Report
of the 7th Global Summit
# of national bioethics advisory bodies

Paris, September 1 & 2, 2008

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Thirty-five countries from 5 continents were present at the Paris' Summit:

Armenia, Australia, Austria, Azerbaijan, Belgium, Benin, Burkina Faso, Canada, China, Croatia, Cyprus, Denmark, Ecuador, Estonia, Finland, France, Gabon, Germany, Greece, Iceland, Japan, Luxembourg, Mexico, Morocco, Netherlands, Portugal, Russia, Senegal, Singapore, Sweden, Switzerland, Tunisia, Ukraine, United Kingdom, United States

In an introductory speech, Roselyne Bachelot-Narquin, French Ministry for Health, has proposed several trails for debates and thinking:

This gathering of 35 nations attests of a will to resist the nihilist speech according to which, to each his own, we should give up putting values on a hierarchical scale.

The existence of a debate on the values, within each nation, is certainly an indication of this conviction that it is necessary and possible to agree on them. The ethical debate that is restive with the relativism lies on the implicit belief in the possibility of a criterion that could be made universal, which would make it possible to legitimate practices.

The ethical debates should not be reduced, indeed, within their strictly national stakes. The exercise of compared right, always useful, has also, in this respect, an ethical value, since it can induce a salutary testing period of our own certainty.

And there is certainty only from fantasy or from fanaticism.

Alain Grimfeld, the President of the French national advisory ethics committee (CCNE) evoked the –as of now- utopist search for an universal ethics, leaving us today in the necessary humility of debating general concepts in the respect of everybody's moral and cultural background:

(…) But it would be illusory to think of building / developing, in the immediate future, a universal ethics. It is nevertheless essential to be able to discuss, between countries, around these general but so fundamental concepts, by taking account of the diversity of our lifestyles, our cultures, our religious convictions, our political and daily environments.

The summit was organized around three main themes, **the respect of the person**, **the autonomy of the person** and the essential topic of the **relationships between the Ethics committees and the public debate**. The largest place has been given to discussion both after the talks and at the end of the day in the form of a dedicated debate on the themes of the day.

In addition, the last session of the meeting was devoted to the activities of international organizations such as UNESCO, the European Council, the COMETH, the European Commission, and the World Health Organization.

The Division for Ethics of WHO expressed its wish to be informed of the work performed by the National Bioethics Committees, so that it can make them easily accessible to all the Committees. It wishes also to facilitate exchanges between small groups of two or three Committees, some recently established, others older, in order to support experience sharing, and finally to develop an ethical survey and a real capacity to detect problems before they come to light, in order to stand in a phase of Ethics that would be more proactive than reactive

RESPECT of the PERSON

Chairs: Jeanine-Anne STIENNON & Peder AGGER

The theme of the respect for the human body illustrates the tension existing between respect of the person and autonomy of the person. Can we do what we want of our own body? But, wouldn't a common thought pushing to answer "no" to this question be likely to derive towards a paternalist or even totalitarian attitude? It is thus essential to find the right balance in the definition to be given to the concept of respect of the person. A Belgian humorist said that in the life, there are two things that one cannot make halfway: It's to be born and die. The beginning and end of life concentrate ethical issues as they are subject to highly variable social, cultural and religious thoughts and behaviors. In this respect, it was important to bring the topics of organ transplant and medically assisted procreation at the center of the discussion on the respect of the human body.

Respect of the Human Body

- Organs & Tissues Transplant
  Christiane DRUML, President of the Austrian Bioethics Committee
- Reproduction
  Edith DELEURY, President of the Canadian Committee for Science and Technology Ethics

Some fundamental ethical principles are accepted by many countries, in particular Western countries: i) inviolability of the human body, ii) absence of patrimonial right over one's body, iii) absolute exemption from payment of the donation and of the transplant, iv) anonymity of the donor and its family (except in the event of a living donor), v) prohibition of publicity with lucrative goal, vi) principle of equity of the citizens with respect to transplants, and vii) respect of public health (bio-safety). The declaration of Istanbul, written at the conclusion of a congress organized in April and May 2008 and bringing together specialists in transplant from the whole world, is a document of consensus proposing a definition of the traffic of organs, marketing of grafts and transplant tourism.

