raises all kinds of ethical dilemmas. The consequences of this experience were both good and bad. The fact of the matter is that when you are in an English department, you must know how to handle sensitive material. On a regular basis, we teach material such as Huckleberry Finn and other such sensitive texts. However, we discovered that we could be even more aware of the consequences of teaching certain texts in a multicultural classroom. The English department the next year ran a series called "Ethics in the Classroom." We did several events with speak ers and workshops and, as you can imagine, there were various kinds of responses. However, while this hate speech crisis seemed to damage the reputation of the English Department initially, over time the department was seen as a model in terms of havling identified a problem and addressed it. Also, the Director of Composition subsequently took a firmer hold on the training of graduate students, which extended to the full-time faculty as well. The dilemma translates into action and action has consequences that raise other ethical dilemmas.

The other issue that arose at the same time involved a senior a student grievance against a faculty member who had left a verbal evaluation of the student on the student's answering machine. The evaluation was negative, and the faculty member clearly indicated that he was basing this evaluation on his own personal feelings. To make matters worse, the instructor had no syllabus for the class. There were several issues here. Should instructors be required to have a syllabus in a class? What is the responsi-



Introduction to the Walsh Commentary and Ruwart Response

Associate Editor's Note:

In the following commentary Betsy J. Walsh, JD, MPH, responds to Mary J. Ruwart's article "Is Death by Regulation Ethical?" (Ethics on Call, Fall/Winter 2004). Dr. Ruwart replies to Ms. Walsh on page _.

Dr Ruwart's initial article argued against U.S. Food and Drug requirements for proof of clinical efficacy both on libertarian grounds regarding the right of individuals to make decisions for themselves when the individual alone is the principal beneficiary or victim of the consequences and on empirical claims that regulation kills "about 100 times" more lives than it saves. Her 2004 presentation to the American Association for Pharmaceutical Sciences reported that between 14 and 32 percent of all Americans dying of disease in the 1962-1999 period would have lived if it were not for the provisions of the 1962 Kefauver-Harris amendments to the Food and Drug Act.

Dr. Ruwart pointed out that even FDA-approved drugs are highly variable in their therapeutic and iatrogenic effects on specific individuals, thereby rendering probabilistic statistical judgments indeterminate in a given instance. In light of such uncertainty in application, individual freedom to choose ought to be the operative principle. She went on to argue that the well-established placebo effect justifies making available remedies that may lack any demonstrable pharmacological efficacy. She dramatized what she called a "medical holocaust" with the case of Thomas Navarro, who died of a brain tumor after being denied timely access to a promising alternative to chemotherapy and radiation.

Although this libertarian argument could justify not only recourse to such discredited therapies as laetrile but also the decriminalization of medical marijuana, Dr. Ruwart did not draw those conclusions.

An Exploration of the Avenues for Drug Regulation

Betsy J. Walsh, JD, MPH Novant Health

Where are we and how did we get here?

As far back as the early 1900s the American people have demanded that their government take action to protect them against industry practices that pose harm to the public. Prior to the publication of Upton Sinclair's The Jungle in 1906, Americans typically reacted to tragic loss of life due to unsanitary food, physician malpractice, or even tainted elixirs with rugged individualism. Those who chose to subject themselves to such risks bore the consequences. Besides, locally manufactured and distributed products typically did not harm people. As our society moved towards mass production, how ever, the risks posed by one dishonest or careless manufacturer increased dramatically. Even more importantly in that era, if our economy was to thrive, consumers needed faith in the safety and efficacy of goods and ser vices. What father would stop growing vegetables with his own hands to serve his family canned goods that might be contaminated? What mother would spoon potentially tainted cough syrup in her child's mouth rather than rely on a poultice she made at home? In order to move into the industrial age, Americans needed faith in the increasing array of products that were becoming available to them. The Food and Drug Act ushered in a regulatory scheme that not only increased the quality of food and drugs available in the market, it made those products more attractive to the purchasing public. Indeed, the existence of some system that creates trust between consumers and producers is part of the social capital that is a necessary condition for achiev ling a functioning market-based system of national or linternational scale.

