

Building stairs into slippery slopes

An interview with Arthur Caplan, Director of the Center for Bioethics at the University of Pennsylvania (Philadelphia, PA, USA)



EMBO reports (ER): Professor Caplan, why do we need bioethics?

Arthur Caplan (AC): There are obviously ethical and value questions that can be asked about any of the sciences, so we need bioethics, but it's not enough to have just bioethics. Another important reason to have bioethics is that there are general questions in the life and health sciences about resource allocation and who gets the fruits of research. A critic of the need for bioethics might say we don't really need 'Teflon ethics' in order to talk about the safety of cooking. It is true we don't need cooking ethics to pay attention to safety issues, but we don't care about who gets a frying pan in the same way we care about who gets a heart transplant. Health and biomedicine are just different. People have tried to do environmental ethics, agricultural ethics and engineering ethics, but they

haven't taken off in the same way. Another reason for bioethics is that the life sciences have always been in tension with religious views about what is human nature. So people aren't disconcerted to find out that rocks are formed in a particular crystallization process, but they care a lot about the role of genes in driving their behaviour and whether you can change them and change that behaviour. The animate objects get our attention more than the inanimate objects. And those who think humans transcend mere science sometimes view science as valueless.

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ER: When did this interest in bioethics start?

AC: Bioethics really got going in the late 1960s. There were four issues that started bioethics in the USA. One was a rebellion against medical paternalism—early bioethicists were extending the civil rights movement into patients' rights. Second, the American anguish over abortion was playing out in the '60s. That led to a lot of bioethical discussion about the rights and wrongs of abortion. The third was the introduction of new technologies to save lives—the intensive care unit, respirators, artificial heart machines, kidney dialysis—and issues about who got them and were they worth paying for drew attention. The last one was human experimentation scandals. In the USA, there was a series of terrible mistreatment of human research subjects that culminated with the Tuskegee study, which became public in 1971. In the 1930s, US physicians that were affiliated with the Tuskegee Institute withheld treatment for black patients with syphilis so they could observe the course of the disease. They then continued the study after World War II even when a cure, penicillin, became available. When all of those issues came together, bioethicists started looking at clinical medicine and at patients' and subjects' rights. That first generation of people who founded bioethics tended to come, interestingly enough, from religion. In the '70s, they were joined by people who studied philosophy, like me. Then in the '80s and '90s, more physicians and social scientists came in. Eventually bioethics became international, and things like the genome project and stem-cell research later became drivers. But the early days were scandal-driven as well as clinically driven, and bioethics sounded very American. Bioethics has talked with an

American accent for a long time. It's only starting to change now.

ER: Has bioethics now completely veered away from the clinical side?

AC: No. It has subdivisions and subspecialties, and there are programmes that focus on clinical ethics or bedside ethics. The issues of end-of-life care, doctor–patient relationships, and even the economic aspects of rationing and allocation are all still there. But the basic science part has taken off, and it's definitely attracted some people and many headlines. Most of bioethics is still physician-driven, so there is a dearth of people who actually follow the life sciences sufficiently to engage the issues. That's a problem for the field right now.

ER: You came from a history and philosophy of science background.

AC: I did a genetics degree as part of that history and philosophy of science, although the genetics I did is now hilariously dated—counting fruit flies and tracking wacky traits. But it at least gave me enough jargon to interact with the scientific community, and you need that. In fact, one of my next goals at my school is to secure more training grants for life scientists to study bioethics. Most of the programmes that exist are for MDs.

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ER: Is there any bioethics component of life sciences degrees in the American education system?

AC: No. In Europe and the USA, medical schools teach ethics and doctors get acquainted with it. In the life sciences, it's usually when someone's accused of doing something wrong, strange or wacky that bioethics breaks out—it's not because it's a part of their training. In fact, getting anybody off the bench to spend five minutes doing anything else is almost a career breaker, both in Europe and the USA. If I tell a senior scientist I want to pull a junior person out of the lab for six months or a year to do an ethics programme, sweat breaks out on their

brow. The basic science culture is not friendly to looking at ethics in the way that medicine is.

ER: There has been an intense discussion in Europe about bioethics, with Lewis Wolpert and Steven Rose representing two opposing views. Wolpert argues that bioethicists should leave the scientists alone, while Rose claims that science must face social responsibility.