In many countries, the entire process is under the control of an "Agency" (the Bio-Medicine Agency, in France) that ensure of the maintenance of a medical list of priorities for transplants, by organ, at the national and European level, seldom at an international level. It also takes care of computerized files containing, in the event of possible brain death, the list of donation refusal for countries which chose the "supposed assent" (France, Spain, the United Kingdom, Sweden, Italy, Austria…), and of the express assents for countries which chose this legal frame (Germany, Holland, Switzerland…), a choice in which local cultures, beliefs and laws were determinant. The European Council (March 2004) recommended the setup of a register of organ donors, allowing a rapid national and international medical access. This register has to be modifiable at any time by each individual, constantly, and with complete freedom.

In practice, as Christiane Druml underlined it, the doctors ask anyway the families for authorization to make sure that the patient was actually ready to becoming a donor. She also emphasized the international shortage of available organs, the cause of which leads to several kinds of interpretations.

In the event of a brain death, if the objectives are clear - to connect a brain death to an immediate medical use and to develop to the maximum the transplant of organs in a requirement of public health - their integration in our ethical and philosophical context is the subject of a very current, and recurrent debate: the “utility” aspect of the diagnosis of death, governed moreover by law, is for certain a fundamental error which makes run the risk that the utility takes the step on ethics in the thought about the sense of life and death.

Attitudes respective to donation of organs differ according to societies, often because of cultural and social factors. The same applies to the rate of donation refusal by families, which strongly varies in Europe from 6% in Portugal to 42% in the United Kingdom. In the Buddhist and/or Shinto (India, Japan…) countries, the transplant from living donors prevails, but remains rare. The transplants from brain deaths are still opposed to the concepts of integrity of the body and the determination of the exact date of death.

The Summit participants expressed clearly the need for protecting the living donors, while fighting against transplant tourism and organ traffic. Hence, it appears important to envisage for these people a gratification enabling them to benefit of a health insurance thus protecting them about necessary care consecutive to the organ removal.

Even more than organ donation is the field of human reproduction a never ending matter of debate between and within countries.

Starting from the Canadian example - that of a legal stake resulting from the duality between federal right and provincial right, it could be easily perceived that the conciliation between the interest of the couples and that of the children, the dissociation between design, gestation and birth by the place granted to the technique, the requests related to religious or personal motivation, are questioning concepts such as what is being a parent, or the parental project, and reconsidering the new relations that are established between the child and his/her parents resulting from such practices of medically assisted procreation.

Some countries set up the parental project in source of right for all. The term of assistance with procreation has thus more than a single medical significance. The social dimension is extremely important and family ties do not stay within an institutional framework but may lie in the field of the will. Nevertheless, the principle according to which children have all the same rights and the same obligations has still to be followed.

The variety of legal controls of the medical assistance to procreation between different countries, sometimes close to each other, calls for caution about a possible procreative tourism, as it is, for instance, the case between France and Belgium. In addition, the issue of incest was put forward as it is difficult to make sure that an increase in the donation of gametes could not lead to unintentional incest that some religions consider as an absolute interdict.

We all agree, concerning both organ transplant and reproduction, that the laws and the recommendations vary considerably from one country to another. But of which kind are these differences? Are they differences of values, convictions, and ethical considerations or, on the contrary, methods and techniques to reach goals that we all share? The harmonization of those recommendations and/or regulations should not be an end in itself. The essence may be to try to understand which are our common values and to develop on this basis suitable methods enabling to reach them and to ensure that they are respected. It is thus important to start by determining in what we differ.

Respect of Private Life and of Confidentiality

- Ethical Issues Concerning Electronic Files
  Hele EVERAUS, President of the Estonian Ethics Committee
- Genetic Tests & Research
  Hin Peng LEE, President of the Advisory Bioethics Committee of Singapore

It is interesting that a representative of Estonia has presented the ethical issues concerning medical electronic files, as this country has opted for the creation of personal medical records for all the population, a program launched in 2008. This implementation in itself does not comprise a method of enlightened assent. According to the point of view of the Estonian Ethics Committee, the personal medical records must take on a permanent accessibility and an availability of the data, regulations, duration of the treatments.

