879-BIOETHICS AND MEDIA RESPONSIBILITY

Lei Xiong
China Features, Xinhua News Agency, China

Abstract

The media has been enthusiastic in covering life science stories, especially as life sciences are expected to bring major breakthroughs in the 21st century. A striking contrast to this enthusiasm is the media ignorance of the ethical principles central to research in the field of life sciences, evidenced by a rough survey on several portal and news websites in China. Up until late 2000 discussions about bioethics were by and large confined to academic circles. Alongside this inadequate media coverage of bioethics are violations of ethical principles or even human rights in the field of research.

Exploration in life sciences is no longer pursued purely for lofty scientific goals, but can also be profit-driven. As research involves human bodies and organs, it can no longer be exclusively academic. The media must be concerned with ethics in research and focus on reminding researchers of bioethics to keep their research decent and on the right track. The media must also alert the public to their rights and keep them informed.

The media must expand knowledge of bioethics among the general public and raise public awareness of bioethics to push research in the right direction.

Keywords: bioethics, media, informed consent agreement, bioethical divide

1. Introduction

Before we discuss the issue of bioethics and journalism, I'd like to share some Chinese cases with you:

Case 1 involves a patient who was injured in a traffic accident. While undergoing bone transplant surgery at a hospital in the city of Shenyang in Northeast China in February 2005, the patient had bone marrow extracted by a doctor from another department of the hospital. At the time, she was under general anesthesia and completely unconscious. Neither the patient nor her family were informed of the extraction until five months later. Till this day, she still doesn't know the exact amount they removed.

The director of the hospital's research institute admitted to the patient that researchers had extracted her marrow "for purposes of scientific research" related to stem cells and assured her the amount taken would "do no harm" to her health and recovery.

The hospital offered 30,000 yuan – about US$3,750 – for her silence. But by now, this patient could barely stand up and so she sought larger compensation. She never thought to challenge the hospital for violating her right to know.

And what has become of the doctor who performed the secret extraction while she slept? He has been promoted.

Case 2 was reported by the Chinese media in early 2004. A Beijing hospital performed a drug trial for an American company, recruiting nearly 40 HIV-infected peasants from Central China's Henan

province in 2003. The farmers competed to participate, assuming it was an opportunity to obtain good treatment. Two months into the trial, two participants died.

In this case, all the participating farmers were asked to sign a document that was full of terms they could not understand, including some "foreign letters." Later, when it occurred to some of the participants that something might be wrong and when they challenged the hospital for the truth, they were told that they had been informed of the trial – the alien document with their signatures was an informed consent agreement. Not one of the farmers had been given a copy of that agreement. They were charged 48 yuan – about US$6 – for a copy of the agreement when they tried to use it to sue the hospital and the US company.

Case 3 came to light at an American Society for Reproductive Medicine convention in San Antonio, Texas, in October 2003, when a Chinese research team announced that they had created fetuses from three genetic parents using nuclear transfer gene technology. This kind of human stem cell research had been banned on ethical grounds by the US government in 1998. So the American researchers had found partners and moved their operations to Guangzhou, South China. The shock announcement drew international criticism, and soon after the Chinese government banned the research.

The researchers at the Zhongshan Medical University claimed the pregnant woman was an informed volunteer who had previously suffered fertility problems. But nobody knows exactly what they informed her or in what context she gave her consent.

Case 4 involves genetically modified – GM – food. In China, no official permit for the commercial release of GM rice has ever been issued, but GM rice has reportedly found its way into markets in central and southern China. Before GM rice, edible oil made from imported GM soybeans had already come to dominate the Chinese market.

Soybeans originated in China and soybean oil is widely used for cooking. For years, China led the world in soybean production and exports. Now it is dwarfed by the United States, Brazil and Argentina. The watershed year was 1996 when China shifted from being a net exporter to a net importer of soybeans. And most imports were GM varieties.

