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Ethical and Psychosocial Aspects of HIV/AIDS

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1. Introduction

Since its global appearance, the Human Immunodeficiency Virus (HIV) has represented the most evident tear between bioethics/rhetoric and the reality of everyday life.

All AIDS related issues are different in two macro areas, the first pertains to the clinical-psychological aspect, the other a psycho-social dimension.

The first derives from the consideration of current disease and health, and the second one focuses primarily on prevention and spread of the disease, considering that the only way to effectively fight AIDS is by preventing contagion. Over the past years, the approach towards AIDS has changed, from being seen as a social sore to a social-sanitary alarm, this in a certain way has favored the perception of the illness, which now is no longer necessarily associated with death.

However something from the past has managed to survive, medicine and science have both evolved, and there have been numerous studies that highlight the process related to the disease, but the psychosocial perception has not changed, damaging who is affected finding themselves fighting against stigma, prejudice and exclusion.

AIDS is not only an illness, but moreover configured as an attack on civil society, so those affected by it are removed or living in a constant state of discrimination, even if behind media campaigns and legislative measures aimed at supporting their quality of life.

The AIDS epidemic infected more than 50 million and has claimed the lives of more than 20 million people worldwide; its devastating effect is particularly seen in the Third World.

Sub-Saharan Africa is the epicenter of HIV, with 67% of the 33 million infected with HIV in the world and with 75% of deaths due to AIDS (UNAIDS, 2008).

In eastern and southern Africa, infant mortality is one third to two thirds higher than it would have been in the absence of HIV and AIDS, and child mortality continues to rise, leading to a dramatic reduction in life expectancy (De Cock et al., 2000).

Currently the progression of the infection in Western countries is slowing down, both because of the use of more effective therapies and the improvement of information and prevention of infection, and thanks to greater attention paid to early diagnosis.

Furthermore, the rate of neonatal transmission is only about 2% thanks to the introduction of antiretroviral drugs and the use of elective Caesarean section.

However the world is divided into two different approaches concerning HIV infected and AIDS, while in western countries they are slowly abandoning the concept (Ehrenkranz et al., 2009) of exceptionalism, in developing countries this is still the most common approach.

In the meantime, screening tests are performed when requested by the patient only after he or she has signed a formal consent form and after having gone through formal counseling; this means that in Africa where there is a higher prevalence of this infection, one out of five are not aware of their status (World Health Organisation [WHO], 2008).

The opt-out testing is still the subject of heated debate between the philosophical currents of consequentialism, liberalism and free paternalism; however there is no denying that the consequences in terms of social impact, although heavy, collide with the benefits of a precocious intervention which results in being a survival rate for those infected (April, 2010).

Such a chronic, infectious disease offers tremendous opportunities for ethical dilemmas and psychosocial discussions. Our job will be to face different topics about the HIV infection.

2. Clinical research

The clinical trials are increasingly conducted globally and Sponsors tend to shift their activities to developing countries where they can save between 10-50% of their investment compared to the rest of industrialized countries.

Moreover, in countries described as "poor", the laws are less stringent due to a low possibility of checkups and it being easier to enlist patients (Altavilla, 2010) for which, often, researching is the only way to obtain drugs. The European Medicines Agency set up a Work on Third Country Clinical Trials in order to clarify the ethical standards used in clinical trials conducted outside the European Economic Area and which were then introduced to the European market.

The validity of the regulations of good clinical practice is universally recognized, however, there is no denying that they have a different impact between Western countries and so-called developing countries.

Even the simple definition of standard of care and treatment, essential for the comparison of innovative therapies, qualitatively absorbs different connotations when assessed in the Western health care system compared to the rest of the world.

In addition to the traditional principles of Bioethics, HIV/AIDS has added new issues, like: accessibility, affordability, standard of care, stigma and discrimination, post-trial benefits, equity and sustainability of interventions, that have generated intense debates both locally and internationally, which nevertheless, did not reach universal ethical standards in the world.

Indeed, the expansion of studies on HIV throughout the world has helped the issue of the adaptation of ethical standards emerge even more, developed in industrialized countries, and exported to developing countries.

One thing is certain, the potential imbalances in various countries and between communities/groups within countries demand that ethically acceptable clinical trials and strategies are planned in different locations so that communities and countries in need of early interventions can be benefited.

It is no coincidence that the debate on the ethnicity of carrying out clinical trials in developing countries in search of a land "more pliable" is still ardently and culminated in the publication of multiple guidelines from the developed worlds (National Bioethics Advisory Commission [NBAC], 2001), (Nuffield Council on Bioethics, 1999).

In this regard the HIV Preventive Trial Network (HPTN) Ethics guidance document developed by HPTN Ethics Working Group of Family Health International (HIV Prevention Trials Network [HPTN], 2003) has addressed the crucial points of the clinical trial in the so-called "host countries", ranging from the reduction of risk associated with stigmatization, to ensure informed consent for complex research with potentially vulnerable participants, from determining ethical authority and accountability in international collaborative research to design research that meets local needs as challenges.

Incidentally the social contexts and cultural specifications of the host communities and countries should be given due consideration to protect the dignity, safety and welfare of the trial participants (Indian Council of Medical Research, 2000), when it intends to undertake a study of international cooperation, remembering that many countries, such as India (ICRM, 2001), the Philippines (Philippines National Health Council, 2001) and South Africa (South Africa Code of Ethics, 2000), have developed their own guidelines to suit the local requirements.

A typical problem of studies made in poor countries is related to the testing design, because while in industrialized countries generally a comparison between new and old pharmaceuticals is made, in developing countries it is rather difficult to find a pharmaceutical of control, therefore it is preferable placebo confrontation or research with a lower dosage or short-term studies.

Under this aspect, not even Helsinki's 2008 version managed to reach global agreement.

Another peculiar aspect of clinic trials held in developing countries, is represented by the vigorous debate of the necessity to guarantee drug coverage to all of those who take part in the experimentation, after of course having finished the study.

Since 2000, researchers, pharmaceutical companies and international bioethics bodies have engaged in a fierce debate on access to post-treatment trials, culminating in note 30 of the Declaration of Helsinki (World Medical Association, 2004) – which recommends that access to treatments for all participants-and the 2005 European Directive (Commission Directive, 2005), which requires foreseeing the cures that will be adopted after the study right from the initial protocol.

Specifically, US National Institutes of Health Division of AIDS (National Institutes of Health [NIH]) and other international Organizations, such as Council for International Organizations of Medical Sciences (Council for International Organizations of Medical Sciences [CIOMS], 2002) and United Nations Programme on HIV/AIDS (United Nations Programme on HIV/AIDS [UNAIDS], 2001), only state that post-trial access to medications and medical care should be "considered" in the trial planning process.

Indeed, the hesitation of the pharmaceutical dispensing of drugs after the study is due to the need to fill the shortage of adequate health structures well beyond the scheduled period of experimentation. In other words, the Sponsors, attracted by low costs of running an experiment in developing countries, would ultimately leave that decision on the burden of dispensing post-trials (Weijer & LeBlanc, 2006).

According to the UNAIDS report of 2010 (UNAIDS, 2010), the average price of the most common regimens for an adult is about US\$ 0.17 per day (the cost of condoms has also declined to as low as US\$ 0.04 per unit); while stopping a single case of infection among infants now costs a mere US\$ 5.

Besides economical reason many Authors (Macklin, 2001) (Grady, 2005) believe that constituting post-trial services would mean trial sponsors would have to take on many

responsibilities, so it would be preferable to perform this task having already appointed a government agency or a non-profit entity with larger budgets.

However many International research ethics guidelines do not specify how post-trial services should be organized and a simple hint is not enough to solve the problem, seeing as every drug has its own specific risk and each one possible beneficence should be taken into consideration.

Whether a post-trial service is present or not should be the topic of the information given to the patient in order to avoid false hopes, which would then undermine the expression of consent.

Currently, trials conducted on antiretroviral drugs do not have the explicit reference to post-trials service as a standard or rule in the Protocol or in the information given to the person who is undergoing clinical trials (Ciaranello et al., 2009).

In this regard, it is wisely stressed “the burden and benefit of any collaborative study should be equally borne by the collaborating countries”; besides “Guidelines, rules, regulations and laws of the participating and sponsoring countries should be equally respected” (Muthuswamy, 2005).

The testing of vaccines is another area of heated controversy, which already has several critical issues in the industrial world, but becomes exacerbated in developing countries.

The above HPTN guidance document (developed by the Ethics Working Group) emphasizes protecting the vulnerable from exploitation, promoting equality through non discriminating access to the benefits of research and minimization of research related harms including medical, psychological, social and economic harms.

However, each of these aspects opens new scenarios that did not find unanimous consent, even more so if we turn our attention to the experiments carried out on pregnant women or infants, which, however, we will discuss in the next section.

The last aspect of the clinical trial, in general, concerns the lack of studies on palliative care and end-of-life in patients with AIDS.

In this area the differences between industrialized countries and developing countries is dramatically incurable; to understand the difference, just think that a comparative study carried out on terminally ill patients in Kenya and the United Kingdom, pointed out that first it was more important to quell the pain while the latter played a primary role of emotional pain.