The prospect is that the data concerning a patient are accessible to his/her doctor, with the colleagues of this one, even with the patient himself (what brings nevertheless to wonder which information must be brought to his/her attention).

Some of the general principles worked out by the Estonian Ethics Committee, relate to the anonymity of the data. On another hand, discussions in this committee have raised the possibility for the patient of restricting him/herself the access to the data relating to him/her.

In any case, Estonia has retained a mode privileging the health system, solidarity and safety to the accessibility of the data for the patient.

The confidence of the citizens towards such devices is related to the ability to reach a balance between individual and collective interests. The law prohibits the insurers and the employers to have access to the personal medical data. As of now, the system provides that the collected data could not be used for research. It does not appear that the Estonian initiative was the object of a public debate. Vigilance with regard to confidentiality of the data is placed under the responsibility of official services. However, there is no definite answer to the concern for a possible use of the data at discriminatory ends.

Confidentiality and discrimination issues are also at the center of the debate on genetic testing, predictive medicine, and more generally about modern human genetics.

Genetic research has been the topic of one of the first opinions published by the Bioethics advisory committee of Singapore that has been created in 2001. The background is that genetic research and genetic testing are aimed at helping us fight and defeat genetic diseases. There is worldwide a rapidly increasing demand for such tests.

Genetic data are supposed to have an important predictive value for the person, but are also of interest for his/her family (in situation of possible hazard), for his/her employers or insurers. Hence comes a dilemma: do geneticists have to deliver this information to their patients? How then to cope with the maintenance of a relationship of trust between doctor and patient? The later is entitled to the respect of his/her private life, but isn’t it the duty of the doctor to alert family members in situation of risk. The disclosure of genetic data without the formal assent of the person, and restrictive conditions appear to be wide open questions and a matter of international debate. In any case, it calls also for a particularly important responsibility of the geneticist.

Nevertheless, basic principles on genetic testing and genetic research seem clearly known and shared by a majority. They call for the respect of the autonomy of the subject, in particular on the issue of the assent, the respect due to vulnerable people and finally of the respect of private life and confidentiality. Those are expressed in more general terms in the Convention on the Human rights and biomedicine, issued by the European Council in April 1997. The human being must be protected in its dignity and its identity. Any person must be guaranteed of the respect of his/her rights and fundamental freedom with regard to the applications of biology and medicine (Article 1). It could not be carried out test predictive of genetic diseases or making it possible either to identify the subject like carrier of a gene responsible for a disease, or to detect a predisposition or a genetic susceptibility to a disease, that at medical ends or of medical research, and subject to a suitable genetic council (Article 12 of Convention). - Any form of discrimination against a person because of her genetic inheritance is prohibited (Article 11 of convention). An unsuitable use of the results of a genetic test could involve discrimination for the access to employers or insurances and cause stigmatization for the person concerned.

The discussion on this topic related to the respect of the person, has given a perfect transition towards the matter of autonomy, as it has been reported that certain populations have a communitarian way of life, meaning that the personal assent should not be split from the communitarian assent. It also means that there is a strong sensibility onto the way results are published as they could well stigmatize part of a population. This concern appears as a generalized one since more countries welcome diverse ethnic groups. Moreover, the permanence of genetic data implies that something that was not critical at one time can become a very sensitive subject several years after.

AUTONOMY of the PERSON

Chairs: Jean-Pierre CHANGEUX & Jalloul DAGHFOUS

Jean-Pierre Changeux raised the question of whether autonomy is based on self-conscientiousness. In any case, it is based on the fact that each one has a concept of what is well, good or right. The ethical debates starts at the boundaries of conscientiousness and at the point where everyone’s concept of good and right interfaces with another.