AC: And if you look to the States, Paul Berg sounds like Wolpert. It's sort of like pleading logical positivism. It's a view of science I don't even think philosophically makes sense. You can't get very far without values appearing, even in some strictly molecular activities. I would also say that you scare the public if you continue to assert that you don't think about the ethical aspects of what you are doing. The fear of the 'mad' scientist isn't really that he or she is mad, it's that he or she is indifferent to the ethics of what they are doing.

ER: So would you side with Rose?

AC: Yes, I think the best bioethics is proactive. It's very hard to put out a house on fire. It's very easy to put in fire alarms and smoke detectors. Good bioethics should be installing 'fire alarms'. Scientists sometimes worry that all the bioethics does is get in the way. But that isn't true. In the States, I spend most of my time asking why we don't go faster, why we don't do this, or why we haven't done that. You can be a bioethicist without just saying 'no' all the time.

ER: The USA has the Presidential Council on Bioethics, the UK has the Nuffield Council on Bioethics and Germany has the Enquete-Kommission—all to advise governments on bioethics. Often their recommendations are conservative or prohibitive. Do you think that bioethicists should have an influence on government policy?

AC: There certainly are conservatives in bioethics but that's the nature of politics. If you wanted a gung-ho bioethical panel with much more sympathy for research it would be easy enough to structure one. Bioethics panels, whether they're in Europe or the USA, are political bodies, but that isn't the only place where policy gets done. There was a big fight about Proposition 71 in California to allow the

state to fund stem-cell research. It passed and the state is now supporting stem-cell research in a big way, even though the government and the national ethics council are opposed. So it's possible to do battle and win even with a politically stacked national panel.

ER: Do you see an influence of moral or religious views on scientific agendas?

AC: I think the problem is that religion is on the rise almost everywhere except Western Europe. It's certainly in the USA, it's obviously in the Muslim countries, and there's some of it going on in India. Sometimes it's hostile to science, sometimes it isn't. Fundamentalist Christianity in the USA does have issues with some areas of science. The same would be true in some parts of the Muslim world. But it's important to remember that religion doesn't have to be opposed to science. In some parts of the world it's certainly not and in the places where it is, the question is whether scientists should spend time engaging those tensions. If it's a battle about teaching evolution or a battle about trying to understand sexuality—which makes some religions nervous—those things have to be engaged and debated otherwise I think the power of religion will win out and that would not be in the public's best interest with respect to these issues.

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ER: Why is it that many fundamentalist Protestants in the USA and the Catholic Church in Europe have so many objections to some areas of biomedical research, while the Jews, Muslims and Buddhists seem to be much more tolerant?

AC: Part of the more fundamentalist Christian concern is that some of the work of the biomedical sciences today is seen as antithetical or as not supporting core metaphysical beliefs about life. For example, a highly contentious issue is “When does life begin?” And if you think about it from the point of view of morality, there's something very admirable about an ethic that says

'respect all life, all the time'. Now, my friends who are believing Christians tell me that the Church always wants to be in line with science. So have scientists done their job? Scientists constantly tell me that they have nothing to say about when life begins because it's a political or religious question. That is false. Science has much to say about when life begins. We know that life does not begin at conception. Unless you implant an embryo into a uterine environment and the right chemicals are going back and forth between womb and embryo, there is no potential for life. The other thing we know is that not every conception begins a life. That message is lost because scientists are afraid to get into this discussion. It's not that religious zealots are imposing their view, it's that scientists throw their hands up and say "We have nothing to say, it's a social decision". That makes no sense. Scientists get upset about religion, but how many of them write a letter to the editor, write an opinion article, or talk at a high school? If you choose to work inside a fortified tower, you shouldn't be surprised when the peasantry shows up with pitchforks. There is an obligation to communicate these things to the broader community and I don't see that being done. It's the wrong stance for science.

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ER: Earlier this year, 48 Nobel laureates in the USA signed a letter to support Democratic presidential nominee John Kerry and to accuse the George W. Bush administration of misusing science for political purposes. Are scientists now more inclined to get involved?

AC: These are the ones who always would have gotten involved, it wasn't really a grass roots movement. You can't as a scientist just say "I know there are 10 or 12 leaders of science and they will communicate my message." You better communicate that message at the local civic organization or at the local high school. I think every scientist at least once a year should be out in front of a high school audience. Religion does it—every Sunday there's communication through lots of institutions all over the world. I don't mean to rain on the parade of

scientists who protest the distortion of science, but I think it's reactive. Scientists need to be proactive.

