

Political Science:

Bioethicist R. Alta Charo Blends Science with Activism



“The era of the pure scientist is over,” R. Alta Charo declared in a recent talk entitled “Politics of Progress” held at the University of Wisconsin-Madison. Addressing an audience of faculty, researchers, physicians and both medical and law students, the UW-Madison Elizabeth S. Wilson-Bascom Professor of Law and Bioethics delivered her timely warning.

“If scientists don’t learn to communicate and educate the public about their work,” she said, “they will lose access to the right to do their research. They will encounter obstacles in their work that may be motivated by a political group that doesn’t really have an accurate understanding of the science.”

To researchers and physicians who may be more devoted to their science and patients than their politics, her message is not always welcome. But, she says, its reality can no longer be ignored.

Take the example of reproductive technologies. Since its introduction in the early 1970s, *in vitro* fertilization (or IVF) has been entangled in debates about when a human life begins. Almost immediately, government administrations in the U.S. took a hands-off approach to regulating and funding this research, largely to appease right-to-life groups opposed to embryonic research. By the 1980s, the Reagan administration had put a moratorium on it altogether. The result, says Charo, was a generation of patients exposed to potentially harmful scenarios.

“By not regulating it and not funding it, the private sector took over,” Charo explains, sitting on the couch in her office a few days after her talk. Subsequently, she says, IVF research took place in private clinics, funded largely by patients desperate to conceive a child. “Obviously, the incentive for private groups was to get more and more patients (in order to further their research), so IVF was advertised for people where it wasn’t necessarily the right choice.”

The result was an alarmingly rapid expansion of the field, and the much earlier use of human subjects for IVF than some felt was appropriate. “For a long time, we in the community dreaded what results might come of it,” Charo says. Thankfully, their concerns went largely unfounded. “In fact, we didn’t see a real rise in birth defects, but we were all on the edge of our seats for a while there.”

Charo’s edge-of-the-seat story reveals the high-stakes risks inherent in cutting-edge health science fields—risks that, without government support, could put vulnerable parties in the hands of ill-prepared physicians, or may squelch the research altogether.

As bioethicists, Charo and her colleagues in the Department of Medical History and Bioethics at the UW School of Medicine and Public Health identify and analyze the philosophical context and legal parameters around such scenarios. And in the case of reproductive technology—and now stem cell research, which utilizes cells harvested from surplus *in vitro* embryos—Charo concludes that the problem is a government too deeply invested in regulating personal morality. Instead, she says, governments should strive to protect the freedom of speech that is essential to scientific research.

Put another way, “The government should help me live out the dream I have for my life.” For scientists, this includes the freedom to question generally held beliefs—no matter how firmly held by others.

Talking to Charo about bioethics and contemporary politics is like speeding over a vast and sometimes bumpy terrain. In the span of a two-hour interview, she can cover everything from her views on stem cell research (pro) to the elimination of the estate tax (against) and the merits of private property interests in cadavers (debatable). Her speech is livened with poetic imagery and a mischievous drama, and she is refreshingly candid, seemingly unafraid of either the most personal or most political topics.

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This courage—or maybe it’s nerve—to address tough issues serves bioethicists well. After all, they grapple with some of the most controversial topics of our time, and often, as with issues like gene therapy and stem cell research, with dilemmas that have no precedent. Trained in combinations of philosophy, law, theology and medicine, bioethicists can effectively serve as mediators between political action groups and the healthcare and research communities. Consultants and educators, their perspectives increasingly influence policy.

This is especially true for Charo, who at least since she served on President Clinton’s Presidential National Bioethics Advisory Commission, has influenced public discourse about stem cell research, reproductive rights, end-of-life care and more. She is also a resource—and, increasingly, a subject—for journalists seeking her lucid views on tough issues. A profile of Charo recently ran in the *New York Times*.

The author of scores of articles, book chapters and government reports on everything from voting rights to medical genetics, Charo is a first-class scholar. Since 1989, she has been on the faculty of both the UW Law School and SMPH, where she lectures on everything from health law to food and drug law to medical ethics and reproductive rights. Her curriculum offers multidisciplinary perspectives for specialized professionals—mainly future lawyers and physicians—who increasingly find themselves relying on one another’s expertise.