- Life Ending
  Pierre LE COZ, Vice-President of the French National Advisory Ethics Committee (CCNE)
- Post-Comatose Unconsciousness States
  Colin THOMSON, President of the Australian National Council for Health and Medical Research
- Incapacities: Issues Addressed by Dementia
  Hugh PERRY, Member of the Nuffield Council on Bioethics, UK
- Autonomy of the Physician and Demands from the Patient
  F. Daniel DAVIS, Executive Director of the President’s Council on Bioethics, USA

To re-appropriate one’s own death appears as a legitimate will of more and more people, especially elderly people. This means that everyone would be able to die naturally, without “unreasonable obstinacy”, a concept defined by the French Committee as “the refusal to recognize that a man is dedicated to death”. However this unreasonable attitude terrors families, close relations and all witnesses of these bad deaths, these deaths in the pain and not in softness. If part of the French society claims a right to euthanasia, it is undoubtedly because too many people witness deaths that traumatize them: they see their relations dying in the middle of very sophisticated technical devices. Could this social request merely testify to the one time nostalgia when one could die at home, naturally?

To tackle the problem of the request for euthanasia to its root would thus consist initially in challenging certain automatisms at the hospital, to break the routine of an application sometimes too mechanical of standardized protocols. Sliding the technique in between a dying person and his/her surrounding (us) places him/her remotely and can then make us being less human with him/her.

Since 2005, the French legislator considers that the euthanasia known as “passive” does not exist. No one has the right to make others die, but when death already won, we have the right (and even the duty) to let die, without eagerness and unreasonable perseverance. To pre-see the death of a person without knowing the precise moment of it, to be prepared, even anticipate it does not mean that one wants this death. The forecast differs from the intention. This point of nuance is very important.

On very sensitive issues such as euthanasia, the debate is open on the necessity to let the law come to technical protocols. Certain believe that a space should be left between ethics and law as some cases can only be settled in the intimacy of a dialog between a patient and his/her doctor.

Information is missing concerning the reversibility of states of unconsciousness raising a medical and a scientific issue. The assessment of care, as well as taking into account the will expressed by the patient beforehand, depends heavily on the hope of recovery and life that everyone can have. Few cases do exist of patients in vegetative state who, after several months, recover their capacities almost completely. The problem became more and more complex these last years with "lock-in syndrome". This challenges the nature of the conscience itself. Are reversible long-term comatose states, vegetative states only extreme "*minimum responsive state* "?

To deal with people in such a difficult situation requires according to Colin Thomson dignity, benevolence and solidarity. The decisions concerning the care to give the people in a state of PCU ("Post Unresponsiveness Coma") or of MRS ("Minimum Responsive State") must respect human dignity, respond to the beliefs and the desires of these patients (in so far as they are known) and consider the expectations of whole the people concerned, *eg* the family in the broader meaning. It is an extremely complex problem, made even more acute by the enormous geographical differences in compensation and allowances suggested for this kind of trauma.

Deontology calls for very high standards of medical and psychosocial care, compassion and respect. It is essential to communicate permanently on the objectives and results of the treatment, like on further therapeutic options for the long term. One has to give the greatest importance to what can be called "the best interest of the patient", located halfway between his/her desires and the reality of the situation. The consequence is to take into account what we know of his/her wishes, as well as personal opinions and opinions of the family concerning the control of the treatment and decisions on the choices of therapeutic options. Taking into account the desires of the patient will be more prominent as he/she will have consigned his/her preliminary wishes in a "will of life". However, in the facts, very few people write this type of document, especially among the youngest patients.

The amount and quality of discussion around the presentation by the Nuffield Bioethics Committee testify to the particular difficulty to be confronted with the problem of dementia. In fact, the ethical access of such an issue is equivalent to trying to assemble various pieces of a puzzle. The complexity of the Alzheimer syndrome, in its demonstrations and its consequences, raises questions similar to those of all the diseases addressing the autonomy of the person. Their entourage pushes the professionals concerned to determine or maintain the right care and relationships while knowing the incurability of the disease and the progressive isolation that is inherent to it. Among ethical questions are those to know: i) when a patient would have to be informed of a diagnosis of dementia, ii) how to address the obvious stigmatization of the patients by the society, iii) how to conceive decision making concerning the daily life of the patient and the choices which can require the recourse to a legal representative, (iv) how to question on the role of the will of life in such a context. The interrogation then relates to the difficult compromise between the limitation of the risks incurred by the sick person and the freedom of movement he/she is entitled to, knowing for example that the use of house automation intrudes in his/her private life. The same applies to the compromise between telling or not telling the truth to the patient and the attempt to preserve the bond that he/she can still have with reality.