ER: Many people said that the 2004 US presidential election, more than any previous one, concentrated on scientific topics and the ethics around them. Afterwards, polls indicated that many people were concerned about moral issues. Do you think that the general populace are going to be more interested in scientific issues now?

AC: I think some of the topics were science or science-related and drew out the more religious vote. In the USA, abortion and stem-cell research do bring them forward. I also think their fears and misunderstandings about homosexuality bring forward those with strong religious values. And they worry about the technological creation of non-traditional families and reproductive technologies. I think if you asked them whether they care about science, they would say no. But if we asked them if there are things that scientists work on that make them nervous or interest them, then they would say yes. I think these are important areas and that is where bioethics matters.

Bioethics has made a big difference in public policy. Before bioethics there was no informed consent, there was no discussion about brain death, there was no right to stop your treatment either in Europe or the USA, and there was less privacy for medical information. Bioethics has had a big impact on how health care works. Something like that is at work now in the life sciences—are we going to do research on embryos, are we going to allow cloning for research, are we going to move forward with reproductive technologies that might allow you to ascertain genetic predispositions in children? We need to engage these issues and not leave them simply to those who care about them for religious reasons.

ER: In the USA, many conservatives, such as Francis Fukuyama and Leon Kass, take a very gloomy view of biomedical research, while in Europe a lot of the criticism comes from the left.

AC: There is criticism on the left in the USA, it's just that the left is so atrophied that you don't hear much from them. Some of the strains that motivate the left, such as respect for nature, fears about corporate exploitation, and worries about

equity, are not what motivates the right in the USA. To some extent, you see the right-wingers or the conservatives concerned not so much about inequity and maldistribution as they're worried about a loss of privilege. It boils down to fundamental cultural differences in how Europe and the USA see the power structures of the world. The Greens in Europe are worried about what companies are going to do to us while we're asleep, and the conservatives are worried that if you don't let the companies do what they're supposed to do, problems will develop.

ER: You advocate a free market approach to many advances, such as neuroethics, IVF or preimplantation genetic diagnosis. Is a free market approach always the best solution or do you need regulation in some areas?

AC: IVF is a nice test case because Britain has had tougher oversight than the USA, and in general there have been many more excesses and abuses in the USA. There are no regulations of substance for the infertility industry in the USA. There are some regulations about safety, but I'm talking about a human fertilization authority that licences what's going on and who can do what. So if you look at the USA, here's what we've seen. Eggs obtained for money from women on the internet. You can't buy a baby but you can buy a womb (a surrogate mother), and you can buy egg and sperm. We've had stolen embryos used to make babies. We have 400,000 frozen embryos and no one knows what do with them because we don't have a policy like the UK has. Doctors will implant 8 or 9 embryos, risking multiple pregnancy, and then use selective abortion if multiple pregnancies occur, which they don't do in the UK. I think that's completely immoral to do such a thing. We have lousy informed consent for women, both egg donors and infertility patients. We have people offering preimplantation genetic diagnosis for illnesses like breast cancer where it's not clear why you would care because you're not going to get this disease for 30 years anyway. We have people doing sex selection

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of embryos with no counselling. Yes, I think there's a need for more regulation or oversight with respect to markets. There are slippery slopes. I think you should build stairs, or terrace the hills—that's what bioethics should offer. You have to step in and try to make sure that reproductive technology, or whatever the area of medicine, is not just the Wild West. You need an occasional sheriff to show up and say "You can't steal embryos and turn them into babies". If you're going to make babies in new and unusual ways, then you have to protect the kids' interests, and they're not protected if all you're listening to is what the paying customer wants. I'm not anti-market actually. But we need oversight and more controls. I think the British experience is better than the American.

ER: So why haven't the USA implemented more regulations?

AC: Nobody likes to tell anybody else how to reproduce—even Americans with more conservative values. The people who use these services don't want regulation. The level of desperation among infertile couples is very high, and talking about regulation to them is not easy. Reproductive services are a big industry now—probably US\$4 billion

and rising fast. That industry wants no regulations. And anything that gets you near embryos is a political quagmire, so American politicians won't go there.

ER: Would the USA look to other countries to see how regulation has worked?

AC: No [laughs]. Absolutely not. You can introduce that evidence in arguments, and I do sometimes, but it's clearly falling on deaf ears.

ER: What other great ethical challenges do you see in the coming years?

