

IV World Conference on Bioethics: standing for the defense of human dignity

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The shores of the Cantabrian sea around Gijón, the most populated location of the Principality of Asturias, served from November 21 to 25, 2005 as the stage for the IV World Conference in Bioethics, convened by the International Society of Bioethics (SIBI) and presided by Dr. Marcelo Palacios, head of its Scientific and Organizing Committees. The meeting had five main topics: Privacy and genetic data, Biological Weapons, Access to Health Services and medicines, On Violence, and Life and its development.

A Cuban delegation attended the congress, headed by Dr. Daniel Piedra Herrera, Senior Professor and Secretary of the Cuban Committee on Bioethics, and with the participation of Dr. Carlos Delgado Díaz, philosopher, Senior Professor of the University of Havana, Diana García del Barco, MD, researcher and head of the Bioethics Committee of the Center for Genetic Engineering and Biotechnology, Tatiana Zaldívar Vaillant, neurogeneticist and vice-president of the Research Ethics Committee of the Institute for Neurology and Neurosurgery of Havana city and staff member of the Bioethics Department at the “Calixto García” School of Medical Sciences, Ricardo Hodelín Tablada, neurosurgeon of the “Saturnino Lora” provincial hospital and head of the Bioethics Department of the Medical University at Santiago de Cuba, and Marcio Estrada Paneque, neuropsychiatrist and Senior Professor of the Pediatric Hospital at Manzanillo.

A total of 38 countries from five continents sent delegations to the meeting. The presence of the Nigerian Wole Soyinka, Nobel Prize in Literature in 1986 and one of the most prolific African thinkers of the last century, was the highlight of the opening day. There is more to Wole Soyinka than just being the pseudonym for Akinwande Oluwale Soyinka, since he was not only the first black person to receive the Nobel prize in Literature, but has, in addition to his lengthy literary work, left his mark in philosophical monographs, plays, essays and translations, through which he has never failed to stand for the defense of human dignity. Invited by SIBI, Soyinka declared during the opening conference: “I am not here to prescribe magic recipes, but to transmit a message: only empathy between human beings will be able to place bounds to the limits of science”; and he added later: “This consensus must go beyond declarations from UNESCO or any other agency, because I think we should all be looking for domestic solutions to let us accomplish our common goal of preserving our planet and, in the long run, the human race and all living beings”. He also insisted on the need for

“medicines to be cheaper and therefore, accessible to everyone”.

The following day, with the meeting at full gear, privacy and genetic data were the topics discussed. An outstanding lecture entitled “The protection of genetic data related to biological samples for biomedical research” was delivered by the renowned Spanish bioethicist Carlos Romeo Casabona, head of the Inter-university Department of Law and Human Genome of the Deusto and Basque Country universities, who argued that “in therapeutic cloning, the end does not justify the means. You can accomplish very important goals with means that make them worthless. So, you have to wonder” -he emphasized- “whether cloning techniques constitute a serious challenge to human life. I do not think so, I think that cloning techniques can be used for research purposes as long as their use is properly justified”.

In this context, Dr. García del Barco introduced her oral communication “Preservation of integrity, privacy and confidentiality in genomic research projects: a Cuban experience”. This lecture proved how the bioethical implications involved with the execution of scientific projects aimed at finding genes associated to complex diseases that represent important causes of morbidity and mortality do not always turn into ethical conflicts when using the proper methodology that takes into account their possible occurrence and measures to avoid this.

In the sessions of November 23, the intervention of Volnei Garrafa, president of the Directive Council for the Latin-American and Caribbean Network of Bioethics, was warmly received. Garrafa insisted on the need to defend the bioethics practiced by Third-World countries against the colonization of bioethics by North America.