As Harding et al emphasizes (Harding et al., 2003), there are five critical elements that a clinical trial should consider, namely: availability of pain relieving drugs, pain and symptom control, access to services, extent of coverage programs, education and training (including clinical, administrative and other skills), identification of relevant needs and determination of outcomes for care at the community level, and evaluation of the impact of education of policy makers and program directors about palliative and end-of-life care (sometimes termed advocacy); furthermore relevant outcomes may include policy, strategy, sustainability, availability and utility of education and training, and integration of end-of-life care into health systems.

The context of deaths in developed and developing countries are different, and context matters in end-of-life care.

In industrialized countries, people die of cancer and cardiovascular diseases, in developing countries, HIV / AIDS, TB and malaria cause over 300 million illnesses and more than 5 million deaths each year (WHO, 2000). As a result, projects in support of the terminally ill need to be different. As Singer and Bowman well debate (Singer & Bowman, 2002), the

discussion of quality end-of-life care points out that there is a lack of information about the current state of end-of-life care among populations; and this should be seen as a global public health problem, because “it seems difficult to know how to improve quality end-of-life care without any understanding of what the current level of quality is, what determines it, and how improvement could be measured”.

This is even more interesting considering that we are entering the third and fourth decade of HIV-infected, which now have a longer life expectancy thanks to current therapies.

2.1 Cultural barriers

HIV prevention trials conducted among disadvantaged vulnerable at-risk populations in developing countries present unique ethical dilemmas.

The inclusion of participants from under-represented or vulnerable populations calls for special consideration because the interests of those populations may conflict with clinical trial objectives (Fouad et al., 2004).

This is especially true when the object of research may cause a degree of stigma for the participating population. Generally, people with HIV are excluded for various reasons, some because they fall into illegal-behavior (for example injection drug users or sex workers); others because they are members of an ethnic minority; many have served time in jail or prison; many are poor.

Protection against discrimination and stigmatization is an important issue with regard to recruiting HIV/AIDS people, so appropriate composition and training of the monitoring recruitment team are particularly relevant to successful recruitment; besides basic comfort at the study site is fundamental.

Next to a perfect organization for what regards the technical aspects of the implementation of a clinical study, it is essential to pay particular attention to the specific characteristics of clinical research conducted on this disease.

Basic ethical principles when recruiting study participants include respect for persons, beneficence and justice (Beauchamp & Childress, 1994), but for this illness, confidentiality and providing safety from abuse are critical.

So the definition of ethical guidelines on the approach to these patients, with particular attention to the confidentiality of data, is essential.

First, a statement about maintaining confidentiality should be included in the informed consent letter, guaranteeing the rights of participants to maintain control over access to information about their health status.

About McNutt et al. (McNutt et al., 2009), “research participants commonly provide limited waivers of confidentiality for many studies. These waivers may be for protected information to be provided to researchers (eg, medical records) or disclosed among research participants (ex: research on couples or family counseling).

In these situations, participants typically provide waivers of confidentiality that are limited to requirements for good scientific research”; so if the requirements for research participation are unacceptable, then individuals can choose not to participate.

Certainly, a study to be ethically valid, must also be scientifically valid and unfortunately introducing a selection bias, only enlisting groups of patients who accept in full the questions of the study, may adulterate the results.

On the other hand, to ensure dignified treatment, it should be guaranteed that study participants are treated with full respect for their dignity and their rights as persons.

Dignity, which may be defined as an achievement or acquisition, not only depends on the individual but also on the other surrounding people who either directly or indirectly interact with the subject (May, 1991).

Unfortunately in the current management of HIV infection is not ethical, the individual loses his dignity, because his rights as a human being are being undermined.

HIV/ AIDS affects the most intimate rights (Chummar, 2008) of free expression, such as, life, health, physical expression of love, transforming relationships, requiring a physical and metaphorical wall between man and man.

This social tear then clashes with the territory's culture and economy exacerbating the individual's difficulty to manage the disease and the intervention policies against the spread of infection.

Universal Declaration on Human Rights states that health is a right and that it must be preserved by States (Article 25), but this remains a purely theoretical exercise, where there are places that lack of food and water to ensure minimum subsistence.

Yet, prevention programs and the same international clinical research depart from a European conception of the individual, and therefore end up clashing with local realities, especially when they have totally different approaches to society by the Western schematics.

The implementation of consent to clinical research, preventive vaccine trials and trials preventing vertical disease transmission, had been influenced by several factors like family-centered decision-making; cultural dynamics pertaining to sex; relationship to older persons and the care-giving arrangement.

Furthermore, some principles of individual informed consent may not be in keeping with the cultural norms and practices of non-Western societies.

The requirements of Good Clinical Practice require that the enrollment of a patient in a clinical trial is preceded after giving clear and comprehensive information before taking the consent.

Unfortunately, if you do not have any knowledge of the concept of clinical trials, as in many developing countries, enlistment should be preceded by an intensive information campaign on the basis of research (randomized placebo, responsibilities and rights of the Promoter and the participant etc.) before explaining the protocol study (El Sadr & Capps, 1992).

All this implies the willingness and patience to really want to inform those undergoing clinical trials, as well as clearly being an economic burden for the implementation of information plans, considering the low cultural level which is bound to be encountered.

Moreover, these problems are not easily foreseen by Sponsors who do not include considerations for cultural factors, age, gender and social-economic status in their recruitment strategies .

As a result, many social needs (such as lack of funds for public transport, food etc) prevent their most needy patients to participate in clinical trials; still, in the most depressing areas you will find therapeutic misconception (Slack, 2005), bringing the subject to agree undergoing a clinical trial for a vaccine with the illusion of being able to heal the infection.

Vaccine research is challenging on many fronts and has become the subject of many debates (Guenter, 2000). The case of Kenya AIDS Society vs Arthur Obel (Kenya AIDS, 1997), the Nyumbani incident (Siringi, 2004), the HIV net 012 trials carried out in Uganda (Ahn, 2003) and the debate on the use of placebo during International clinical trials (CIOMS, 2002), are only a few of the examples that testify the complexity of the ethical implications in vaccine trials. The vaccine guidelines provide for Community Advisory Board (CAB), whose role is

to facilitate community support for vaccine research and to disseminate information to the community hosting the research.

In order to avoid growing skepticism in the community, Oduwo (Oduwo, 2009) suggests facing the issue regarding vaccine trials focusing attention mainly towards: "a detailed analysis of the duties in each role should be done to resolve duplicities and conflicts among the roles; the legal framework for HIV vaccine research trials and the legal basis for each should be clarified; discussions on HIV vaccine trials ought to be encouraged, particularly domestic perspectives as they may provide a nuanced appreciation of the challenges of research environment; the role of state to facilitate and sponsor HIV vaccine research, which is expressed in the HIV vaccine sub-committee and its interaction in the research framework may benefit from further analysis and discussion".

There is therefore the general tendency to exclude women - especially if pregnant - from the clinical trial, forgetting that in fact they are being denied treatment.

Furthermore, the different hormone levels do not permit a full correspondence between the results obtained in men and those obtained in women.

The Department of Health and Human Services has prohibited the enlistment of pregnant women except in cases where the fetus is exposed to a risk or minimal risk necessary (Federal Register, 1978). The International guidelines (World Medical Association, 2000) for the protection of the subjects in experimentation do not however exclude either fertile women nor pregnant women from the trials, even though recognizing the extra caution that must be taken (45 C.F.R. §46 Subpart B, 2002).

For fear of repercussions on the fetus many drugs are not tested in pregnant women or even on fertile women. In fact, the consequence is that these drugs will enter the health care practices that have no knowledge of how to use them.

The same Declaration of Helsinki (Edinburgh version, 2000) states that "the purpose of biomedical research must be to improve the diagnostic, therapeutic and prophylactic methods and understanding of the etiology and pathogenesis of diseases" (art. 4).

The lack of reliable data makes it even more complex to manage health in everyday life, since it authorizes the use of drugs not tested in extreme situations.

The situation is even more complex for HIV/AIDS; for example, the process of the zidovudine drug was troubled long before its arrival and authorized in pregnant women.

Since 1987, when the FDA approved the use of the drug in adults with a concentration of CD4 + cells <200 mmc, it was not until 1994 (Morb Mortal Wkly Rep, 1994) that a study was created to show how the incidence of vertical transmission of HIV had reduced, with adequate safety for the fetus.

In this case, the precautionary principle referred all the fetuses of women who took antiretroviral drugs to risk, however, in the absence of any experimental data on these risks.

Many pregnant women, as in this case, have comorbidities besides the HIV infection and do not have adequate data available making their clinical management more difficult.

Kass et al. (Kass et al., 2000). claim in this regard that clinical decisions should always be taken with caution knowing that what the health of pregnant women needs is usually what is in the best interest of the developing fetus.

The problem of the recruitment of women in clinical trials, besides the scientific and economic justification, is dictated, in poor countries, especially by cultural barriers.

While the presence of children does not allow them to make appointments on time, those that a search require, on the other, their involvement is strongly influenced by the willingness of men (husbands, fathers or sons) to subsidize their existence.

