Ethical issues in the management of pediatric HIV infection in an African environment [1]

Focus on ethical problems

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Until recently, little attention was given to HIV pediatrics-related ethical issues, particularly in african environment. Is it because the complicated and not yet solved problems of the mother take the lead and monopolize the reflexion ? Or, is it because the child plays the passive role in a tripartite relationship which in fact, turns to a paren/care provider dialogue ?

It is clear that for a pediatrician, whose day is tuned up by pressing situations of vital threat, the main objectives af his/her mission are certainly to diagnose and treat the disease and this is particularly difficult because of the big number of patients, shortage of staff and intervention means, difficulties to communicate with parents, etc...

In this situation of endless war against emergency, sparing a space of reflexion for the ethical considerations of the action remains a permanent challenge. Most certainly in the past, the necessity of that geographical and psychological space was evident in the assistance to the chronic and mortal diseases of childhood, during genetic counselling or checkup of materno-fœtal transmission of congenital diseases. But, the emergence of AIDS has confered it a new dimension, because any medical emergency can reveal an ethical emergency. Moreover, the prognosis of the disease, the current limits of a medical treatment, the implications of the diagnosis on the mother and beyond her, on the unpredictable shackles of the contamination chain form as many factors changing deeply the caring relationship.

We are not addressing the ethical issues in biomedical research during which the point is just while achieving the objectives to respect the commitments stipulated in the protocol, although they need a particular attention in our countries where many factors could appear as encouraging or mitigating circumstances of serious ethical infringements.

We will focus our attention on the real experiences of a practitioner involved in the assistance to children by this time of AIDS and who is lonely on the threshold of human tragedy, any time a seropositivity is disclosed and therefore locks him up in an always new psychological adventure.

We will insist on three selected axes, on account of their basic place in the assistance process, their recurrence or the necessity to put them at their justifiable place in the reflexion of ethical issues that HIV infection raises in pediatric environment. The three axes are :

- Consent to HIV test ;
- Confidentiality issues related to the announcement of the child's seropositivity ;
- The seropositive mothers breast-feeding choice.

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I. Consent to HIV test

Whether it is during etiology investigation in cases very likely associated with HIV infection or the determination of the HIV status of a seropositive mother's child, the consent issue in pædiatrics is unique owing to the fact that the patient who is tested is excluded from the decision taking ; the request is addressed to the parents (very often to the mother who is usually the escort) or the guardian of the child of a seropositive mother.

The first problem comes from the formulation of the request for the serologic examination, the advisability of which can be discussed when the mother is psychologically weakened by the child's disease and socially isolated in hospital environment.

How can this request affect the mother who, yesterday, was in good health and who, today, may suddenly be informed about her own contamination and her responsibility in her child sufferings.

> " *What is exactly the reality of a consent when a mother is totally desarmed in front of a practitioner who is not ready consciously or unconsciously to surrender power related to HIV knowledge and status ?* " (1).

Is there not a risk to see her refusal expressed by the exit of the child without the care providers'knowing and may be a breaking off of contact and avoidance of health services for good ?

In addition to the mother's consent, is it not necessary to obtain the father's one as he holds the family authority ?

What to do when the two parents' decisions differ ?

Facing the complexity of that request and the possibility to have produced "*extra stress for nothing*", if the result is negative, the test is often carried out without the parents knowing when the clinical picture shows the possibility of HIV infection. The main difficulty therefore remains in the announcement of the seropositivity, the result of which on the mother, amplified by the absence of consent and pre-test counselling, is comparable to "*a thunderclap in a serene sky*". Unless to come back to the beginning by asking her consent for the child test whose status was already known !

Another case is when the child is under the responsibility of a guardian and not his own parents. That situation is common in Senegal with the practice of child fostering (2). Now, in a community in which HIV infection is still arousing fears and prejudices, the assumption of seroposotivity included in the test request could jeopardize the child and adoptive family relationship. In case of seropositivity, is the guardian's information, which may reveal the mother's status, not like a violation of the medical confidentiality ?

II. Announcement of the seropositivity and sharing of the confidentiality in the married couple

The announcement, seen as a procedure that the counsellor uses to make his/her patient be aware of his/her seropositivity and its medical, behavioural, family and social implications, cannot be evaded in a counselling project. The announcement shows the importance of the pre-test counselling which depends mostly on the counsellor's abilities to face that fateful moment when it is an obligation to " *make the unspeakable comply with the assertion* ". (3)

Still, we are struck by the scarcity of practical experiences reports on that in the large variety of hearings about assistance to people living with HIV.