That day, Dr. Carlos Delgado delivered a speech entitled “The enigmas of designed life: biotechnology, scientific knowledge and ethics”. He expressed: “As a creative activity, there is nothing radically new from an ethical standpoint to be discussed about genetic engineering: It is a scientific and technical discipline like any other, devoted to finding means to investigate, broaden and deepen human knowledge and to obtain useful products”. Father Alfonso Llano Escobar, Colombian bioethicist, spoke highly of the arguments presented by Dr. Delgado.

In the same topic of privacy and genetic data, Dr. Erwin Deutsch, Professor of Law of the University of Göttingen, lectured about “Rights and obligations of the persons concerning their genetic data”. He

referred to the genetic code: "The intrusion into the genetic make-up of a person is much more dangerous than all other possible violations combined known up to now. The genetic code not only shows that every person is an individual, but it reflects the tendencies in a person that might affect his personal life. The privacy of families or partnerships between men and women have been questioned again in that the genetics of their offspring may be doubtful. Therefore, it is necessary to protect the person as much as possible as far as genetic components are concerned, and to limit the exemptions".

Later he argued that "DNA is used in many countries. In some, exclusively to see whether someone is the father of a child born out of wedlock and there have been many regulations forcing prospective fathers to undergo such DNA-tests. On the other hand, if a husband is sure that his wife has been unfaithful, he might bring a suit against the wife, the child, or both, claiming that he is not the actual father. If this is allowed under certain conditions and within a certain time frame by the national law, then usually the DNA test is applied as well".

Michele Stanton Jean, Chair of the International Bioethics Committee and Member of the Quebec Commission on Ethics in Science and Technology, offered a dissertation on "Confidentiality and genetic data: how to ensure a democratic and responsible framework of governance". The renown bioethicist analyzed the Universal Declaration on Bioethics and Human Rights, expressing: "The first principle established by the Declaration is the respect of human dignity and human rights, with an emphasis on the following two points: The interests and welfare of the individual should have priority over the sole interest of science or society and if the application of the principles of this Declaration is to be limited, it should be by law, including laws in the interest of public safety, for the investigation, detection and prosecution of criminal offenses, for the protection of public health, or for the protection of the rights and freedom of others. Any such law needs to be consistent with the international human rights law".

Dr. Juan Ramón Lacadena, representing the Complutense University of Madrid, presented his lecture "Privacy and genetic data". The physician offered an interesting historical tour of other declarations, criticizing their negative aspects. He finally concluded that "Genetic data banks may have two types of applications: Health-related (involving individuals, families and population groups) and legal (legal genetics: identification, paternity, criminality). Generically, it could be said that the ethical and legal problems posed by genetic data banks, as in other data banks, are intimately related to privacy and confidentiality".

Professor Aitziber Emaldi Ciri6n, of the University of Deusto, presented an interesting talk on "The rights of the subjects over their genetic data". She defended the right to not know, and argued: "A person might not want to know a certain piece of information, on the grounds that this knowledge may become a burden, and therefore reclaim his or her right to not know. As a matter of fact, the afflicted person often avoids finding out

whether he or she is actually a carrier of an illness, or even whether there is any probability of being affected by it in the future; which implies that a big problem lies ahead when the future promise of individualized medicine becomes a reality". Confronting a question from the public, the professor answered: "The right to the protection of private life without external interferences has come back as a guarantee of individual choice, with the implicit understanding that the right to not know is nothing but another expression of the right to privacy".

On November 24, Garrafa called everyone's attention again with her lecture "The bioethics of intervention and the access to the Health system and medicines", very much in tune with the conference delivered by another renowned Chilean bioethicist, Dr. Miguel Kotow, entitled "Health Justice: Between the State and the ethics of protection". According to Kotow, "Every moral agency has the principle of the protection of communication through veracity, of promises through fulfillment, of social practice through the culture of trustfulness. We can only trust that our peers care for our interests during our mutual interactions. The mutual protection we owe to each other is expressed in our trust that by accomplishing our interests we will not go against, but instead, hand in hand, with a respect to the interests of others".