Congress passed the Food and Drug Act in 1906 under the powers granted to it by the Commerce Clause of the United States Constitution. Without question, Congress had the right to regulate the interstate transporta-



■ UNCCHARLOTTE ==

11

Center Advisor Highlight Cont.

with both Pulmonolgists and cardio thoracic surgeons, all of which I attended with my grandparents and usually one or both of their daughters, a course of action rather than inaction was chosen. By the time things were through, I had been present as a family member in the operating room for the removal of the upper portion of Grandfather's left lung, learned from the surgical pathologist during the operation (and before the patient) the prognosis, and had him discharged home from the hospital two days early to my care to spend Christmas with the family.

The next year at Easter dinner, with the whole family around the table, I broached the uncomfortable subject, and had everyone in the family designate a health care proxy and sign living wills.

Having gained perspective from the role as patient's family member, my time served on the Ethics Committee at Albany Medical Center during my residency brought dimension to many of the cases we reviewed. As a facility with a fifty bed NICU, many of the consultations came from this area of the hospital. The most difficult cases were those in which there was a conflict between the nurses required to care for an infant and carry out orders for blood draws and procedures that they felt might be painful and futile in opposition to the orders given by the physicians who were working with the wishes of the parents as directive. The Pediatric Department had its own ethics meetings, and there were no shortage of topics or cases for discussion. As a resident, I was involved in several.

My dual training in internal medicine offered the opportunity to participate in end of life decisions and ethical decision-making. The adult ICU and HIV wards provided fodder for many lively talks, mostly with the pulmonary attendings. The most difficult were with the families of patients that I had not met, during early morning hours, trying to help provide information and comfort to people whose life I happened to be touching because I was the resident on call that night. There is no shortage of concrete examples that I might list here,

unfortunately. And any of them, as Dr. Tong pointed out in her column of the spring/summer edition of this publication, could have been avoided with an advanced directive.

And now, at this point in my career, I have come back to where I first learned of medical ethics. I am in practice and in the hospitals, and am faced with many of those issues that I had studied and discussed. The prior scrutiny makes each real life event no less strenuous, but the tools and experience I have gained make the process of assessment easier. Examples of confidentiality, participation in clinical trials and suspected spousal abuse are familiar. Some of the more difficult situations still trouble me: the end-stage cancer patient who asks "you're my doctor, should I try this experimental protocol - it's the only option left?" Family members who keep things from one another - terminal conditions and prognoses- but are both my patients.

I sit on the Davidson College Medical Humanities Advisory Committee, and am excited to see the enthusiasm and passion still engendered by both the students and their professors by the subject of medical ethics. That this publication exists is a testament to the relevance and importance of ethics in not only the medical profession, but to every profession and in application to everyday life. The recently held Barnhardt Seminar is also a marker that Charlotte is a leader in this area. UNCC is a leader in the study and application of ethics, and challenges local and national leaders to reflect upon their emphasis on ethics. Bravo and keep at it!

-T

Faculty Associate Highlight Cont.

bility of the faculty here? Is it appropriate for faculty to evaluate a student on voicemail and what are the parameters in which the evaluation should be given? My responsibility as the chair of the department entailed an assessment of how to respond to the faculty member and the student both, and an assessment of what was appropriate in terms of the documentation used. I did feel that the faculty member had been acting inappropriately. Because the faculty member was tenured, I needed to identify an appropriate college process by which the student could tell her story and the faculty member could be appropriately judged by his faculty peers. These are issues that have to do with how one teaches and how one interacts with colleagues.

BA: It strikes me that when confronted with an ethical dilemma or challenge even in the face of moving to action and resolution that there are, at the very least, consequences, some of which are unintended. In both situations you described, the parties involved found themselves having to make decisions on how to proceed in the future. In the first instance, the student was traumatized and did not go on to finish her doctorate and the Director of Composition resigned. In the second, there seems to be an issue about one's response to a tenured faculty member whose choices are difficult to understand or support, especially in the context of that faculty member's educational role. What strikes me is that what you are describing is that when ethical problems present themselves they give rise to other ethical issues and challenges.