The point here is not about whether GM food is safe or not. The point is whether we as consumers have the right to decide and choose what variety we'd like to have and whether we are able to make that choice. As GM food flooded our market, we were passive: taking what was given to us, without ever knowing why we must have it.

2. Loophole

I could go on and on with similar cases, all illustrating the gap between our enthusiasm for the amazing breakthroughs in life sciences and our ignorance of the ethical problems that may be involved in these advances.

This gap is evidenced by a rough survey of China's media coverage of life sciences and bioethics. As of February 27 this year, using the key words "life sciences" to search related news stories on www.sina.com.cn, one of China's leading portals, 35,219 items popped up. In the search for "bioethics", we only got 1,387 related news stories, barely 4 percent of the total for life sciences. On www.sohu.com, another leading portal of the country, the ratio is much better: 9,574 versus 3,729, a ratio of about 2.5 to 1. But on the news channel of www.baidu.com, the divide widens again: 97,500 against 2,080, meaning coverage of bioethics amounts to a mere 2.2 percent of all life science articles. Looking at the leading Chinese news websites, we found 2,178 news stories on life sciences versus 12

on bioethics at www.xinhuanet.com, or a ratio of 181.5 to 1. At www.people.com, the website of People's Daily, we found 689 versus 63 or a ratio of 11 to 1. When it comes to bioethics in China, we retrieved zero stories on websites including Sina, Xinhua and the *People's Daily*.

This appalling imbalance has of course left open many a loophole in the implementation of internationally recognized bioethical principles and regulations.

A typical example is the Program for Population Genetics, or PPG, at Harvard University. Initiated in the mid 1990s, the program collected blood through various projects across China. Up to the year 2000, at least 12 projects collected genetic data for studies on diseases including asthma, hypertension, obesity, diabetes to osteoporosis. It remains unknown how many blood samples were taken out of China, but for asthma alone, the principal investigator of the program admits that more than 16,000 DNA samples were shipped to the United States. This was almost eight times the number approved by the funding source of the project: the US National Institutes of Health.

These genetic studies, involving thousands of people in rural Anhui Province, had not gone through prior examination or review by any ethics committee. Participants were not adequately informed. And it is not clear at all that they all voluntarily donated blood: the forms in some studies included complex language difficult for rural Chinese families. Other forms failed to list the risks and discomfort associated with some tests. Still other forms appeared to have been backdated, containing different samples of handwriting, dates and signatures. Many different forms appeared to have all been written by the same hand. The participants were unlikely to benefit from any resultant medical findings. Numerous departures were made from the approved documents without review by any ethics board. For instance, the number of approved subjects for the "molecular genetic epidemiological study on asthma" was 2,000. But in actuality 16,686 subjects were recruited.

Even the Chinese partners of the Harvard program were not fully informed of many things a partner should know. Up to January 2001, the Anhui Medical College, one of the Program's major partners in China, had no idea that Millennium Pharmaceuticals Incorporated, a US biopharmaceutical company founded in 1993, had funded Harvard's various Anhui projects and had made a very handsome return purely by boasting of its access to Chinese DNA. Following its pioneering $3 million investment in Harvard's asthma program in the mid 1990s, Millennium itself received $100 million funding from some big multinational companies. Yet when Millennium Pharmaceuticals articles appeared in the Chinese press portraying a successful biomedical start-up, no one mentioned its true history or its role in the problematic Harvard Anhui projects.

In their blind belief in the reputation of Harvard University, the Chinese administration in charge of human genetic resources entrusted the US team to produce a working contract, which they approved without hesitation. However, although the Chinese authorities approved only three projects for the year, at least 15 projects were carried out in Anhui province.

It seems that all those studies that are impossible in an industrialized country became possible in a media environment of indifference to bioethics.