A speech with the title "Registering patients with neurogenetic disorders" was presented by Dr. Zaldívar. She offered a detailed explanation on the Cuban experience acquired during the registration of patients with three neurological disorders: Duchenne/Becker muscular atrophy, spinal muscular atrophy and Huntington's disease. She emphasized the importance of genetic counseling and the need for multidisciplinary research teams.

Dr. Marcio, on the other hand, offered a conference on the "Ups and downs, dilemmas and paradigms in health care for HIV/AIDS carriers and patients in the Third World". He concluded by saying that "the universal behavioral patterns have still not changed to a point of equality of opportunities, rights and liberties that guarantees the dignity of all human beings suffering from HIV/AIDS. Therefore, much coordinated work is needed, taking into account that this plague has changed radically to become a chronic disease that requires new options for research and approaches from a social point of view".

The oral communication "Involved observation: about the 'elder being' and the 'nurse being' " was presented by the registered nurse Carmen Chamizo. Based on her long experience with geriatric patients, her participation was a call to the attention and care of the elderly. She explained the need to continue "working with the elderly, discovering and learning from their problems and needs". Emphasis was placed on the fact that "no treatise or printed body of knowledge can substitute our careful evaluation each time we go to Manuel's or Maria's home and find out how they live, the story of their lives, their beliefs, their environment, their family, their illness (if there is one), the way they have come to terms with themselves, the smell of their ulcers, etc. Only then will we know the patient and this, together with our

personal and professional experience, will ease the task of shaping in an effective and realistic way, our nursing service”.

A very commented conference was offered on November 25 by Prof. Piedra. Entitled “Health care in poor countries: Is it possible?”. Based on the Cuban experience, the conference was an update on the Cuban health care system that illustrated how it is possible to build a good health care structure if the political will to achieve this goal is present. During that afternoon, Dr. Hodelín Tablada talked about “Persistent vegetative state patients: Dead or alive? Current bioethical thoughts”, which came at the best possible moment, given that earlier that day, a very conservative and reactionary lecture with discriminatory tints on the same subject had been presented. Dr. Hodelín defended the thesis that “although some authors consider them dead, vegetative state patients should be considered to be alive, since they have anatomic and physiological possibilities for a functional recovery”.

“Ethics at the beginning of life” was the presentation of Víctor Penchaszadeh. The Argentinian bioethicist argued that “The product of conception can not have the same moral attributes as the newborn child, although some symbolic respect is granted. The fetus progressively gains new biological and physiological attributes as it grows *in utero*, and so develops its moral status, getting progressively closer to that of a neonate”. Confronted with a question from the audience on what was more important to him, whether an embryo or a child, he answered categorically “a newborn child will always be more important to me than an embryo”.

Other highlights of the meeting were a joint communication from the participants in support of the “Universal Declaration of Bioethics and Human Rights of UNESCO, particularly due to its engagement to social problems and the protection of the environment”; and the “Declaration of Gijón against the use of biological weapons”, approved in a plenary session due to its engagement with, among others, “an open advance towards a fair, coparticipatory, corresponsable, cooperative, sustainable, equitable and solidary world order that may end armed conflicts, wars and terrorism”.

During the closing ceremony, honored by the presence of Mr. Vicente Álvarez Areces, head of the government of the Principality of Asturias, Prof. Baroness Mary Warnok, from the UK, received the SIBI 2005 Award. Dr. Marcelo Palacios was designated by Prof. Warnok to receive the award in her name, since she could not attend the ceremony.

In spite of the low temperature -between 3 to 6 degrees centigrade- the warmth of its people was noticeable in this historical city which was the only open port to the sea on the Silver Route (one of the most important trading networks during the Roman Empire). Our delegation, which represented Cuban bioethics with dignity, would like to thank Dr. Marcelo Palacios, the organizing committee and everyone at the meeting for the warm welcome we received in this beautiful Spanish city, where the blue sea joins the green mountains. The green color of hope, hope for bioethics to become a useful tool to all of society, a tool that makes us grow while always defending the dignity of human beings.