In fact, women have little freedom to make decisions under the lack of economic independence which is often associated to a cultural level so low, as not to guarantee self-determination. Besides this in many communities there is also the belief that being pregnant imposes fidelity onto the women and the use of contraceptive methods stimulate betrayal (Mills et al., 2006).

2.2 Participants' autonomy

Diminished study participant's autonomy is a common phenomenon in poor-resource countries.

The principle of autonomy is based on the assumption that a capable person, that is capable of self-determination, can responsibly make a free choice, deciding on everything that concerns him, outside of any external interference or overlap. The principle of patient self determination links the person who gives his consent to research in the field of HIV, to the person who first receives the information about the disease in question, and the research itself; all of this because it is dealing with a person who realizes what is happening.

A reduced range of candidates for research is a common phenomenon in developing countries in relation to the problem of obtaining adequate informed consent in these populations. In these countries the application of the research comes up against a widespread low-level socio-cultural phenomena with wide margins and a general attitude of distrust towards the helpers.

This may lead to a reduced perception of the fundamental aspects of research, with a low level of awareness about the candidate's proposed procedures and a general lack of grip of the population participating in the trial.

For these reasons, the research aimed towards people in developing countries must take into account the possible interference of some specific aspects, culturally mediated, that may influence the perception and understanding of issues related to the risk of HIV infection and consequently the autonomy of decision making.

It is true that there is a universal ethics of human research but it is true that the application and interpretation of general ethical principles must take into account, as stated above, the specific factors of stakeholders, such social conventions, the cultural factors and economic conditions.

In developing countries, where access to specialized care is very difficult, HIV infection is usually depicted as a hopeless disease, which inevitably causes suffering and death.

This leads to a dissonance than the messages that speak of a disease potentially preventable and controllable.

In each country, and sometimes in each ethnic group in that country, operators encounter different interpretations of medicine, illness, sexuality, death, shame, reputation; they have to deal with strong differences in male and female roles, and are confronted with diverse cultural beliefs about AIDS.

In some populations, for example, the idea persists that certain blood groups or some people are immune to the virus, or that a god may protect certain individuals more than others.

Information on the trial, then follow a general pattern where, instead, each ethnic group has its own rules and beliefs that dictate the expression of pain, the description of the symptoms and how to communicate, beliefs about the causes of the disease, expectations about the prevention and the practical aspects.

The range of choices of participants in the HIV trial is, in essence, linked to personal variables (personality and socio-cultural characteristics) and environmental (presence of an

adequate social support and in particular the presence of emotionally significant people; characteristics of the facility and ability of professionals dedicated to building a relationship of empathy, understanding and containment).

Mannheim (Mannheim, 1999) points out that there should be no constraints for which the patient or, more generally the free man, should feel constrained in those actions that Goethe had described as the "moving through the various domains of human activity" (Stuart Huges, 1967). According to Wilson (Wilson, 2007), in medical ethics when it comes to autonomy three different concepts are evoked: "the ability to make autonomous choices" free choices and "sphere of privacy decision-making" (meaning "with respect to those decisions made without coercion and interference of third parties "). There are those who think at the time information is received, as when news is given, which puts the subject in a position to express a decision in line with their values. Yet the right of veto in which one substantiates, is not automatically to be respected, because one might be faced with arbitrary decisions.

2.3 Illiteracy, language difficulties or inadequate information

Language barriers, as well, raise significant concerns with regard to candidates' full comprehension of the technical, product and methodological information of the research should be adapted to the context of the developing world or poor people as well, where certainly the notions of 'chance', of 'inactive medical'.

The central role of autonomy of the person involved in the research is based on the information that should include the necessary input, appropriate to his level of knowledge, to enable him to actively take part in the various decisions.

The normal asymmetry of information between doctor and patient reaches the apex of developing countries in relation to the lower socio-cultural level and communication difficulties for the difference in language (and sometimes between different tribes of the same country) and cultural barriers. This state of affairs can induce operators to a mere provision of a technical piece of information rather than to create a real relationship of communication. Often the research subjects are not able to understand the purpose, or know the process in which they concretely provide their consent, merely to accept some form of treatment as an alternative to the lack of access to care.

In this case what is being acquired by non-consensus is actually invalid because it is underlying information implemented by a consensus but no qualifying adjectives that can not demonstrate the ability of the participant in the choice of self-determination.

It is therefore necessary to build a common language within the physician-patient relationship through interventions that facilitate conflict resolution and help overcome the cultural barriers that impede communication.

Researchers often work with the community leader to explain the research to the people and obtain informed consent. This expedient however is not sufficient and it is desirable that operators of the trial not only enrich their education in the field of HIV but also of transculture.

They must increase their awareness of cultural, religious, social and political factors that have an impact on patients' lives, fleeing from interpreting according to their own frame of reference, dealing with their own prejudices and stereotypes, confronting them directly.

They must also learn how to translate the discomfort of the patient in their own cultural language and return the message in a language that the patient is able to understand.

3. Status of affected women, young girls and/or pregnant women

The situation of women and cultural context is tragic.

Over the years, 'AIDS is increasingly becoming a disease of gender, in fact, more and more women are infected by the disease, 56% of the population ill are women between 15 and 49 years old.

A disease that is differentiating between the sexes not only in developing countries but also in Europe.

In fact, in 2007, over 30% of people who contract the disease are women and one of the main predisposing factors is the risk behavior of their partner.

According to WHO (WHO, 2000), HIV transmission from man to woman in a sexual relationship has double the chance of contracting it than the transmission from woman to man, with a greater risk for young women.

The impact of disease on women in all aspects of life and women living with HIV are very influenced by the country itself, in all spheres in which they are involved, from the family to take care of their health.

Excluding Western society (where at least formally) there is equality between man and woman, in many traditional cultures there is a subordination of the female gender towards the male gender. This implies a sort of tolerance in women to sexual violence, including both at home and away, exposing them to a higher risk of becoming infected with HIV.

Moreover, the inability to support themselves, restricts the freedom even in sexual matters, so they are forced to give in to having physical relationships with people already knowingly infected. If, however, polygamy exists, albeit in a system free from violence, the risk of infection increases, particularly given the common practice of sexual gratification with sex workers and husbands living away from their wives and whom for economic reasons, can not get home during the weekend.

In addition, the superstition that having sexual intercourse with a virgin provides immunity from the HIV infection, generating real rats of adolescents and children, even at a very early age. Still today, in refugee camps women and girls are victims of violence by their own armed forces that should be defending them, or rather they are "prey" of the barbaric savagery of the soldiers during the civil wars, as it happened in Rwandai (Fynn, 2010), where it is estimated that 250,000 to 500.00 "ETIN rapes" had occurred.

The food is, then, the main reason for surrender in unprotected sex for women, as they may engage in transactional sex to procure food for themselves and their children.

A study from Nigeria reported that 35% of female sex workers are poor and due to the lack of food they had accepted unprotected sex with clients (Oyefara, 2007).

Parallel to this there was a breakdown of family values, with an inclination towards fleeting relationships with people that are almost strangers, increasing the possibility of transmitting the HIV infection, and therefore women are either infected with HIV because of their behavior or due to the "gain" after the debauchery of their peers.

For many Africans HIV/AIDS is an ethical problem, meaning that it is the result of forgetting old values with nature, which enlivened the community before the advent of "intellectual" colonialism of the West.

In Africa, the individual has always been part of a community that has guided the choice of a mate and has alleviated the suffering in times of need. With the individualistic approach introduced by the Western world, the values which underpin the community have

deteriorated and AIDS, a symbol of the corrupt new approach to life, has brought with it a tendency to remove the sick from society.

Discrimination and stigmatization is one of the dramatic consequences HIV/AIDS have to face and a major obstacle to prevention and care.

Women in sub Saharan Africa are more likely to be living with HIV and to access health-care facilities offering testing, but any decision to implement expanded HIV testing in Africa must weight the desired biomedical outcomes of testing against the possibility of discrimination (April, 2010).

Fear of discrimination and stigma causes people to avoid testing and prompts those infected with and affected by HIV/AIDS to remain silent, depriving them from essential treatment and social care. These problems are perhaps magnified by the existing taboos regarding sexuality, affecting more intensively women.

A woman who discovers she is living with HIV risks, in all parts of the world, losing economic support, being abandoned to suffer physical and emotional abuse, of being discriminated against and witness her family relationships be destroyed.

Kilewo et al. (Kilewo et al., 2001) revealed that in Tanzania 77.8% of pregnant women infected with HIV participate in trial clinics to avoid maternal fetal transmission, at a distance of 18 months after diagnosis they had still not communicated the test result to their partners; while during a study carried out in Kenya by Galliard et al. (Galliard et al., 2000), a good 76.1% of the interviewed women did not have any intentions in revealing their status'. The reasons for the reluctance were fear of abandonment, rejection and discrimination, violence, upsetting family members, and accusations of infidelity (Medley, 2004).

The diversity of findings between and within populations reflected a wide range of different ethnic, cultural and religious groups among the women surveyed, who reported important differences in beliefs and preferences relating to formal and informal maternal health care. These variations were explained by differences in women in autonomy, gender relationships and social networks, which are influenced by embedded social structures, religion and cultural beliefs. A woman with HIV who knows her status can make a better choice with regard to her reproductive life and, if pregnant, may undergo specific interventions, such as prophylaxis with antiretroviral drugs, which significantly reduce the risk of maternal-fetal transmission.