3. Principles

There are strict stipulations concerning research involving human subjects in the United States and the international community. Just after World War II, in 1947, the international community formulated the *Nuremberg Code* in reaction to the criminal medical research that had been conducted by the fascist countries during the war. This was the first international code on norms for clinical experimentation. Its

very first principle was “the voluntary consent of the human subject is absolutely essential.” Collection of human blood samples should fall well within the scope of clinical experimentation.

In 1964, the 18th World Medical Assembly held in Finland adopted the *Helsinki Declaration*, further regulating the ethical principles for medical research involving human subjects. Then the World Medical Assembly amended and revised the *Declaration* in 1996 and 2000, perfecting the stipulations about informed consent. The 2000 version of the *Helsinki Declaration* stipulates that “in any research on human beings, each potential subject must be adequately informed of the aims, methods, sources of funding, any possible conflicts of interest, institutional affiliations of the researcher, the anticipated benefits and potential risks of the study and the discomfort it may entail. The subject should be informed of the right to abstain from participation in the study or to withdraw consent to participate at any time without reprisal. After ensuring that the subject has understood the information, the physician should then obtain the subject’s freely-given informed consent, preferably in writing. If the consent cannot be obtained in writing, the non-written consent must be formally documented and witnessed.”

What is essential to notice here is that it is a must to acquire the personal consent of each potential subject for biological research, and the basis of that consent is adequate information. The prerequisite of this informed consent is that the participant must be free from any research, medical or administrative institution coercion in any form. What he or she is to be informed must include everything about the research, ranging from its aims, methods and sources of funding to the anticipated benefits, as well as the participant’s rights and interests. The requirement for the participant’s “freely-given informed consent” manifests an important and substantial ethical principle, showing a respect for people and for human dignity and independence.

The Belmont Report published by the US Department of Health, Education and Welfare on April 18, 1979 specifies ethical principles and guidelines for the protection of human subjects of research. Aside from the questions like “who ought to receive the benefits of research and bear its burdens,” the bioethical principles also insist that informed consent ought to be voluntary and that “this element of informed consent requires conditions free of coercion and undue influence.”

The Universal Declaration on the Human Genome and on Human Rights endorsed by the United Nations General Assembly in December 2000 makes it clear that in international collaborations in life sciences, especially those with developing countries, it is essential that the bioethical principles are followed. In life sciences research, the paramount principle is voluntary informed consent.

On June 14, 2000, the Council for Science and Technology of the UNESCO Bioethics Committee adopted the document *The Fundamental Principles of Research on the Human Genome*, which clearly states that “scientific research should conform to the respect for human dignity” but should by no means violate human rights in the name of scientific research as was the case with the fascist regimes of World War II. It emphasizes genetic diversity and opposes gene discrimination. It stresses the rights of participants or subjects. It has detailed stipulations on informed consent, such as “a research sample may be collected from an individual subject for research on the human genome only after having given the participant sufficient explanation beforehand and having obtained the consent of the participant on his/her own free will (informed consent);” “the consent should be expressed in writing;” and “individuals who are requested to provide a research sample but do not consent to that request should not be disadvantaged for his/her refusal.”

As legislation and regulations on bioethics sometimes lag in developing countries in comparison with the United States, the relevant US authorities have particularly specified that any US-funded international research project – even when conducted in a different environment, with a different

culture and customs – must honor the bioethical norms concerning voluntary informed consent universally agreed upon by the international community.

On top of these principles and regulations are the institutions and organizations that supervise the implementation of these principles. “On undertaking any research on the human genome, its research plan should undergo a prior review by an independent, multidisciplinary and pluralist Ethics Committee,” which “should examine a submitted research plan” “mainly from the ethical, legal and social points of view.” “The Ethics Committee should guarantee its transparency in its organization and reviewing deliberations.” At the level of the United Nations, there is a Bioethics Committee under the UNESCO Council for Science and Technology. National ethics committees or institutional review boards have been set up in various countries, performing a similar function. International collaborative projects, such as those Harvard projects in China, could only become legitimate after they passed the examinations of ethics committees at various levels in China in addition to those on the funding side.