But it’s Charo’s role in government that takes her scholarship to the U.S. Congress, the laboratories and even the streets. She has sat on several critical federal committees, including the National Institutes of Health’s Human Embryo Research Panel in 1994. Since 2001, she has been a member of the National Academy of Sciences’ Board on Life Sciences, and she has just been appointed to the Institute of Medicine’s Board on Population Health and Public

Health Practice. Not surprisingly, she receives countless invitations to teach around the world; her temporary addresses have included France, Argentina, China and Cuba. Since January 2006, in fact, Charo has been a visiting professor of law at the University of California-Berkeley Law School, where she will remain until December.

While Charo may be one of the most in-demand, informed and passionate bioethicists in the world, she firmly believes that the responsibility to better inform the public about scientific progress lies squarely on the shoulders of those whose interests she seeks to protect. “Scientists must become political activists,” Charo insists.

New medical procedures have long introduced to the public a slew of ethical dilemmas, she argues, but today’s political climate and sensational media coverage demand that scientists accurately inform the public about their work. In other words, because science has become, in part, the domain of politicians, lawyers and philosophers, the “pure scientist” must learn to articulate the innovations and ramifications of his or her science to these humanists.

Being better involved doesn’t have to mean a career change, she says. Scientists need not become overnight public relations experts, delivering eloquent treatises on their research to crowds. But, says Charo, they do need to become “personally invested” in the political process on some level.

“Knock on doors, contribute to a campaign, speak at a rally, serve on a community board,” she suggests. “I simply want scientists to have contact with the political process so when they need to step up to the plate, they can.”

Exactly what happened in recent decades to force scientists up to the plate hinges on what Charo calls a “civil war” between the science-literate and the science-illiterate in this country.

“Right now we have people who turned their backs on science after the sixth grade,

and scientists who have turned away from politics and the rest of the community,” she explains.

As a result, the public is exposed to what are highly complex and evolving scientific procedures only when these issues make sensational headlines. Most people understand only what they hear from media and prominent interest groups—groups that, she says, “look at science through a different lens than that of scientists.” The groups may infuse an issue with moral overtones, or magnify the intrusive or risky qualities of some technologies for the sake of their larger message.

“What we have is a kind of general fear of science,” Charo explains. “There is this Frankensteinian myth surrounding it.”

Nowhere is this more apparent than in the field of biotechnology, which since its introduction in the 1990s has been perceived by many as something intrinsically—if vaguely—dangerous. Charo recognizes that there is a good reason for this caution—after all, science has the power to fundamentally threaten our notion of social order.

Charo cites gene therapy as an example. Most people view genetics as a fairly simple field, she says, and they have a crude understanding of DNA. As such, people assume that each gene controls one property and that repairing or changing that property is only a matter of altering the related gene.

“In fact,” she says, “genetics are usually used for diagnosis and choice,” not treatment. But the ramifications of genetic therapies are enormous—and very political.

Amniocentesis, for example, has given women choices that put them squarely in the path of both feminist groups who defend the right to choose to abort a fetus, and disability rights activists who find efforts to avoid disabilities disrespectful to those living with them.

In fact, with the advent of amniocentesis, the experience of pregnancy itself has changed. Now the first trimester has become

what Barbara Katz Rothman has dubbed “the tentative pregnancy”—a three-month stretch in which women downplay their pregnancy until the option to terminate it in response to test results has passed.

What’s more, says Charo, amniocentesis has “moved the responsibility of nature and chance onto the shoulders of women.” Choosing to abort a fetus with known disabilities, or to deliver that child knowingly, ignites social and political debates with powerful, organized proponents on all sides.

Significantly, Charo notes, a recent public survey on this issue revealed that it is the parents of children with disabilities who are simultaneously the least likely to abort a child with that disability and the most likely to support the full rights of others to choose for themselves.

What this illustrates, she says, is that a familiarity with the disability—and not philosophical or moral tenacity—gives people a tremendous tolerance toward other peoples’ choices. Nevertheless, it is the interest groups, with their strict agendas, that most often influence legislation.

“I still wish that science and medicine were free from the motivations of these interest groups,” Charo concedes. “But scientists will be more effective if they make themselves sensitive to these issues.”