Clearly, this occurs where there are health services that allow you to see a woman with HIV in an appropriate manner in relation to current scientific knowledge.

At a time when a pregnancy is emerging as a threat to the management, to which requires integration of knowledge and technical means, of course we should move to a good environment with qualified staff, able to handle the complex clinical problems that the case imposes and suitably sensitive to its ethical aspects.

Neonatal infection remains a terrible scourge for developing countries to poor women who receive care during pregnancy and childbirth.

This state of things pushed 68 priority countries to consider newborn and child health care that are part of the Countdown to 2015 Initiative.

UNICEF, the United Nations Population Fund (UNFPA) and the World Health Organization (UNICEF, 2008) recommend at least 4 antenatal care visits during pregnancy, during which very little would be sufficient to ensure good health to mother and child, such as treatment of hypertension to prevent eclampsia, tetanus immunization, intermittent preventive treatment for malaria and distribution of insecticide-treated nets, prevention of mother-to-child transmission of HIV, micronutrient supplementation, and birth preparedness, including information about danger signs during pregnancy and childbirth.

Natural childbirth at home is the only opportunity for many women and even where it is possible to perform a Caesarean section, it is unlikely that one may have a proper post-partum check-up.

Prevention of mother-to-child transmission of HIV is most effective when antiretroviral drugs are received by the mother during her pregnancy and continued through delivery and then administered to the infant after birth.

Every year a million women infected with HIV deliver babies without professional help. Marc Bulterys and colleagues suggest here that traditional birth attendants could be involved in preventing perinatal transmission of HIV by offering services such as HIV testing and counseling and short courses of antiretroviral drugs (Marc Bulterys et al., 2002). Antiretroviral drugs are effective in reducing the risk of mother-to-child transmission of HIV even when prophylaxis is started for the infant soon after birth.

The American Academy of Pediatrics recommends documented, routine HIV testing for all pregnant women in the United States after notifying the patient that testing will be performed, unless the patient declines HIV testing (“optout” consent or “right of refusal”) (Committee on Pediatric AIDS, 2008).

Assuming then that we have taken the test and a pregnant woman is affected by HIV, can she refuse to take antiretroviral medicines?

In the absence of specific laws that impose a compulsory treatment, the principle of autonomy recognizes that women have full freedom of choice.

In a recent study (Cannovo et al., 2010) we faced an emblematic case of a woman suffering from HIV who chose to complete her pregnancy notwithstanding a compromised pathological clinical picture (diabetes mellitus complicated by nephropathy, retinopathy and hypertension prior to conception, history of alcohol abuse and prostitution).

In this case the self-determination has prevailed over the woman's prescription.

Another issue that plays a key role in the spread of HIV infection is the FGM / C; For UNICEF estimates that in 27 countries of Africa and the Middle East, 70 million girls and women aged 15–49 have undergone FGM/C.

4. Privacy and confidentiality, stigma and discrimination

The attention to the confidentiality of information towards patients with the human immunodeficiency virus involves complex ethical considerations, especially in individuals in developing countries, that regardless of nationality, race or custom, each case involves, a condition of human confidentiality/secretcy inviolable to be protected if fulfills the conditions for the collection of identification data (concerning the identity in the broad sense) and sensitive (those suitable to detect the state of health and/or sex life) on HIV positive people.

The topic is complex and ethically sensitive under a human aspect, when speaking of subjects located in developing countries and within local communities where the knowledge of an infectious disease can result in exclusion from the patient's environment in which they live.

4.1 Legislative approach

In USA, already in 1997, the Health Insurance Portability and Accountability Act (HIPAA) regulations and the Americans with Disabilities Act (ADA) protect people with HIV and

their right to control disclosure of their status (Doyal, 1997), then in 2006, the Centers for Disease Control and Prevention (CDC) issued revised recommendations for HIV testing of adults, adolescents, and pregnant women in health care settings and recommend that opt-out HIV screening, with no separate written consent, be a routine part of care in all health care settings (Hanssens, 2007).

In 2003, India adopted a specific law for HIV/AIDS covering the ethical, legal and social implications of this disease, trying to curb discrimination and stigmatize the disease (The Lawyer's Collective, 2003).

In 2006, the major world experts in human rights and scientific fields created the Joint United Nations Programme on HIV/AIDS and the US President's Emergency Plan for AIDS Relief (PEPFAR) Interim Guidelines on Protecting the Confidentiality and Security of HIV Information (UNAIDS, 2007).

These guide lines focus (Beck et al., 2010) their attention on three aspects, intercurrent privacy, confidentiality and security, all facing the protection of sensitive data.

Privacy has both a legal and ethical concept, since it refers both to data protection provided by regulations and to the regulation of access to one's data referring to human rights. The Confidentiality is identified with the right of individuals to see their data protected during collection, storage, transfer and use in order to prevent unauthorized disclosure of that information to third parties. Security refers to technological means by which data is protected from inappropriate disclosure.

The 2008 European Guideline on HIV testing (Poljak, 2009) (2001 update of European Guideline for Testing for HIV infection (Thorvaldsen, 2001), approved by the European Office of International Union against Sexually Transmitted Infections (IUSTI) and European Office of the World Health Organization with the incorporation of various new developments) recommends giving HIV test after having complete consent by the person who has been informed that the result will remain confidential, but confidentiality is not absolute as health-care providers may be legally bound to disclose HIV status information in exceptional circumstances (Rogstad, 2006).

This means that no health professional and / or hospital can refuse to treat or remove a patient if HIV positive, and also that the data on their health or sex life may not be distributed arbitrarily regardless of the type of experimental study or treatment in place.

Conversely, however, only if there is prevention, investigation and prosecution of these crimes, may it be reported to the competent authorities.

In literature it was proposed to introduce a coding system that will stand the test of time (Sajeev, 2006).

The non-uniqueness of understanding on the issue of confidentiality of data worldwide, is clear thanks to a study conducted in 2007 showing that over 80 countries and UNAIDS offices were divided into groups of those who had already issued guidelines on this matter (G -countries) and others intending to develop them (NG-countries).

This research has shown that few countries scaling up HIV services had developed guidelines on protecting the confidentiality and security of HIV information at the time of completing the survey, but 90% of G-countries had a privacy law against 57% of NG-countries.

It should also be noted that even those who have died are entitled to their privacy, since, for example, in South Africa, the law does not protect the confidentiality of deceased persons (McQuoid-Mason, 2007).

It then follows that control over privacy, or the confidentiality of the best data on HIV-infected patients in the NG-countries, is a huge ethical problem related not only to the socio-cultural-economic, but also to the inadequacy of the health system, unable to operate due to lack of transportation and operators to manage the significant and complex reflections of the disease.

Can one rely on the secrecy, confidentiality, dealing with a phenomenon which is such a widespread social alarm?

It is evident that this extraordinary public importance of HIV obligates behavior, without sacrificing the need for knowledge and discussion, to fully respect the dignity of the patient/citizen (of any nationality, race), and their fundamental rights.

Protecting the patient with HIV means allowing the holder of information to freely and independently decide the extent to which personal data, which reveals his identity and other issues related to his health, can be brought to the attention of others and to control treatments to which such data are submitted.

The HIV epidemic has pushed the affected individuals of the developing world to the margins of their societies. Stigma and discrimination can hamper all AIDS patients.

The secrecy of one's HIV status (crucial point with which people infected with HIV compare themselves due to the fear of stigma and discrimination) in populations in developing countries, the fear of the news being spread into one's community, increasing the possibility of being abandoned, isolated or to alarm and frighten relatives, especially the possibility of causing them shame is pushed to a limit.

This is particularly difficult for some participants because it can lead to the revelation of sexual choices up until then lived in secrecy or hiding (because not tolerated by the community of origin) or extra-marital relations (sometimes subject to severe punishment), with the risk of breaking family ties, loss of economic support or exposed to physical violence.

This condition, in Italy, essentially contains the concept of privacy, according to Rodotà (Rodotà, 1991) it provides a set of actions, behaviors, opinions, preferences, personal information, on which the applicant wishes to maintain exclusive control, not only to ensure confidentiality but to ensure full freedom of choice.

In much of the world, including some US states and European countries, disclosure by a physician of an individual's HIV status without the patient's consent is illegal. In other locations, physicians have a duty to warn partners through mandated notification programs. Further, professional ethics codes may differ from local laws, complicating these issues.

In Italy and other European countries there are multiple and meaningful provisions related to the main aspects for the protection of privacy relating to the implementation of the seropositive and HIV testing.

In Italy the reporting of AIDS cases is also governed by an ad hoc law (DM 15 December 1990 and Circular of the Ministry of Health February 27, 1987, 5 and November 25, 1988, 14 in which restricting the flow of information from the doctor directly to the Regional Operations Center and the Ministry of AIDS is clearly marked) and for any transaction information only the code number assigned will be used for each case.

The doctor, investigator, hospital, pharmaceutical company are obliged to respect the confidentiality of personal data of the patient.