DG: The second instance also indicates the difference between the business world and the academy. In the former, there is a hierarchy that everyone acknowledges, while in the latter, there is an apparent hierarchy, but one which operates in a very non-hierarchical manner. One just can't fire a tenured faculty member nor would one want to. As chair, I am the equal of my senior colleagues, yet have the responsibility of administering the department and making

sure everything functions, and that the students are served. The absence of hierarchy sometimes makes it difficult to address problems in which a faculty member acts unprofessionally. It is a much different context than that of business administration.

BA: In ethics we talk about principles that are at stake and perhaps the value that is at stake here is the desire to have consensus, participation, and inclusiveness. Given this, the question becomes how to reconcile an ethical dilemma involving these values in the academy, and whether this resolution differs if in a business environment. Do you have any comments for students and faculty as we are in the throws of the 21st century?

DG: The issue is that we understand that UNC Charlotte, a public institution, is expanding its responsibility and mission. For example, we are now educating many more undergraduates in this institution and not all students are equally prepared. The mission of the university is to provide access and support services, faculty, courses and curricula that will allow all students to succeed, to get a degree, and to become contributing citizens and ethical human beings. When I went to school, freshman composition weeded out those who were unable to do college work. Those who couldn't do this work fell by the wayside. We are not in that world now. We accept all qualified students and believe that we must educate them, so our undergraduate educational mission has expanded. Our graduate education has also expanded. We have a full range of graduate courses from the more traditional pure research offerlings to the more applied programs. This is because we recognize that the application of knowledge is as important as creating knowledge. We also believe being embedded in the community is vital so we have much more of an interest in partnering with community agencies. All of these responsibilities exist in a world where state resources are declining. The ethical dilemma here is how to use and create, as an administrator in higher education, other revenue streams so that our various constituency needs can be met and served in a way that



Faculty Associate Highlight Cont.

is consistent with the university's mission. If resources are thin, what are the values and principles that we use to decide where the money goes? If I am going to say as an administrator that I think we need to serve the undergraduates and place all money there, and I don't look at the research mission, then I am hurting faculty and students. But if I spread the funds, then I seem to spread the hurt as well. Practically, I have to decide where the hurt would be the least.

BA: It does sound like trying to make decisions with integrity does require one to be mindful that this is a difficult period of transition for this university, and that as an administrator in higher education, as we confront the challenges of growing as an institution, it will require more of the stake-holders, particularly if we try to reach those goals. Reaching out to the community, growing the research base, and being mindful of the ever-expanding undergraduates may become challenging and may present new ethical dilemmas.

DG: The one dilemma I am very aware of is the issue of intellectual property-specifically, the creation of knowledge within the university, who owns that knowledge once it's created, and who owns the application of that knowledge. When the knowledge application results in money, who gets that money and how is that determined? When intellectual property is created, if there is collaboration, who gets the recognition and how does that recognition occur? These things become trickier with the application of new technology. Lawyers often think that there are clean lines we can draw, and that technology does not make a difference in thinking about the concept of intellectual property in the abstract, but I don't think that is the case. Technology does really muddy the waters.

BA: That is a good example because it helps to magnify how the university is changing. It is not the case that we haven't had intellectual property issues on campus; however, they are increasing. When thinking of the other challenges you mentioned (expanding undergraduate numbers, a commitment to growing the

non-tuition revenue base, and the push for greater research productivity), they have an impact on the culture of an institution. Could you comment on this? Do you see any ethical challenges or dilemmas with regards to the shifting culture for an institution like ours because, after all, universities are communities?