Is it because the emotive load and the weakness at the time of announcement impede any self-observation, therefore any possibility to reproduce the experience ? Or is it because of the lack of formula and the originality of every case (" the same is never said twice ") that the announcement braves any theorical reflexion and systematization attempt ?

Among the various points to review when announcing the status, we focus on the one related to the choice of the person who shall receive the announcement. It has a specific interest in pediatrics, where any announcement may be double because of the possible mother-child HIV transmission. It seems fair to us that the mother, who is responsible for the confidentiality and who gave her consent for her child's HIV test, must be the first to know the results. A dilemma occurs when the biological father claims his child's medical file, specifically the diagnosis, prognosis and further follow-up programme. Then, the disclosure of all the file truth would lead to the breaking off of the confidentiality agreement that linked the physician and the mother ; the seriousness of the agreement lies in the probability of the mother's

seropositivity and the possibility of a serologic discordance in the married couple.

III. The seropositive mother's choice of breast-feeding modes

The issue of the seropositive mother's breast-feeding had been in embryo for a long time before forcing itself now as an unavoidable debate. At the beginning of the epidemic, the question was whether breast-feeding was a mother-child transmission mode or not ; when the response was positive (4), the question appeared in the form of risk estimation (5) then, universal dichotomy of seropositive mother's children according to the resources and local pathologies (6) and finally in the form of a research to minimize the risk of an almost unavoidable practice in developping countries (7).

As a matter of fact, there was no such choice in those countries where the policies in that subject echoed the intemational recommandations : " where malnutrition and infectious diseases are the main causes of infant mortality and where artificial breast-feeding may be beyond the families' possibilities, it is necessary to encourage natural breast-feeding whatever the mother's HIV status is ". (6)

Presently, the choice of breast-feeding for a seropositive mother, regardless biomedical and economical aspects, raises an ethical issue (8), it is essential to precise its programme and stakes. To speak of breast-feeding mode, supposes first the recognition of the mother's HIV+ status and wide information on its implications for her and her child. The debate occurs then in medical environment where the one who is privileged to know the status of his/her patients has to show his/her credit by what he offers them in term of listening, support and assistance.

It is in that prospect of assistance and participative counselling relationship initiated immediately on the announcement of the seropositivity that the strange colloque between the mother and the physician on the choice of the new-born's breast-feeding mode must be placed. Once, this new programme is set up, the follow-up of the child is no more only the passive description of the "natural history" of HIV vertical transmission, but shows a real programme of socio-medical assistance including effective vaccination, growth surveillance, prevention treatment of common infant diseases. But, it must also include the suppression of any risk of HIV contamination of the child taking into account of the support of an artificial breast-feeding freely chosen by a seropositive mother. With these conditions, it is clear that the risks of artificial breast-feeding are diminished and vertical transmission reduced

Gray's works in Soweto (9) showed that this programme is possible ; though his results are preliminary and his sample limited, they are stimulating in the search for alternative solutions to natural breast-feeding by the seropositive mother. In addition to its necessary nutritive qualities, ideal diet must be culturally acceptable, available and economically accessible to any mother who decided to protect her child to a potentially infectious alimentation.

Certainly, promoting natural breast-feeding is excellent ; but the minority of those mothers aiming at artificial breast-feeding must be given as much attention if at the end the objective is to ensure the childs'survival in disadvantaged condition. In the same way, educational messages promoting natural breast-feeding in our countries must also state clearly the risks of post-natal HIV infection when the mother is seropositive.

Not to mention that risk could cast suspicion on any message designed for the disavantaged communities. Silence on that is no more admitted since a gleam of hope was born on September 27, 1996, with the temporary declaration of WHO related to HIV and the child alimentation which stated positively " the necessity to allow parents, specially the seropositive mother, to take well informed decisions for their child's breast-feeding and to support them in their decisions " (10).

Now the meaning and the type of the assistance must be quickly defined for the practical application of a promoting health policy in HIV affected families ; a promotion which remains an important part in the parents' psychosocial assistance.

Thirty years ago, Professor Payet wondered whether " it was necessary to withdraw from alimentation peanut cake, possibly carcinogenic, with the risk to leave infant mortality at its disastrous rate in Senegal ? " (11).

Debates on the choice of breast-feeding by the seropositive mother in disadvantaged environment shows the reality of the problem. Our task now is, all together, to come to invert the terms of the ethical dilemma in Africa, by changing them from the choice of the lesser of two evils to the choice of the

better of two goods.

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