When speaking of scientific publications of clinical data or observations relating to individuals, the physician should ensure their non-identifiability.

The specific consent of the patient applies to any further processing of the data, but only within limits, in form and with the exceptions laid down by any standards.

The assessment must also take into account the historical moment facing the subject (environmental, socio-economic and cultural).

In the event that the subject does not show the capacity of decision to authorize the above, the doctor will have to act ethically, ethically with the utmost respect for the dignity of the human activating only those projections that protect the patient's health condition of which only psycho-physical well-being should result.

4.2 Psychosocial issues

Prejudice, exclusion, stigmatization are the three conditions that are still sadly dominant both from an individual and social point of view, that is where the community, family, friends and the context of membership accepts the condition of the patient with AIDS, it could be the patient to perceive and push himself to the point of isolation.

From a collective point of view, unfortunately, poor information is still a problem that leads people to believe that there is a possibility of infection simply being near a person infected with HIV.

Starting from the stigma, over time there has been a change in communication, in fact we have moved from the definition of risk groups to risk behavior, shifting attention from person to action, with the aim of protecting the individual. Nevertheless, those who contract AIDS are labeled for their behavior, but also because, often, the situations are associated with promiscuity. Hence the effect that the disease is closely related to the condition of homosexuality, therefore, still remains, those who declare their homosexuality live in situations of social exclusion for fear of infection, regardless of whether or not they have been diagnosed with the disease.

The situation worsens when the HIV infection is detected, there is exclusion from the family, not for fear of contagion, but the condition of homosexuality and the subsequent voluntary and conscious exposure to the disease.

Another recurring problem is the exclusion in relation to meeting new people, the person with AIDS avoids meeting new people in order to avoid a situation in which he might have to reveal having the disease. Therefore he/she remains anchored to the people who know his/her condition, closing himself/herself into a secure network, a micro-cosmos from which it is advisable to exit. This is amplified greatly for the couple. For these reasons, it often happens that people with AIDS, who may attend self-help groups, prefer to meet up with each other even outside of group meetings, forming closed groups and that most of the time marginalize themselves from the rest of the community.

The key problem of AIDS is information, in fact, most often incorrect when speaking about infection and transmission, while simultaneously resulting in excessive worry or superficiality. It is worrying to know that there are those who think that simply touching or sharing space with people with HIV can transmit the disease, in other cases, however, actions are taken without considering the risk such as oral sex without using precautions.

In recent years, this omission of information led to an increase of the disease in the heterosexual population, as opposed to the homosexual population who have increased awareness and therefore paid more attention to prevention.

In fact, in the case of heterosexuals, not perceiving the risk of infection not belonging to "risk groups", lowers the threshold of concern and risky actions are performed such as

unprotected oral sex. It is not usual to see a heterosexual test for HIV, among gay people, however, the test has become routine every six months, promoting early diagnosis and therefore a more effective treatment, but, above all, preventing the risk of infection for potential partners.

Consequently, even the onset of the disease is different, in fact in many cases it occurs that heterosexual couples discover infection when taking AIDS diagnostic tests related to pregnancy or when clinical problems in either partner occur.

Another equally problematic aspect is the moment in which the news is given, it may provoke reactions of fear, fear of death and social problems.

The news of the disease can occur in three ways: a) the subject goes to a specialized center for testing; b) the person takes the test in any laboratory and c) the patient performs checks due to medical conditions.

In the first case the news is given to personnel who then takes charge of the patient, providing in-depth information on the disease and on all related issues and support with psychological support.

In the second case, the person often reads the result on a sheet of paper that reads *HIV: positive* and from that moment a long and painful ordeal begins, marked by confusion and disorientation, not knowing, knowing little or not well informed causing more fear, until the person hopefully reaches a structure where people are able to respond and support him.

In this case, unfortunately, the news of the disease may push the patient to respond with suicide.

In the third case the patient receives the news from a point which sends him to specialized facilities that take care of providing assistance and support, but in all cases, the news of the disease results in anxiety due to the severe loss, fear of what is happening and the absence of certainty.

We often associate related disorders such as manic depression, mood disorders and anxiety disorders, however, the psychological effects of the news vary according to previous living conditions, in fact, the more prosperous the person, having had both a safe emotional, social and work condition, the more the disease is the collapse of everything he had built and is plunged into the abyss of self-destruction. This also happens in cases where behavior risks are a reaction of anxiety due to suffering and uncomfortable situations. In any case, following diagnosis is an internal reorganization of forces, not only to address all the threats and fears related to the disease, but to address those old ghosts that re-emerge at this time, all the unresolved issues that suddenly emerge, the fears of abandonment, etc..

After the illness is metabolized and after processing coping strategies, fluctuating moments will follow, alternating from calm periods to periods dominated by the uncertainty that determines hypochondria and panic and every little discomfort is associated with threatening entities.

Studies show that women suffer more prejudice and discrimination than being actually infected with HIV, they are most at risk with regard to the possibility of having more aggressive and dangerous forms of the disease and having a harder time dealing with this situation.

Finally, though in recent years it is increasingly common to see women facing a pregnancy and giving birth to children immune to the virus, it is easy to imagine the effort that a woman must make for such a challenging and important project like having a child, knowing that their health can be a burden, an obstacle during their child's growth, perhaps even during these sensitive stages in which it is essential that a mother is near and present.

It follows that the progress and results discovered about AIDS are important and significant. However, there should be more emphasis on information and communication so as to prevent low levels of attention, while it is important to create a welcoming social network and cooperation that will ensure that those who are infected with HIV are not in situations of isolation, hardship and distress.

5. Role of different stakeholders in improving health care and health information in HIV/AIDS patients

Decision-making about controversial public health projects may thus be primarily a function of emotional reactions to drug addicts of disgust, dehumanization and stigmatization rather than reactions of sympathy, humanity and the right to optimal health for all.

Within a disgust/dehumanization framework, effectiveness and cost-effectiveness are usually not important aspects of a program or policy. Rather, it is the congruency between the symbolic value of the program and the emotions of disgust, dehumanization and stigmatization that is critical.

As well pointed out by Soldini (Soldini, 2001), when speaking about the HIV/AIDS infection, issues of health policy are "the result of the ethical debate" that will have to provide the necessary and essential arguments in order to draft a legislation that provides appropriate solutions to curb the problems that characterize this infection.

We must, therefore, even before acting on a deontological and legal level, with health care professionals, behave ethically responsible towards patients with HIV/ AIDS.

They only needs to be respected with dignity as human beings and their rights can not be disregarded in any way, diminished or taken away just because of their infection status.

In the world there is a huge difference between countries on how HIV is handled, specifically when speaking about the laws on testing, the use of informed consent, data confidentiality, notification of decisions, and ultimately support .

The Recommendations (2006) of the Centers for Disease Control and Prevention (CDC) suggest testing for HIV with the tests carried out routinely during the hospitalization of an inmate, serving as a battering ram against the wall of silence that makes being infected by the HIV disease, "exceptional. "

Suffice it is to say that informed consent can be considered valid even if the patient gives a general consent at the moment in which he decides to go under medical activity, starting from the definition provided by the American Medical Association, that informed consent is "a process of communication between a patient and physician that results in the patient's authorization or agreement to undergo a specific medical intervention (American Medical Association, 2008)".

Clearly, this assertion does not consider the difference between informed consent in general and those relative to specific situations, which then contextualizes the patients' expression of will to where they live; there is not an easy application form for these regulatory differences, and it could become a standard care, but we must not forget the elements of the tripod that support its HIV exceptionalism - which, incidentally, we have already spoken of- counseling, informed consent and confidentiality.

Not all states that claim the patient's consent for testing, provide counseling, limiting for example, only positive cases - as in California (Maine Revised Statues, 2008) - wasting the opportunity to help prevention in a slice of the population who still may be at risk, even if the response is negative.

Finally, confidentiality and notification of results to interested parties are issues of fundamental importance that can not be left to the good sense of the person concerned.

In USA (Li et al., 2007) there are ethnic differences with respect to the disclosure process, for example, Hispanics are more likely than African Americans and Caucasians, to communicate a positive diagnosis to their relatives in order to prevent spread of infection in the family clan, while Asian Americans, in relation to their culture, ethnic community and their family role have difficulty coping with the problem. Generally, the reason that drives a person to speak comes from the desire to preserve the family from infection, but there is a difference in how these communities in the U.S and Asian countries of origin behave. It is more difficult than having an unintended revelation in the USA where the reporting guidelines are very strict.

In Asian countries there is more reluctance because discrimination is not only found in the family but also in the community, which also ends up pressuring the family clan.

In China, thanks to the "Four Free One Care" national campaign promoted by the Government, a greater awareness is growing with family involvement in accepting not only infection but also in preventing the spread of infection (UNAIDS, 2004).

On this issue it is worth reporting the example of the State of New York, where the District Health Officer is in charge of tracking the individuals concerned and notifying the results if a patient has received a positive response to the HIV test.

Another case in point is represented in South Africa, where the State guarantees the post-exposure prophylaxis treatment (PEP) only to those who meet the definition of "appropriate victimhood", while complicating access by those regarded as co-responsible for their predicament and accordingly as undeserving of treatment (Pieterse, 2010).