In addition, there are dissensions as to proceeding to research implying insane persons. The Nuffield Bioethics Committee underlines the need for pursuing such studies and that of establishing ethical principles as well as a legal frame for protecting and accompanying the patients. The discussion then turns to the scientific and medical representation of dementia. It is recognized that the Alzheimer's disease is the one about which one speaks, more than all the various existing forms of insanity that probably constitute a vast clinical field.

The American bioethics is dominated by the idea that the individual precedes. Such is the literal meaning of the term "autonomy". It is even the core of the principle of the respect of autonomy and of the as well moral as legal principle of self-determination and private life. This autonomy exerts an hegemony in the American bioethics: this principle is thus called upon since it is a question of regulating conflicts related to the bioethics, so much in the context of the relation doctor - patient than within the framework of deliberations carried out by the various committees in charge of these issues. It was thus important to address the ethical challenges posed by the concept of autonomy in the United States. Three of those challenges were discussed: i) the first relates to the argument according to which physicians are not obliged to deliver treatments considered to be vain while they are requested by the patient and/or family, but could be constrained to refuse or to cease such treatments; ii) the second relates to the clause of conscience that doctors can oppose to the realization of certain acts which they consider contrary to their morals; iii) the third challenge concerns the argument according to which patients in final phase do not have constitutional right to ask and obtain that they are given experimental treatments whose effectiveness is not proven.

Daniel Davis cited the French author Alexis de Tocqueville in his book "Democracy in the United States", at the beginning of the 19th century: "*L'individualisme est une expression récente qu'une idée nouvelle a fait naître. Nos pères ne connaissaient que l'égoïsme. L'égoïsme est un amour passionné et exagéré de soi-même, qui porte l'homme à ne rien rapporter qu'à lui seul et à se préférer à tout. L'individualisme est un sentiment réfléchi et paisible qui dispose chaque citoyen à s'isoler de la masse de ses semblables et à se retirer à l'écart avec sa famille et ses amis ; de telle sorte que, après s'être ainsi créé une petite société à son usage, il abandonne volontiers la grande société à elle-même. L'égoïsme naît d'un instinct aveugle ; l'individualisme procède d'un jugement erroné plutôt que d'un sentiment dépravé. Il prend sa source dans les défauts de l'esprit autant que dans les vices du cœur.*

[*L'égoïsme dessèche le germe de toutes les vertus, l'individualisme ne tarit d'abord que la source des vertus publiques ; mais, à la longue, il attaque et détruit toutes les autres et va enfin s'absorber dans l'égoïsme. L'égoïsme est un vice aussi ancien que le monde. Il n'appartient guère plus à une forme de société qu'à une autre. L'individualisme est d'origine démocratique, et il menace de se développer à mesure que les conditions s'égalisent*]."[1]

The autonomy of the physician exacerbates the conflict between autonomy of one and another. The design of the patient's own interest is based on his singular vision of the good. However the doctors cannot put themselves at the place of the patients, but apply their own idea of the good based on science and clinic. It is their duty to proceed like this; that does

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[1] *"Individualism is a recent expression that a novel idea gave birth to. Our fathers knew only selfishness. Selfishness is an impassioned and exaggerated love of oneself, which leads the human to consider things only for himself and to prefer himself to anything or anybody else. Individualism is a thoughtful and peaceful feeling, which pushes each citizen isolate himself from the mass and to isolate himself only with his family and friends; so that, after having created a small society for his use, he gives up readily the big society to itself. Selfishness is born from a blind instinct; individualism proceeds of an erroneous judgment rather than of a depraved feeling. It takes its source in the defects of the mind as much as in the vices of the heart"*

Alexis de Tocqueville, De la démocratie en Amérique.

not concern autonomy.