As in any civil war, Charo says, the real solution lies somewhere in a middle ground of mutual understanding. “Only when the scientific community is integrated—when its message is not just talked about at a press conference or in a sound bite but is talked about every day—will people understand what scientists really do,” she says. In other words, a greater familiarity with an issue can lead people to consider its more nuanced and multifaceted sides.

To Charo, it is this blending that determines whether we will embrace the next great scientific advancement or succumb to the fear that will hold it back.

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“The only thing that saves our country are moments of real integration,” she says.

As a lawyer who specializes in scientific matters, and a scientific thinker from her earliest years, Charo acknowledges the challenge in this inclusive stance.

Given her upbringing in Brooklyn, her aptitude for integration is perhaps not surprising. A daughter of a television repairman from Poland and a math teacher who was herself the daughter of Russian Jewish immigrants, Charo grew up with two older brothers in a world where science—physics experiments in the kitchen, the rooftop telescope—was a family game.

“We thought it was fun,” she says now. “These were things you did to amuse yourself, it wasn’t work.”

It was also a means toward scholarship and even personal liberation; her father, while from a world where women didn’t drive or drink alcohol, for example, happily drove his daughter once a week to the library, where she read voraciously.

Her father also had ambitious educational plans for his daughter, not just his older sons, both of whom now hold advanced degrees in scientific fields. And so it seemed only a matter of course that she would receive a bachelor’s degree in biology from Harvard and a law degree from Columbia.

“Science was asexual in our house,” Charo observes. “It was always assumed I would go to college and graduate school. In my family, education transcended gender.”

While it’s tempting to cast Charo as a kind of cultural translator—from both old and new worlds and fluent in both science and law—she resists this image.

“I don’t see myself as a ‘translator,’” Charo says, “but more as someone who lives in a Tower of Babel in which

everyone is struggling to abandon their specialized vocabulary, or ‘shorthand,’ to talk to one another.”

Happily, she says, her work puts her in the company of other multi-disciplinarians—scientists, lawyers, writers, philosophers. Together, they are influencing some of today’s most innovative changes in scientific and medical fields. “It’s a challenge, it’s how things change,” she says, “and it’s so much more fun, too.”

Indeed, when asked what’s really stimulating to her these days, she describes her present work on the National Academy of Sciences committee to review the U.S. Food and Drug Administration and the national system for the assurance of drug safety. Assembled to conduct an independent assessment of the current system used by the FDA to evaluate and ensure a drug’s safety post-marketing, the committee analyzes the incentives and disincentives generated in existing systems.

One of their concerns, for example, is the fact that presently the pharmaceutical companies that develop drugs are also responsible for researching their product’s safety. “Why,” she asks, “do we have a system in which the organizations that are most interested in the drugs are also the body responsible for reporting any problems with them?”

For Charo, the opportunity to reevaluate a system that she considers far less than efficient—or even logical—fuels her passion.

“This is the stuff that really makes me say, ‘Wow!’” she says. “It gets into the world of business, global competitiveness, public trust, credibility, politicization of science, and ongoing debates about the role of patent law, basic political philosophies about personal autonomy—everything!”

Scholar, speaker, policy maker, attorney: Alta Charo grapples with

bioethical dilemmas on every conceivable front. But at this suggestion, she just shrugs. “Eh,” she says, looking out her office window onto Bascom Hill, “it’s just academia.”

What really thrills her, she says, is politics, where policy is in the hands of individuals. “I see myself as a failed and frustrated political activist,” she concedes, lamenting that the years of low-paying, unstable work characteristic of entry-level politics felt too risky for a child of working-class immigrants.

“Now I watch *West Wing* with my heart in my mouth because I want their jobs—I don’t know which one I want more,” she says.

But while Charo has not completely divorced herself from the world of politics (she served on Senator John Kerry’s presidential campaign’s medical policy advisory group), for the moment, she works within a system that other people run.

“I feel really good that I’ve been able to do what I could on national commissions and campaigns,” she says. “But I’ve had to take a more conservative route.”

For this once ambitious kid who now fills a room with her presence, the optimism inherent in her work contradicts the caution in her past.

“No rules are written in the cosmos,” she says. “They’re written on paper. And they can be changed.”