Today, the HIV battle is won with information and training, both of which are attributable to public institutions; providing HIV screening programs will allow a hand to save more lives by ensuring patients right to care and help their partners stay safe, the other to save public funds and assist people with full blown AIDS now no longer negotiable.

Civil rights must be incorporated in the laws as was the case in Iran (Zare & Mortazavifar, 2010) where the constitution (principles 19, 20, 28, paragraph 42 and paragraph 4 of article 6, article 43) have been used in several types of international declarations (es. Universal Declaration of Human Rights, Convention on the Elimination of all types of discrimination against women).

As Brown emphasizes, "as that base of scientific literature and public health practice literature grows, and given emerging scientific evidence supporting increase testing as a cost-effective public health measure, legislators and medical communities must work together to ensure that legislation in all states supports the ability to offer large-scale ED HIV testing" (Brown, 2008).

Therefore only when the government and health professionals can ensure the confidentiality and security of HIV information collected in community or health facilities and information repositories, more people will decide to get themselves tested for HIV and to go to assistance and prevention centers created for people with risk of infection (Hargreaves, 2007). The privacy law serves as a legal blueprint to establish policy practices (Stewart, 1988), but the application of and education about the law may require various strategies, which countries must study and implement. This is perhaps the main task to which the states are called to carry out, and that may eventually be the key to defeating the indiscriminate spread of HIV infection.

6. Conclusions

HIV infection, resulting in AIDS is a special event that involves elements that are very personal to the people who come in contact, which also involves upheavals on the biographical, psychological, social and cultural sphere, not just on the person who contracts the disease (who is also found himself in having to radically change his habits) but also on his family and people who are close, which may not be prepared to face a difficult and delicate problem as far as that treaty.

In fact, the infection can occur through physical contact between two people, mediated or not by a syringe or a bag of blood, or through unprotected sex with people already infected. According to popular imagination, these people belong to that particular category of outsiders, such as drug addicts, prostitutes or persons in serious economic difficulties, which unfortunately in our society tend to be seen as persons "guilty" who deserve to be expelled from the "healthy" community which is regulated by "moral" principles that outsiders would infringe with "disgraceful" conduct.

The Greek word encompasses, through the richness of a language, most of the original concept just said. In fact, this word is translated with the Italian word "brand", therefore something that identifies a person negatively, or even with "tattoo" a particular sign and distinctive easily detectable, or even the "spot", either physical or moral, or, finally, surprisingly, with the word "bite", as if to predict a mode of transmission of this disease.

It is therefore the "stigma" of HIV or AIDS that is pushing away the very people who should be helped and protected by society, the weakest that most easily feel their fundamental rights of equality and health are being mined from those with whom they should be living with, with the consequence of continuously being pushed outside that fundamental network that gives support and relief in such delicate moments. One of these is the shocking moment in which the patient receives the bad news of having contracted an incurable disease. Fearing expulsion from society and from affection, it is logical and natural that people who have a "risky" behavior, are normally not the ones who spontaneously take tests to check something. Something that could make them "outsiders", even at the risk of not knowing whether they have actually contracted the disease and give up immediately to treatment. Treatments that could delay the onset of much of the disease, to avoid infecting people who are close to them and even to give or to unknowingly give their partner an infant that would otherwise be born healthy, since you can prevent the transmission vertical mother-fetus if the virus is recognized beforehand. Another problem then is the "self stigmatization" that can affect those who discover they have contracted the disease and as a result of this discovery decide to isolate themselves because they are considered a danger to their loved ones, or because they feel "ashamed". In addition, a psychological breakdown is hardly be avoided in the absence of adequate information and assistance for this purpose.

The peculiarities of the consequences of this disease and the difficulties of a curative and preventive approach are exacerbated by the cultural attitude and anthropological-ethical territory in which you are studying, whether it is an industrialized country, or a developing country, because besides the differences already discussed in previous sections, the problem of the "stigma" unites these two heterogeneous realities. If we should promote, from a cultural point of view, a real campaign against the stigma of living with HIV or AIDS, with appropriate counseling offered to those who may be in need, as well as the stigmatization of any other carrier of incurable diseases and, more generally, "different, "the ethical side should be able to resolve a painful impasse, constituted by the problem of

how to balance the privacy rights on the highly sensitive data such as those relating to health, or, in other words, the confidentiality of the results of examinations, with the principle of beneficence, which, as evidenced by Ngotho (Ngotho, 2009), may have both negative and positive aspects. Ngotho writes that the success of the different policies will depend on the mutual entirely respect for confidentiality of the patients' care that flows from the patient to medical practitioner". Assuming that the doctor must always pursue the good of the patient, must he behave as if he knows that the patient is suffering from HIV or AIDS? It is his duty to inform the community and identify those who are ill or who may have been infected to get them to start care and prevent them from spreading the infection, even at the risk of going against the right to self-determination and privacy of his patient? Is it right to leave the doctor alone to face this problem without giving him the measures to make this choice less excruciating?

Or, is it ethically acceptable to transform the HIV test into a routine examination for all admissions or for all pregnant women, perhaps preceded and followed by ad hoc counseling, as discussed by Salari and Azizi (Salari & Azizi, 2009) useful to try to balance the right of women to self-determination with the right to health of the unborn? But if such tests were to become routine, will the request of the informed consent of the patient mark the difference between the bid, rather than the imposition of such a test, or it could it even further stigmatize people with HIV/AIDS, as noted by Bayer and Edington (Bayer & Edington, 2009)?

The Code of Medical Ethics of the American Medical Association (opinion 5.5) and global politics tend to affirm the principle that the health information the doctor comes to learn must remain confidential unless it is ethically and legally justifiable its disclosure, to avoid undermining the doctor-patient relationship which is based primarily on trust. But can the preservation of that relationship based on trust be considered a priority even in the case of HIV or AIDS, where it is not only questioning the patient's health, but also the entire community? It rises so difficult to answer another question that has always interested the discussion on bioethics, one of whose leading exponents is the famous bioethicist Hans Jonas (Jonas, 1997), namely the balance between the interests of the individual with the interests of the entire community, that can be summarized in the question: when must the right to the common good take precedence over the right of the individual?

This problem has already been extensively discussed in bioethics in respect of experimentation with human beings, which so far has always tried to protect the rights of the individual more than the community, except in regard to cases of highly contagious or infectious diseases, where instead it is intended to give precedence to the good of the community over the rights of the individual that necessarily weakens the protection of human health. One may wonder then if this is the case HIV or AIDS.

Still, one may wonder what is respectful of another pivotal principle of bioethics, to allow individuals the freedom to announce or not having the infection, leaving the responsibility to indirectly complicit in a "murder"? How must doctors react when they do not agree with the decision of the patient to not inform their partners of the future infection?

As for the principle of autonomy, another key element of bioethics, which has always stressed the importance of self-determination of the patient, can this be protected in cases where the patient's autonomy may be lethal to other human beings?

But these are not the only problems that arise when one is confronted with various and diverse effects of HIV and AIDS.

As noted above, other issues may arise again, but much more complicated because they are linked to economic and historical issues, when considering the differences in approach to the prevention, diagnosis and study of the phenomenon of HIV and AIDS in industrialized and developing countries. In this case, the principle of fairness should never be broken in a society that respects the dignity of human beings, one of its hinges, and it can not take second place in the financial resources of a country. Health is a decisive factor for the development of human beings, families and communities throughout the world and you can not imagine a civil and human progress without respect for the fundamental right to health that is inherent to every human being regardless of his economic possibilities, of the place where he was born or is living or his social status.

No law nor the Universal Declaration can ever resolve the problems and discrimination facing people living with HIV or AIDS until each individual is allowed to heal properly, and while deep divisions continue to exist between ethics and law, between theory and practice, between individual rights and community rights, which can not be resolved by common ethical thinking, but they need the active and conscientious participation of the economically more advanced countries that have more resources to combat this phenomenon.

Only by launching a trans-national dialogue on ethical and social aspects of HIV/AIDS with the aim of building a consensus on policies to be implemented, to address this pandemic and to achieve more shared laws - not only to help the individuals with the disease and the people close to them at risk of infection, but the doctors called for the diagnosis, prevention, treatment and progress of the search for a cure - both the right of individuals to privacy and self-determination and the right to health of the general community can be guaranteed without hateful discrimination based on the economic, historical and social structures of a country.