AC: I do think that eugenics is coming. If the human genome delivers on its promise to correlate genes with traits, then the application to reproduction will come. The second big ethics problem is personalized medicine, because it undercuts the entire basis of the pharmaceutical industry as we know it, which is built on lots of people taking the same drug rather than highly specialized medications for subpopulations. It raises questions about access, price, what's going to happen if the companies have to charge a lot for targeted drugs and are they willing to work on them if they cannot sell them for high prices. Conversely, if you can identify

people who are more at risk for side effects or non-responding, who deals with them? I think the genome project is going to send ripples through how we understand pharmaceutical medicine. It's going to affect clinical research—if you have drugs that are targeted to a small number of people, then how do you prove safety?

I think the use of vaccines to prevent diseases will raise interesting questions about risk and benefit. How effective does a vaccine have to be before you license it? If you have an AIDS or malaria vaccine that's 60% effective, a lot of people in countries that have epidemics will say that's good enough. It wouldn't fly in the USA or France. That's going to raise questions about double standards.

The neurosciences will keep all the bioethicists busy for a long time. One reason is that the link from genes to behaviour is like this [indicates wide gap]. But the link from the brain to behaviour is like this [indicates narrow gap]. So it's nice if somebody can tell me I have a risk factor for a gene that might make me obese or depressed, but if I can see such patterns in my brain, that gives me a lot more to go on in terms of intervention. We will see that knowledge of the brain challenges how the legal system deals with crime and responsibility. Our attitudes



there's no hesitancy on the part of DARPA [the US Department of Defense's Defense Advanced Research Projects Agency] to say "You can't publish" or "You can't do this, this is ours. We own it." The other thing that scientists don't talk about is commercialization. Universities both here and in the USA are completely beholden in partnership to industry, they're racing to get money from their patent rights and that is a far bigger restriction on enquiry than anything that anybody in a pulpit ever came up with. But it's not debated because the money looks positive to the scientific community. If the evangelicals really wanted to control science, they'd open up grants to promote some research areas and discourage others.

ER: Do you get any feedback from the scientific community when you talk about these concerns?

AC: I was at a meeting on synthetic life forms recently and talked to people who were involved in synthesizing a polio vaccine or looking at microbes to clean up radiation. They say, "What can I do? That's where the money is." They wouldn't hesitate to criticize someone who said "On religious grounds, I think you should never destroy an embryo," but they have nothing to say when someone says "You cannot publish any research that's funded for military purposes." It's almost unpatriotic to point out this return to the militarization of research. Scientists have always been terrible about being bought out by military and commercial funding. This notion of a conflict of interest has been resolved by saying "disclose it". That's it? That's enough? I would say no. You ought to have tougher conflict-of-interest policies and discussions than anything that is being done now. The universities have no policies for managing what they're doing either. When people get a lot of money, they just build a new building.

ER: Professor Caplan, thank you for the interview.

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about punishment, even capital punishment, may have to shift towards a medicalized model if we start to see the underlying physiology of mental states linked to crime. I think people will become obsessed about using neuroscience knowledge for their kids, to target aptitudes and abilities and problems early, which raises all kinds of questions about stigma and rights and interventions. Using Ritalin® to treat hyperactive kids is an early version of that, but there's a lot more to come.

Finally, I think we will see a revolution in agriculture. The genetic engineering of plants that set off the debate over genetically modified organisms [GMOs] was crude, it was like debating about Wilbur and Orville Wrights' airplane technology. And the companies who introduced GMOs nearly killed it by using it to complement their herbicide and pesticide business. But the next generation of GMOs should get rid of the chemical revolution in agriculture and replace it with the genetic revolution. If you can put vaccines in food and vaccinate the Third World or if you can put tamoxifen into food to prevent cancers, that's a different game. This generation's debate about genetic engineering of plants and animals is going to swing in very different directions. I wouldn't be surprised in 10 or 12 years to see people

yelling at meetings of the EU for the right to have genetically engineered plants, instead of keeping them out.

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ER: What about concerns over the freedom of basic research versus moral views, or bioterrorism and national security?

AC: What has captured scientists' minds now is the role of religion in basic research. That's a mistake. The religious communities both in the USA and in Europe are like Jehovah's witnesses. Jehovah's witnesses don't like blood transfusions but they love the rest of health care. And outside a tiny range of issues, the average Catholic or fundamentalist Protestant likes science. But the greatest threat to the control and dissemination of research is this marriage with the military and anti-terrorist activities. The scientific community hasn't given five minutes of thought to how to preserve their rights to publish and pick the topics they want. And