ETHICS COMMITTEES & PUBLIC DEBATE

Chairs: Alain GRIMFELD & Bocar KOUYATE

- Ethics Committees & public policy
  Dafna FEINHOLZ, Executive Director of the Mexican National Bioethics Committee
- Ethics & cultural Diversity
  Edmundo ESTEVEZ, President of the Ecuadorian National Bioethics Committee

The talk by Dafna Feinholz highlighted the fact that, since 2005, the constitution of the National Commission of Bioethics of Mexico had an impact on the public policies, in particular on health expenditure, on research at the local and national scales and on decisions about public health. As regards public policies, this commission is working out a method of evaluation of these policies, which could be then adopted within the government. In addition, it has been given the right of setting up local and ad hoc committees. For instance, concerning the ethics committees for research that are responsible for the ethical evaluation of research protocols and ensure the formulation of recommendations and their follow-up, the National Commission of Bioethics of Mexico has tried to make so that these committees are always multidisciplinary and that the parity men - women is respected.

An issue is the increasing number of ethics committees and of their precise role in the society. Another is how to connect them to public policies. It is necessary for that to give every citizen access to public debates. These committees represent true laboratories of the society. They correspond to a practical exercise of democracy and constitute a good approach of the questions of bioethics.

One of the main difficulties that certain countries such as France are confronted to relates to a possible long delay between the publication of opinions and the vote of the law as well as practical application of those laws. In the British system, the regulation on stem cells, for instance, was very fast. Effectiveness is thus an issue. On the contrary, it happens in several instances and countries that law are being voted on subjects that have not been sufficiently discussed by the society. It is important to take the time of the debate.

Edmundo Estevez emphasized the social nature of the human being and his particular abilities make him a creator of culture. Culture is consubstantial to the human nature and it integrates every dimension of his/her being: biology, intelligence, affectivity and ethical dimension. There is no other being in our world that can create and transmit the culture: the culture belongs to human and it is made for humans. It connects us with previous generations to assume the heritage of the history of humanity. At the same time, we build our own history in order to project it towards the future, to create and take part in cultural progress.

The Universal declaration of the Human rights of 1948 recognizes the intrinsic dignity of any human being. The human nature is the consequence and not the cause of the social forces. Individual natures are simply a raw material that social factor model and transform. Of course, it is also important to emphasize that the capacity of culture to change the human behavior is limited.

Our cultures are generally plural, and attempts that can be encountered to institute a moral monism seldom pass the step of the democratic and social debate. We are asked to build a set of commonly accepted principles of justice for all.

Cultural diversity supposes that one tries to respect the identity of each one. In front of the universalism of the ethical step, it is important to consider also the conditions of the dialogue. Hence, one of these conditions is, according to Achille Massougbodgi, to start desecrating one’s own practices. To go towards the other while having the feeling that my practices are basically untouchable and that I hold the truth, poses necessarily problem and does not allow to develop a constructive exchange. Each one must, in contact with the other, question his/her own practices and authorizes the other to question, to challenge him/her. This effort of humility is one of the notions that we will have to promote strongly in the future, in particular in countries of the South where there might be a tendency to curl up on values that may appear somehow outdated.

The future of ethics and of humanity requires an enormous amount of work concerning bioethics culture, solidarity, tolerance, alterity/otherness in front of the difference, reciprocity, conscience, universal citizenship and common sense. We should rebuild the world of values.

It is true that some principles such as altruism or solidarity may elicit divergences. However, there is certainly a common indignation towards certain practices that could help us agree on what we reject, like torture, slavery, or what is more related to our present topic, drug assays in vulnerable populations or merchandising human body parts. If it is difficult to agree on what we consider good, we might come to a consensus on the bad.

The confrontation of various cultures among many national communities raises the issue of the liberty that can be given to their uses and practices. Canada has, for instance, set up a committee in charge of reasonable compromises whatever the use that the Government will make of it, this process of collective release was extremely useful. It made it possible to the Inhabitants of Quebec to raise the question of the “living together” and to think of their design of the common good.

All our discussions send us back to the possibility: i) to keep our debates alive after the Summit, ii) to share our diverse ethical sensitivities, iii) to contribute to the dialog of cultures.