7. References

- Addictional protections for pregnant women, human fetuses and neonates involved in research (2002). 45 C.F.R. §46 Subpart B
- Ahn, M.J. (2003). Ethics and the AIDS pandemic in the developing world, *Journal International Association Physicians AIDS*, Vol. 2, No.2, pp. 81-87, doi: 10.1177/154510970300200205
- Altavilla, A. (2010). Ethical Standards for clinical trials conducted in third countries: the new strategy of the European Union, pp. 34, *Proceedings of 18th World Congress on Medical Law*, , Zagreb, Croatia, August 8-12, 2010, ISBN 978-953-270-046-6
- American Medical Association (2008). *Informed consent*, Retrieved from <http://www.ama-assn.org/ama/pub/category/4608.html>
- April, MD. (2010). Rethinking HIV exceptionalism: the ethics of opt-out HIV testing in sub-Saharan Africa. *Bull World Health Organ*, Vol. 88, pp. 703-708, doi: 10.2471/BLT.09.073049
- Bayer, R. & Edington C. (2009) HIV Testing, Human Rights, and Global AIDS Policy: Exceptionalism and Its Discontents, *J Health Polit Policy Law*, Vol. 34, No 3, pp. 301-323, DOI:10.1215/03616878-2009-002
- Beauchamp, T.L.& Childress, J. (1994). *Principles of biomedical ethics* (4th edn). Oxford University Press, New York,

- Beck E.J., Mandalia, S., Harling, G., Santas X.M., Mosure D. & Delay P.R. (2011). Protecting HIV information in countries scaling up HIV services: a baseline study. *Journal of the International AIDS Society*, Vol.14, No.6, doi:10.1186/1758-2652-14-6
- Brown, J. (2008). The changing landscape of state legislation and expanded HIV testing, *Public Health Reports*, Vol. 123, No 3, pp 16-19
- Bulterys, M., Fowler, M.G., Shaffer, N., Tih P.M., Greenberg, A.E., Karita, E., Coovadia, H. & De Cock, K.M. (2002). Role of traditional birth attendants in preventing perinatal transmission of HIV, *BMJ*, Vol. 324, pp. 222–225, doi: 10.1136/bmj.324.7331.222
- Cannovo, N., Aganti, A., Sansone, M., Buccelli, P. & Pasquale Martinelli. (2010). Ethic, medical and legal reflections about the fetal protection by a pregnant woman suffering, in comorbidity, from HIV infection, *The Journal of Maternal-Fetal and Neonatal Medicine*, Vol. 23, No.7, pp. 593–594, doi: 10.3109/14767050903192200
- Centers for Disease Control and Prevention (1994). Zivudine for the prevention of HIV transmission from mother to infant, *MMWR Morb Mortal Wkly Rep*, Vol. 43, pp. 285-287
- Chummar, P. (2009). HIV/AIDS in Africa: a bioethical hard blow to human dignity and human rights. *Proceedings of the International Conference on Bioethics*, pp11-21, ISBN , Egerton University, Kenya, August 12-14, 2008, Retrieved from <http://unesdoc.unesco.org/images/0018/001841/184159e.pdf>
- Ciaranello, A.L., Walensky, R.P., Sax, P. E., Chang, Y., Fredberg, K.A. & Weissman, J.S. (2009). Access to medications and medical care after participation in HIV clinical trials: a systematic review of trial protocols and informed consent documents, *HIV Clin Trials.*, Vol 10, No.1, pp. 13-24, doi: 10.1310/hct1001-13
- Commission Directive 2005/28/EC of 8 April 2005 laying down principles and detailed guidelines for good clinical practice as regards investigational medicinal products for human use, as well as the requirements for authorisation of the manufacturing or importation of such products, *Official Journal of the European Union*, L 91, April 9, 2005
- Committee on Pediatric AIDS (2008). HIV Testing and Prophylaxis to Prevent Mother-to-Child Transmission in the United States, *Pediatrics*, Vol. 122, pp.1127–1134, doi:10.1542/peds.2008-2175
- Council for International Organisations of Medical Sciences (CIOMS) in collaboration with the World Health Organisation (WHO) (1993). *International Guidelines for Biomedical Research Involving Human Subjects*. CIOMS, Geneva.
- Council for International Organizations of Medical Sciences (2002). *International ethical guidelines for biomedical research involving human subjects*. Retrieved from http://www.fhi.org/training/fr/Retc/pdf_files/cioms.pdf
- De Cock, K.M., Fowler, M.G., Mercier, E., De Vincenzi, I., Saba, J., Hoff, E. et al. (2000). Prevention of mother-to-child HIV transmission in resource poor countries: translating research into policy and practice. *Jama*, Vol. 283, pp. 1175-82, doi: 10.1001/jama.283.9.1175
- Doyal, L. (1997). Good ethical practice in the dental treatment of patients with HIV/AIDS, *Oral Dis*, Vol.3, pp. S214-S220, PMID: 9456692
- Ehrenkranz, P.D. et al. (2009) Written Informed-Consent statutes and HIV testing. *Am J Prev Med*, July, Vol. 37, No 1, pp. 57-63, doi:10.1016/j.amepre.2009.03.011

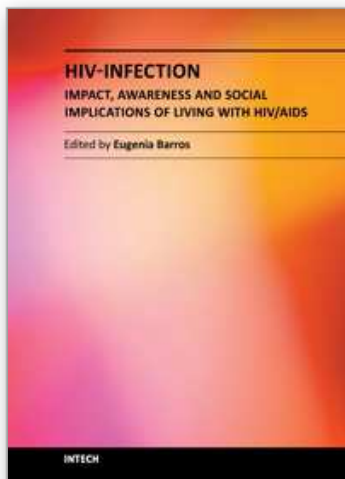
- El Sadr, W. & Capps, L. (1992). Minorities in AIDS Clinical Trials. *Jama*, Vol. 267, No. 7 (February 1992), pp. 954-957
- Federal Register, 45 C.F.R. Sect. 46.102(I)
- Fouad, M.N., Corbie-Smith, D., Curb D et al (2004). Special populations recruitment for the women's health initiative: successes and limitations, *Control Clin Trials*, Vol. 25, pp. 335-52, ISSN 0197-2456
- Fynn, V. (2010). Where there is failing laws: sexual violence against women and children in conflict communities of Africa. *Proceedings of the 18th World Congress on Medical Law*, pp. 34-40, ISBN , Zagreb, Croatia, August 8-12, 2010, ISBN 978-953-270-046-6
- Galliard, P. Melis, R., Mwanyumba, F. et al. (2000). Consequences of announcing HIV seropositivity to women in an African setting: lessons for the implementation of HIV testing and interventions to reduce mother-to-child transmission. *Proceedings of the XIII International AIDS Conference*, p. 334, , Durban, South Africa, July 9-14, 2000
- Grady, C. (2005). The challenge of assuring continued post-trial access to beneficial treatment, *Yale J Health Policy Law Ethics*, Vol. 5, pp.425-435, PMID: 15742586
- Guenther, D., Esparza, J. & Macklin, R. (2000). Ethical considerations in international HIV vaccine trials: summary of consultative process conducted by the joint United Nations Programme for HIV/AIDS, *J Med Ethics*, Vol. 26, pp. 37-43 doi:10.1136/jme.26.1.37
- Hanssens, C. (2007). Legal and Ethical Implications of Opt-Out HIV Testing. *CID*, Vol. 45, (Suppl 4), pp. S232-S239, doi: 10.1086/522543
- Harding, R., Stewart, K., Marconi, K., O'Neill, J.F. & Higginson, I.J. (2003). Current HIV/AIDS end-of-life care in sub-Saharan Africa: a survey of models, services, challenges and priorities, *BMC Public Health*, Vol. 3, p. 33, doi:10.1186/1471-2458-3-33
- Hargreaves, S. (2007). New guidance issued on HIV data collection. *The Lancet Infectious Diseases*, Vol. 7, No. 508, doi:10.1016/S1473-3099(07)70171-8
- HIV Prevention Trials Network (HPTN) Ethics Working Group (2003). *Ethical Guidance for HIV Preventive trials*, Family Health International, North Carolina, USA.
- Indian Council of Medical Research (ICMR) (2000). *Ethical guidelines for biomedical research involving human subjects*, New Delhi, Retrieved from www.icmr.nic.in/Report_socio.pdf
- Indian Council of Medical Research (ICMR) & WHO (2001) *Ethical Guidelines for Biomedical and Behavioural Research on HIV/AIDS*, (Unpublished), New Delhi, Retrieved from www.icmr.nic.in/Report_socio.pdf
- Joint United Nations Programme on HIV/AIDS (2000). *HIV and AIDS related stigmatization, discrimination and denial: forms, contexts and determinants: research studies from Uganda and India*, Geneva, Retrieved from: http://data.unaids.org/Publications/IRC-pub01/JC316-Uganda-India_en.pdf
- Joint United Nations Programme on HIV/AIDS (UNAIDS) (2001). *Ethical Considerations in HIV Preventive Vaccine Research: UNAIDS Guidance Document*, Geneva, Retrieved from www.unaids.org
- Joint United Nations Programme on HIV/AIDS (UNAIDS) (2007). Guidelines on Protecting the Confidentiality and Security of HIV Information, *Proceedings of the Workshop*, Geneva, Switzerland, May 15-17, 2006, Retrieved from www.unaids.org

