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HEALTH AT THE HEART OF FILES

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Health is a state of physical, psychical and environment well being, according to the WHO. This definition should change in understanding and take into account globalisation based in information highways.

According to Pr Liliane Dusserre, I quote :

« New Information Technologies and multimedia communication are likely to help Doctors in their pursuit of a better quality of care».

They should also benefit the patients and Doctors, who can escape their usual isolation when making decisions.

In itself exchanging electronic medical information is good. However, there are dark areas one cannot deny, because the use of new communication technologies can affect the safety of transferred data, which is often nominative or identifiable.

But users are far from knowing the extent of such affected safety, especially in an unprecedented sanitary environment. I am referring here to HIV and AIDS infections with its social, culture, economic, psychological, legal and political impacts on the individual, family and community.

The patient's basic rights in the area of computerised medical files, health-related data circulation, the important role of Internet in country development, all are factors to take into account in data processing « safety » protection.

When speaking of the security of electronically-transmitted medical information, one refers to three different concepts : integrity, availability and confidentiality.

The latter concept is the most important on account of the stringent sanctions provided by the regulation if it is not respected. But users are not always aware thereof and don't take all necessary precautions.

Thus, the specific aspects associated with HIV/AIDS infection with regard to data processing changes raise questions in the area of human rights and freedom of justice, fairness and ethics.

Dear participants, let me share some field examples with you.

1st example

A young man, 25 year old student, deaf and dumb. He communicated mainly in writing. He had no other activity than prayer, watching TV and accepting his fate. In his sickness phase, he was taken to hospital, and unfortunately, was abandoned, rejected and became a sanitary and social outcast ...

2nd example

A pretty and lively young woman finds out after giving birth to her son, that she is HIV positive, through her medical records that circulated around the various sanitary departments.

3rd example

A surgeon found out about the HIV Infection of a woman during his pre-operation review, and has managed to postpone the surgery.

4th example

A woman, married for 13 years, after several fertility treatments, was happy to have a child. Unfortunately, the child is found to be HIV positive at the age of 3. Unknown to her, the information was circulated to the doctors and to the family. This lady, who is fighting for the health of the child, finds this out 2 years later. She understands better the « attitudes, and especially the looks of her family».

These examples lead to a few thoughts, such as medical confidentiality/secretcy, discrimination, solidarity, denial of care, access to the medical file, to research ...

⇒ Confidentiality is the ethical and legal duty of health professionals not to disclose a client's serological status without his/her consent. Therefore, ethics needs to be defined in its universal principles, as a practice, a sum of actions referring to definitions, to situations, and requires not to « decide between ethics universality and intangibility on the one hand, and its adjustment to local contexts on the other hand».

- ⇒ Care discrimination is real. The Health Policy of our countries relies on the cost collection system such as the Bamako initiative. This system is not functional on the long run, because it is based on the patient's financial participation. Family solidarity, solidarity alone, was destabilised by the arrival of the HIV and AIDS infection. It confused and rocked the principle of community spirit and African solidarity, so magnified and praised for generations. But also, the infection disorganised the community.
- ⇒ The stand of the medical profession in the area of the collection of data related to HIV infection has varied from one situation to the other. Examples of bad care and denied care have been reported.
- ⇒ Epidemiological research requires collecting data and leads to the following though : What is the direct benefit to the population ?

In analysing its various elements with respect to the western world, I wonder about issues such as :

- ✓ information to other health professionals in the patient's interest
- ✓ information to the partner of a HIV/AIDS infected person
- ✓ dilemma : choosing between the patient's interest and the partner's interest
- ✓ the universality of ethical principles : ethics ? northern ethics ? southern ethics ?
- ✓ what is the point of research if specific aspects expressed by the community and choices are not taken into consideration ?
- ✓ Should the various forms of exclusion experienced by people suffering from HIV/AIDS for various social (rejection) reasons, family reasons, isolation, ignorance/unawareness, fear, medical reasons (difficulty to access detection and care facilities (medicines against infections, antiretrovirals...) and the lack of healthcare, not strengthen medical secrecy and data collection and file safety in Africa.

- ✓ What legislative response to future risks : medical data processing systems, will be increasingly sold, and temptations to take advantage of the market value of the files will increase

Based on the above thoughts, it would be advisable to implement or reinforce the legislative framework in Africa in the area of protection, like international legislation, specifically French laws, according to Pr Dusserre's report :

« The collection and circulation, and any other form of processing of personal medical information, should be carried out in openness and in compliance with legal rules : the right to privacy provided for in article 12 of the Declaration of Human Rights, in article 9 of the Civil Code, by Act 78-17 « Privacy Protection» dated January 6, 1978 and by the European directive dated October 24, 1995 (relating to people protection in the area of personal information processing and of the free circulation of data).

In addition to the above, are the articles of the Medical Ethics Code relating to medical secrecy (4, 72 and 73), in the framework of care administered to a patient in usual care processes (transmission of laboratory test result, requests for consultants' opinions, etc...).

Important also are the provisions in the area of epidemiological studies, clinical research, care activity analysis or assessment. It is one of the three bioethical laws, the one dated July 1st , 1994, that introduced chapter 5 second of the Privacy Protection Act and set the conditions of medical data processing in the framework of research».

In quoting this text, I would like to convey that the **not only the taking into account both what is universal and what is dependent on the specific environment is not contradictory, but it is even essential.**

Africa should take advantage of science and technology progress for its growth.

In the age of globalisation electronic communication is central to development. Africa needs this precious tool, the Internet, the medical information circulation-related aspect of which should be compliant with legal and ethical rules.

Data protection is a right of mankind, including Africans, who are not that different from you.

In closing, respect for the fundamental rights of man, specifically, respect for dignity and rejection of any form of exclusion, discrimination in the access to prevention and care ; access to medical information including by the sick, and the right to access their files are guarantees of a sanitary democracy versus democracy alone, because it is about respect for individual choices and freedoms.

Therefore, men and women, peoples of democracy, justice, freedom, equality and ethics, help, support and accompany Africa and its sanitary system through health professional to make **data collection and files secure for a better health at the heart of files.**