DG: The more diverse a culture is, the more landmines there are. If one is dealing with an elite institution where young men from the upper class are educated, then we have a constrained audience and behaviors are understood. When we expand this to include women, the less privileged, students of different races, and noncitizens and international students, you can walk into a room and immediately make the wrong comment. The sensitivity to those differences is difficult to legislate, and it is difficult to learn sometimes. At UNC Charlotte, we are dealing with an expansion of cultures, not just within our student population but within the faculty as well. For example, as the university changes, there is greater possibility for tension. Several different kinds of faculty members need to coexist: an older generation of faculty who were trained primarily as teachers, newer faculty who were trained as researcher/scholars, faculty who teach part-time, faculty whose only responsibility is research and who must earn their own salaries through grants, and so on. The possibilities for problems to arise that have ethical dimensions are manifest.

BA: It seems that we are talking about professional and social identity within a community. When those shift, they raise all kinds of potential problems.

DG: One of the real areas in which there is disagreement is with defining the mission of this university. There are faculty members who believe educating students is not just the primary mission, but should be the only mission. Obviously, this is not the only mission of this university now. There are others who believe that research is primary. Obviously, this isn't the only mission of the university either. But I would say that education and research are both primary.

Faculty Associate Highlight Cont.

BA: I certainly appreciate your comments. Do you have any concluding remarks you would like to offer?

DG: I believe a university is a site where intellectual conflict should be embraced, and the process of disagreement can be one of the most ethical activities in

which a university engages. The fact that this particular university may be a site for conflict due to the transition we are experiencing provides us with the intellectual and ethical tools to make us stronger and more effective in fulfilling the missions we have.

BA: Again, Dean Gutierrez, I would like to thank you on behalf of Ethics on Call for your comments.

Center Advisor Highlight

Beth Ann Jayne, MD Huntersville Pediatrics & Internal Medicine

When the message came back to me in my office that there was "a Dr. Arrigo on the phone for me," I took the call. The name was familiar, but I couldn't quite place it - a familiar position, only having been in the area for a little over a year. When he identified himself and asked me to write a Highlights article, I had a brief flashback from the 70's. Bones exclaiming "For God's sake, Jim, I'm a Doctor, not a ...!" - fill in the blank as appropriate, in this case it would be writer. But the challenge has given me the opportunity to reflect upon the different ways in which ethics, more specifically medical ethics, has been woven into both my person and profession life. Thematic apperception, thank you, Bruce!

My first formal introduction to the concepts and content of medical ethics was at Davidson College as an undergraduate. Suspecting that I might go on to study medicine, I chose to major in a non-science field, and elected to expand the concentration of Medical Humanities into my chosen field. It was through study and dialogue in this department that I consolidated my ideas about the importance of ethics in medicine, and was first introduced to a formal and substantive approach to some of the "big issues" to consider: end of life issues, rights of minors in medical decision making, physician assisted suicide, privacy in

the age of information. I was provided with grizzle to chew on outside of the classroom as well. I went to a pediatric long-term neurologic unit at CMC, saw patients in an outpatient clinic and held "crack babies" in the NICU. Though I didn't have any clinical frame of reference for these experiences, I tried to glean what I could. Rounding out and further enriching my preclinical background were the experiences of attending and interacting with the speakers of the annual Speas Colloquium. Such persons as Eric Cassell made issues come to life and engaged and challenged me to press on with my interest.

The formal became personal during medical school when my grandfather was diagnosed with lung can cer. He was 78 and had only ever been to a doctor a hand full of times in his life. He did not really even understand why I wanted to be one, and certainly didn' feel comfortable interfacing with the medical establishment. He was diagnosed while on a cruise in Alaska with pneumonia, but the x-ray showed a rather large and ominous mass that went along with it. With a long history of smoking, it was fairly obvious that the diagnosis would be cancer, and Grandfather was fearful of intervention, treatment and the unknown that lay ahead His initial reaction was to "just let things be," in which case, Grandma would have been widowed in one to two years at best. My status as a medical professional (second year student) placed me in a unique position of both information and influence. Perhaps. After meetings