- Joint United Nations Programme on HIV/AIDS (UNAIDS) (2008). *Report on the global AIDS epidemic*, Geneva, ISBN 978 92 4 150039 5
- Joint United Nations Programme on HIV/AIDS (UNAIDS) (2010). *Global report: UNAIDS report on the global AIDS epidemic*, WHO Library, ISBN 978-92-9173-871-7
- Jonas, H. (1997). *Tecnica, Medicina ed etica. Prassi del principio responsabilità*, Einaudi, Torino
- Kass, N., Taylor, H.A. & Anderson, J. (2000). Treatment of human immunodeficiency virus during pregnancy: the shift from an exclusive focus on fetal protection to a more balanced approach. *Am J Obstet Gynecol*, Vol. 182, pp. 856-859
- Kenya AIDS Society vs Arthur Obel H.C.C.C. 1079 of 1997 & C. A. 188 of 1997.
- Kilewo, C. et al (2001). HIV counselling and testing of pregnant women in sub-Saharan Africa, *Journal of Acquired Immune Deficiency Syndromes*, Vol. 28, pp. 458-462
- Li L., Sun S., Wu S., Lin C., Wu Z. & Yan Z. (2007). Disclosure of HIV Status Is a Family Matter: Field Notes From China, *J Fam Psychol.*, Vol. 21, No. 2, pp. 307-314, doi:10.1037/0893-3200.21.2.307
- Macklin, R. (2001). After Helsinki: unresolved issues in international research. *Kennedy Inst Ethics J*, Vol. 11, pp. 17-36
- Maine Revised Statutes (MRS) 5§19203-A 2, In: Brown, J. (2008). The changing landscape of state legislation and expanded HIV testing, *Public Health Reports*, Vol. 123, No 3, pp 16-19
- Mannheim, K. (1999). *Ideologia ed utopia*, Mulino Editor, ISBN 978-88-15-07126-2, Milan
- May, W.E. (1991). *An introduction to moral Theology*, Out Sunday visitor, Huntington, ISBN
- McNutt, L.A., Gordon, E.J. & Uuskula, A. (2009). Informed recruitment in partner studies of HIV transmission: an ethical issue in couples research, *BMC Medical Ethics*, Vol.10, No.14. Doi:10.1186/1472-6939-10-14
- McQuoid-Mason, D. (2007). Disclosing the HIV status of deceased persons – ethical and legal implications, Vol. 97, No. 10, *SAMJ Forum*, Retrieved from www.samj.org.za/index.php/samj/article/view/559/92
- Medley, A. et al (2004). Rates, barriers and outcomes of HIV serostatus disclosure among women in developing countries: implications for prevention of mother-to-child transmission programmes, *Bulletin of the World Health Organization*, Vol. 82, pp. 299-307
- Mills, E., Nixon, S., Singh, S., Dolma, S., Nayyar, A. & Kapoor, S. (2006). Enrolling Women into HIV Preventive Vaccine Trials: An Ethical Imperative but a Logistical Challenge, *Epub*, Vol. 3, No. 3 (e94), DOI: 10.1371/journal.pmed.0030094, Available from www.plosmedicine.org
- Muthuswamy, V. (2005). Ethical issues in HIV/AIDS research Indian, *J Med Res*, Vol. 121, pp. 601-610
- National Bioethics Advisory Commission (NBAC) (2001). *Ethical and Policy Issues in International Research: Clinical Trials in Developing Countries*, Washington DC
- National Institutes of Health (2005). *Guidance for addressing the provision of retroviral treatment for trial participants following their completion of NIH-funded HIV antiretroviral treatment trials in developing countries*. Retrieved from http://grants.nih.gov/grants/guide/notice-files/NOT-OD-05_038.html
- Ngotho, D.K. (2009). HIV/AIDS – A major medical ethics dilemma, *Proceedings of the International Conference on Bioethics*, pp. 14-20, Egerton University, Kenya, August 12-14, 2008

- Nuffield Council on Bioethics. (1999). *The Ethics of clinical research in Developing Countries*, London
- Oduwo, E.A. (2009). Rethinking state participation in HIV vaccine trials, *Proceedings of the International Conference on Bioethics*, pp. 31-39, Egerton University, Kenya, August 12-14, 2008
- Oyefara, J.L. (2007). Food insecurity, HIV/AIDS pandemic and sexual behaviour of female commercial sex workers in Lagos metropolis, Nigeria. *SAHARA J: Journal of Social Aspects of HIV/AIDS Research Alliance*, Vol. 4, pp. 626-635
- Philippines National Health Council (2001). *Ethical Guideline in AIDS Investigations in Philippines*, Manila
- Pieterse, M. (2010). Impeding access? Stigma, individual responsibility and access to post HIV exposure prophylaxis (PEP) treatment in South Africa, *Proceedings of 18th World Congress on Medical Law*, p 173, Zagreb, Croatia, August 8-12, 2010, ISBN 978-953-270-046-6
- Poljak, M., Smit, E. & Ross, J. (2009). 2008 European Guideline on HIV testing. *International Journal of STD & AIDS*, Vol. 20, pp. 77-83
- Rodotà, S. (1991), Privacy e costruzione della sfera privata, In: Rodotà, S. (1995). *Tecnologie e diritti*, il Mulino, Bologna, pp. 101-122
- Rogstad, K.E., Palfreeman, A., Rooney, G. et al. (2006). *United Kingdom National Guidelines on HIV Testing 2006*, Retrieved from www.bashh.org/documents/63/63.pdf
- Salari, P. & Azizi M. (2009). The necessity of HIV testing in Iranian pregnant women and its ethical considerations, *J Med Ethics Hist Med*, Vol. 2, No 1, Available from http://journals.tums.ac.ir/upload_files/pdf/12484.pdf
- Sajeev, M.A. (2007). The HIV code. *Arch Dis Child*. Vol. 92 (1), No. 91, doi: 10.1136/adc.2006.107573.
- Singer, P.A. & Bowman, K.W. (2002). Quality end-of-life care: A global perspective. *BMC Palliative Care*, Vol. 1, p.4, Available from <http://www.biomedcentral.com/1472-684X/1/4>
- Siringi, S. (2004). British scientists face lawsuit, *The Lancet Infectious Disease*, Vol. 4, No. 7
- Slack, C. et al (2005). Provision of HIV treatment in HIV preventive vaccine trials: a developing country perspective, *Soc Sci Med*, Vol. 60, pp.1197-1208.
- Soldini, M. (2001). *Bioetica della vita nascente. In puero homo*. CIC Edizioni internazionali, Roma.
- South Africa Code of Ethics in HIV/AIDS (2000), In: Muthuswamy, V. (2005). Ethical issues in HIV/AIDS research Indian, *J Med Res*, Vol. 121, pp. 601-610
- State Council AIDS Working Committee Office and United Nations Theme Group on HIV/AIDS (UNAIDS) in China (2004). *A joint assessment of HIV/AIDS prevention, treatment and care in China*. Beijing, China, Retrieved from www.chinaids.org.cn/worknet/download/2004/report2004en.pdf
- Stewart, R.S. (2007). Protective Measures for Private Health Information. *Perspectives in Health Information Management*, Vol.4, No.5,
- Stuart Huges, H. (1967). *Coscienza e società,. Storia delle idee in Europa dal 1980 al 1930*, Einaudi, Torino
- The Lawyer's Collective (2003). *Legislating an Epidemic, HIV/AIDS in India*, Universal Law Publishing Co. Private Ltd, New Delhi, OL3337658M

- Thorvaldsen, J. (2001). European guideline for testing for HIV infection. *Int J STD AIDS* Vol. 12 (Suppl. 3), pp.7-13
- UNICEF (2008). *Progress for Children. A Report Card on Maternal Mortality*. UNICEF, No.7, Retrieved from http://www.unicef.org/childsurvival/files/Progress_for_Children-No._7_Lo-Res_082008.pdf
- Weijer, C. & LeBlanc, G. (2006). The Balm of Gilead: Is the provision of treatment to those who seroconvert in HIV prevention trials a matter of moral obligation or moral negotiation?, *J Law Med Ethics*, Vol. 34, pp. 793-808
- Wilson, J. (2007). Is respect for autonomy defensible?, *J. Med Ethics*, Vol. 33, pp. 353-356
- World Health Organization. (2008). Towards universal access: scaling up priority HIV/ AIDS interventions in the health sector (progress report 2008), Available from http://www.who.int/hiv/pub/towards_universal_access_report_2008.pdf
- World Health Organization (WHO) (2000). *Fact Sheet: Backgrounder No. 1*. Retrieved from <http://www.who.int/inf-fs/en/back001.html> July
- World Medical Association (2000). *Declaration of Helsinki: ethical principles for medical research involving human subjects*. 52nd WMA General Assembly, Edinburgh, Scotland
- World Medical Association. (2004) *Declaration of Helsinki*. Available from <http://www.wma.net/e/policy/b3.htm>
- Zare, M. & Mortazavifar, N. (2010). AIDS: human rights and government responsibility, *Proceedings of 18th World Congress on Medical Law*, p 174, Zagreb, Croatia, August 8-12, 2010, ISBN 978-953-270-046

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The past few decades have seen the escalation of HIV-infections and the 'frantic' search for new drugs to treat the millions of people that live with HIV-AIDS. However because HIV-AIDS cannot be cured, but only controlled with drugs, and the Antiretroviral (ARV) treatment itself results in some undesirable conditions, it is important to generate wider awareness of the plight of people living with this condition. This book attempts to provide information of the initiatives that have been used, successfully or unsuccessfully, to both prevent and combat this 'pandemic' taking into consideration the social, economic, cultural and educational aspects that involve individuals, communities and the countries affected.

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