These rules are essential to guiding decent research in life sciences and necessary for us in the media to know so that we can effectively play our watchdog role for the public benefit. Yet in China, up to the beginning of this century, discussions of these bioethical principles were by and large confined to the academic circles of ethicists and were hardly followed by media. Our media was passionate in following the research of human genome, making it headline news time and gain, but there was little coverage of the ethical issues that research could incur. As mentioned above, this bioethical divide created a huge vacuum in media supervision, giving rise to neglect or violation of people’s rights and interests.

4. Misconceptions

This bioethical divide has much to do with the following misconceptions.

Misconception 1. Life sciences are solely the realm of academics. This is wrong. Much applied biological research could not happen without people volunteering to participate in it, or to donate organs, blood, cells or genes as research materials. It is unethical and immoral to ask people to participate without acknowledging their rights. Therefore, public participation is necessary, not only in discussions of bioethical issues, but also in the formation of ethical committees and in the drafting of laws, policies and regulations regarding life science research.

Misconception 2. All research serves noble goals and benefits humankind. This is not necessarily true. Scientists can be driven by other, more selfish interests. They can be tempted to ignore bioethical principles in exchange for money and fame.

Misconception 3. The current bioethical regulations are perfect. Wrong. Even though we may not yet have reached the standard stipulated in the currently available bioethical principles, it is dangerous to assume all bioethical issues have been exhausted. Many regulations on research ethics were made when developing countries had little say in international affairs, and so these regulations may not make full consideration of their particular conditions.

Misconception 4. It is unnecessary to observe bioethical principles in developing countries as rigorously as it is in industrialized countries, hence the poor enforcement of research regulations and legislation in some developing countries. Everyone is equal in terms of human rights, and so people’s right to know should be equal too. If there is a difference, then the right to know should in fact be upheld even more strongly in developing countries. More funding and greater efforts should be made to give full information to the communities involved in life science projects, particularly in areas where

literacy is low.

Misconception 5. The informed consent agreement is a mere contract for research participants to sign. No, it is actually a process during which each participant is given adequate information about “the aims, methods, sources of funding, any possible conflicts of interest, institutional affiliations of the researcher, the anticipated benefits and potential risks of the study and the discomfort it may entail,” as stated in the 2000 version of the *Helsinki Declaration*.

5. Media’s Role

The media must cast off these misconceptions and instead assume their watchdog role in covering life sciences. Life sciences today not only involve human bodies, organs, diet and living environment, but also often consume millions in public funds. By any measure, this is no longer a matter to be confined exclusively to academic circles. In this context, journalists, as the fourth estate after the legislature, administration and judicial, are obliged to oversee life sciences research, to make sure that research is on the right track without any abuse of public funding and/or human rights.

In parallel with this role, the media should also shoulder the responsibility of extending knowledge about bioethics among the general public and making people aware of their rights with regard to research. While covering new discoveries and technological innovations, we should not forget to ask the basic questions: Who has gained? Who has benefited from the research? Who are the stakeholders? Are there any potential losers and why? Was everything about the research conducted properly?

Some researchers tend to dismiss the idea that bioethics needs watching over, on the grounds that enacting these high principles -- for example obtaining informed consent -- slows up their research. But numerous examples have shown us that bioethically faulty research cannot last long. The obvious lesson is of course the downfall of Dr. Hwang Woo Suk. Where bioethical issues are discussed exclusively in academic circles – among the so-called “professionals” who consider themselves the rule makers and demonstrate no interest in what others think – research seems likely to turn arrogant and flout bioethical principles, finally producing poor quality research.

While remaining ever more vigilant, the media should identify those researchers who take pains to observe bioethical principles and conduct their work properly. They should publicize and encourage such research. In doing so, both researchers and the public will become more conscious of bioethics and the raised consciousness of bioethics will in turn steer biological research in the correct direction.